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Understanding and Supporting the Adoption of Assistive Technologies by Adults with Reading Disabilities

Katherine Nichole Deibel

A dissertation submitted in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

University of Washington

2011

Program Authorized to Offer Degree: Computer Science & Engineering

University of Washington
Graduate School

This is to certify that I have examined this copy of a doctoral dissertation by

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Abstract

Understanding and Supporting the Adoption of Assistive Technologies by Adults with Reading Disabilities

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Reading disabilities such as dyslexia are life-long conditions affecting an estimated 5–15% of the population. For adults with these conditions, participation in today’s information society can be problematic. By using the very digital media that is helping drive this information society, computing technologies may be a viable means of providing reading support and accommodation. For such technologies to be successful, though, they must be adopted into regular use. Unfortunately, studies have shown that 35–50% of all assistive devices are abandoned after purchase.

This dissertation explores the many sociocultural, technical, economic, and environmental factors that influence the adoption and usage of assistive technologies by adults with reading disabilities. A key element in these factors is the invisible nature of reading disabilities. People with reading disabilities often choose to not disclose their disability. As using an assistive technology may make one’s disability evident to others, choices made about technology usage are complex social negotiations involving issues of identity, normalcy, and disability.

The key approach used in this dissertation is Value Sensitive Design. By taking a multidisciplinary perspective and focusing on human values and a diverse set of stakeholder groups, detailed insights are developed for the design and deployment of reading-support tools better suited for adoption and ongoing usage by reading-disabled adults. Specific contributions include the following:

- A literature analysis establishing critical value issues involving the multiple stakeholders relevant to reading disabilities.
- Case studies derived from online message board discussions and one-on-one interviews involving

adults with reading disabilities and the roles of technology and disability in their lives.

- Value-based reviews of existing assistive technologies and design guidelines for future development.
- A detailed proposal for deploying *socially flexible* assistive technologies that address the critical issues of disclosure, privacy, and stigma management among adults with reading disabilities that is based on the use of meta-tools that assist in recommending and integrating other reading tools.

This work also establishes Value Sensitive Design as a powerful and beneficial approach for conducting assistive technology research and refines and expands upon the Value Sensitive Design methodology.

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ACROYNYS AND ABBREVIATIONS

In addition to acronyms and abbreviations standardized by the American Psychological Association (5th edition), this dissertation also uses the following:

ADA	Americans with Disabilities Act
ADAAA	ADA Amendments Act
ADD/HD	Attention Deficit Disorder / Hyperactive Disorder
AT(s)	Assistive Technology(ies)
CS(&E)	Computer Science (& Engineering)
HCI	Human-Computer Interaction
IDEA	Individuals with Disabilities Education Act
LD(s)	Learning Disability(ies)
OCR	Optical Character Recognition
PD	Participatory Design
PATTC	Person, Ability, Task, Technology, and Context
RD(s)	Reading Disability(ies)
SpLD(s)	Specific Learning Disability(ies)
VSD	Value Sensitive Design
TTS	Text-To-Speech

ACKNOWLEDGMENTS

This dissertation could not have been completed without the great support that I have received from so many people over the years. I wish to offer my most heartfelt thanks to the following people.

To my advisors, Alan Borning and John Bransford. Thank you for the advice, support, and willingness that allowed me to pursue research on topics for which I am truly passionate. I see the same drive and passion in your own research efforts, and I thank you for letting me do the same.

To my mentor, Sheryl Burgstahler. We first met during one of the more difficult times of my life, and you were there to talk and to offer guidance. Thank you for all of the meetings and chats over the years. You recognized that I at times needed to work alone but also made sure to check in on me so that I stayed on the right path.

To Lindsay Michimoto. As the department's graduate advisor, you have been an ever present beacon of support, encouragement, and advice. Thank you for keeping your office door open and available for all the times when I needed it.

To Linda Shapiro. I had given up and was ready to quit graduate school when you came to me and offered help. I can honestly say that without your intervention, this dissertation would not exist. I am not the only student that you have helped prevent slip through the cracks, so thank you for being there for both me and all the others.

To Cindy Atman, Jim Borgford-Parnell, and all of the other people at CELT. Thank you for the opportunity to work as a graduate research assistant at CELT. Providing funding for the last several years of my studies was truly helpful, but I am far more grateful for and appreciative of the collaborations and conversations we have had. Thank you.

To Janet Davis. From the day I began graduate school, you have become one of my best friends. We have seen and helped each other through both good times and bad. I will always remember the great conversations we had over lunch, and I know that we will break bread together many more times.

To Ken Yasuhara. I have always been able to turn to you when I have needed a listening ear, a dissenting opinion, or someone to gauge the spiciness of some food. You are a great friend and a rock of stability in

my life. You also helped bring Susie into my life, but our friendship was strong before and I hope it will continue to be as strong in the future.

To my Mom and Dad. You have encouraged my academic interests from day one, even when my curiosity led to incidents that were kind of hard to explain. Thank you.

To my brother, Jason. While I have taken my own directions at times, I have always appreciated the path that you have blazed before me. You may be the first Dr. Deibel, but you are now no longer the only one.

To Jen, Sharon, Grandma, and the rest of my family. Some of you I have known forever, while some of you have come into my life only recently. Regardless, thank you the ongoing encouragement over the years.

To my therapist, Bryant Vehrs. Our sessions have been about more than my mental health and improving my quality of life. You have been a guide and friend for me throughout graduate school, and this dissertation would truly have never been completed without your support. Thank you.

To Tim Wright and Sarah Read. We have collaborated on multidisciplinary research, discussed politics and philosophies, and shared more than a few pitchers of beer and plates of nachos. You have been two of my closest colleagues and closest friends in the last few years, and I look forward to the day that the beer and nachos are a toast for all of us having finished our PhD work.

To Kraig M. I will never forget my time working as your tutor at Literacy Source. I know you had struggled in school and felt stuck in learning, which is why I worked hard at finding and showing you your learning strengths. From that first moment you gained traction, you began moving forward and never stopped. Your drive and passion for learning will always remind me of why I teach.

To the SIGCSE community. I first joined this community as an uncertain graduate student, but I soon found so many willing to reach out and connect with me. The conversations, advice, friendships, and fun helped shape my development as a researcher and educator. There are too many of you to list here, but do know that I thank you and will honor the help you gave me by repeating the kindness to others as a member of the SIGCSE community.

To Dan Comden, Dyane Haynes, Dennis Lang, Michael Richardson, Jessie Shulman, Charity Ranger, and the other members of the UW disability community. As faculty, staff, or students, you were all involved in my ongoing learning about the social aspects of disability and disability advocacy. The broad, nuanced view of disability in dissertation is thanks to the great conversations we have shared over the years. Thank you.

To Anna Cavender, Shaun Kane, Kristen Shinohara, Jeff Bigham, Susumu Harada, and the other graduate students who did or are doing assistive technology work. In the last several years, I have seen a large and active assistive technology research group come into being at the university. Thank you for the community and the conversations. Continue doing the great work both at UW and wherever you go in life.

To the chemists Runge, Robiquet, Pelletier, and Caventou. Thank you for your pioneering work in isolating and characterizing the chemical properties of caffeine. The results of your work played an admittedly strong role throughout my time in graduate school.

To some of my favorite authors, Mary Roach, Oliver Sacks, and Simon Winchester. Your books have not only provided me with hours of reading pleasure, but your predilection for footnotes and endnotes has also carried over into my own writing.

To so many webcomics artists and authors. Thank you for the entertainment and joy you have and continue to bring to me.

To my study participants. While I have said the same for others in this list, it is literally true that this dissertation could not have been completed without your participation. Thank you.

To anyone that may I have forgotten. I apologize. Thank you as well.

DEDICATION

To my beloved calico, Susie.



Photo by Ken Yasuhara

A true aficionado of books and bookshelves. . .
albeit more for the purposes of napping on top of than reading.

CHAPTER 1

INTRODUCTION

But when they came to letters, This, said Theuth, will make the Egyptians wiser and give them better memories; it is a specific both for the memory and for the wit. Thamus replied: O most ingenious Theuth, the parent or inventor of an art is not always the best judge of the utility or inutility of his own inventions to the users of them. And in this instance, you who are the father of letters, from a paternal love of your own children have been led to attribute to them a quality which they cannot have; for this discovery of yours will create forgetfulness in the learners' souls, because they will not use their memories; they will trust to the external written characters and not remember of themselves. The specific which you have discovered is an aid not to memory, but to reminiscence, and you give your disciples not truth, but only the semblance of truth; they will be hearers of many things and will have learned nothing; they will appear to be omniscient and will generally know nothing; they will be tiresome company, having the show of wisdom without the reality.

— Socrates, as recorded by Plato (trans. 1892, sections 274e–275b)

Nearly 2500 years ago, the great scholar Socrates foresaw that an increasingly popular innovation bode terrible consequences for society if it continued to be used. Human memories would deteriorate. Intellectual skills would crumble. This horrible invention was not a potent, addicting drug nor a contemporary form of social networking, for it was the notion of writing things down that so deeply dismayed Socrates.

Recorded (ironically) in one of Plato's Dialogues (trans. 1892), Socrates expressed his concerns about writing in a parable. Theuth, the inventor of letters, describes to King Thamus the many great benefits that writing will provide humanity. King Thamus rebukes him; the pride Theuth has in his invention prevents him from seeing the true consequences of letters. While writing aids the recall of simple facts and the recording of what was said, writing cannot provide the depth that comes from dialogue with the original speaker. Writing fails to convey the context and wholeness of actual truth.

Modern society owes its thanks to Socrates's peers (and perhaps to the cup of hemlock) in that writing was eventually adopted and embraced despite Socrates's misgivings. His concerns did have and still have

merit, necessitating the development of new literacy skills to address the limitations of writing (e.g., source evaluation (Britt & Aglinskis, 2002)). Today, writing and reading pervade our society; we even refer to the current era as the Information Age. Theuth's invention has dramatically impacted our lives in ways predicted and not predicted by King Thamus/Socrates.

At the same time, many innovations and inventions fail to make an impact. Trivia books and *Ripley's Believe It or Not!* comics are littered with examples of fanciful inventions that trigger laughter (Ripley, 1990). From squirting alarm clocks and Edison's concrete furniture (Ripley, 1990) to revolving medical beds for facilitating labor via centrifugal force (Abrahams, 2002), the designers of such technologies hoped, like Theuth, to improve and benefit the lives of others. No one adopted these technologies into regular use, though and their impacts have sadly been limited to filing cabinets in various patent offices.

The many elements of this journey from Socrates to Ripley are of concern here in this dissertation. Without question, reading and literacy are critical skills necessary for participation in today's information society. For the 7–15% of the population with reading disabilities (RDs) (Sands & Buchholz, 1997), however, participation can thus be a challenge and source of stress. As information is increasingly available in digital form, computing technologies seem an increasingly viable means of support and accommodation. However, there is a catch—said technologies must be adopted into regular use. Unfortunately, studies have shown that, on average, at least one third of all assistive¹ technologies are abandoned² after purchase (Martin & McCormack, 1999; Riemer-Reiss & Wacker, 2000). When designing technologies expressly for the purpose of benefiting the lives of reading-disabled users, understanding the many factors (sociocultural, technical, economic, environmental, etc.) that influence the adoption, usage, and abandonment of these technologies is crucial. This dissertation is a study of these factors and how they influence the adoption and usage of technologies by adults with reading disabilities. Although the primary focus is on assistive technologies, technologies of all kinds are also considered and studied. In the coming chapters, I investigate the factors that shape technology usage, illustrate, their many nuances, and implement solutions that utilize my findings to better promote adoption and ongoing usage of technologies for users with reading disabilities.

1 Assistive Technologies and the Need for Adoption

At face value, successful adoption is important for any technology, be it assistive or not. Consumers do not wish to waste their money. Most designers want their ideas to come to fruition and be used. Manufacturers most certainly want consumers to purchase their wares. Moreover, although a product that gets purchased and is then shortly abandoned does provide some monetary profit, a manufacturer is better favored by long-term usage of a product and the associated return customers and marketing benefits of other consumers seeing the product in use (Rogers, 2003). Plainly put, technology adoption is an important issue to many parties.

Still, the very nature and purpose of an assistive technology (AT) makes adoption (and concurrently, abandonment) of a far more critical importance than most if not all other technologies. Assistive technologies are tools and applications designed to help people with disabilities participate in work, school, and all other aspects of daily life (King, 1999; Technology-Related Assistance for Individuals with Disabilities Act, 1988). As such, they are often purchased on an individual-by-individual basis with explicit care by many parties, including but not limited to the end user, family members, caregivers, and disability specialists (King, 1999; A. Kintsch & DePaula, 2002). When an AT is abandoned, the time, funds, and effort exerted by all these people is put to waste.

A more dire consequence is the potential psychological effects of AT abandonment. Multiple people, including the user, deliberated over the selection of the AT. Time and care was spent identifying the user's needs and finding the right technology that best addressed them. The purchased AT was likely lauded as a near-panacea; this was supposed to be a perfect fit between technology and user. However, this supposedly "perfect" technology was not helpful and was abandoned. This can unsurprisingly lead to disillusionment about the potential of any AT to positively impact the life of the user (Martin & McCormack, 1999). While a user might try again with a different assistive technology, repeated failures will likely lead to learned helplessness and feelings of hopelessness (King, 1999). After that, any suggestions of new technologies to try will most certainly be ignored or rejected.

The point here is that AT abandonment is different than the abandonment of mainstream technologies. In the latter case, the focus is typically on a consumer group. An unhappy customer is to be expected, although hopefully a rare occurrence. The goal is to promote usage among most of the consumer group. For ATs, however, the focus is on distinct individuals. As abandonment has serious implications, AT abandonment rates should be made as close to zero as possible.

2 The Complexity of Assistive Technology Abandonment and Usage

AT abandonment rates are not near zero, though. Various studies have estimated the average rate of AT abandonment to be about 35% (Phillips & Zhao, 1993; Martin & McCormack, 1999; Riemer-Reiss & Wacker, 2000), and Tewey, Barnicle, and Perr (1994) reported abandonment rates ranging from 8% to 75% for different types of ATs.³ Studies with narrower focuses have found differing rates. Koester (2003) found that 7 out of 8 users with disabilities quit using speech recognition software after 6 months. A longitudinal study of usage of a software application for dyslexic users found that only 4 out of 8 users continued to use the software after several months (Elkind, Black, & Murray, 1996).

The varying rates from these and other AT abandonment studies makes translating their findings into workable policies and practices problematic. As Dawe (2006) notes, the studies lump together users with

different disabilities, ranging from mobility impairments to sensory disabilities to cognitive disabilities. Although the findings highlight general themes about AT adoption, the diversity of both the assistive tools and the user populations are obscured. An additional limitation noted by Dawe is that abandonment is a process. These prior AT adoption studies have tended to focus only on whether a technology is adopted or rejected. Emphasizing end states neglects the actual underlying process involved in technology adoption (Rogers, 2003) and thereby limits the identification of potential interventions to prevent rejection.

As an example of an intervention of limited applicability, some studies have found that abandonment is more likely to occur when an AT is incompatible or fits poorly with an activity important to the user (Riemer-Reiss & Wacker, 2000). An obvious recommendation is to pay greater attention to the activities engaged in by disabled users, but this glosses over many complex details. First, each kind of disability affects participation in various activities differently. A person who uses a wheelchair will experience different issues playing in a soccer game than a person with a learning disability. Similarly, writing an e-mail message will involve different issues and challenges for both individuals. Generalization within a single disability type is also problematic as people with the same disability type may have different degrees of limitations and may also not engage in the same activities with the same frequency. Furthermore, a user is likely to use the same AT across multiple activities. Issues of compatibility will likely differ across the activities.

Even when the activity and assistive technology are compatible, additional factors influence its usage. Consider the following scenario: a student who is blind and a student with a reading disability both access their textbooks through text-to-speech (TTS) software. TTS software takes an electronic copy of a text and reads it aloud. While attending a lecture, the need arises for both students to refer to their textbook. Both have their laptops present, so they can use the TTS software. To do so, they must either play the text out loud or wear headphones / earpieces. The former has the potential to be disruptive to other classmates and attract their attention. The latter will make the students stand out as wearing headphones is not typical during a lecture and may be viewed as discourteous to the instructor. Would the two students use their TTS software during the lecture?

The blind student will most likely use TTS to access the textbook. Although either usage option has potentially negative consequences, it is easy to rationalize and accept that the blind student needs to do so because otherwise the textbook is inaccessible. Due to social interactions within the class, the instructor and other students will likely have learned of the student's blindness and that he needs to use the technology to participate in class. Even if the student has not explicitly indicated his disability to others, he will likely have shown several visible indicators of his blindness.⁴

For the reading-disabled, however, whether the TTS will be used is not as clear. Unlike blindness, a reading disability is not visually recognizable, and thus the instructor and classmates will only know of the disability if

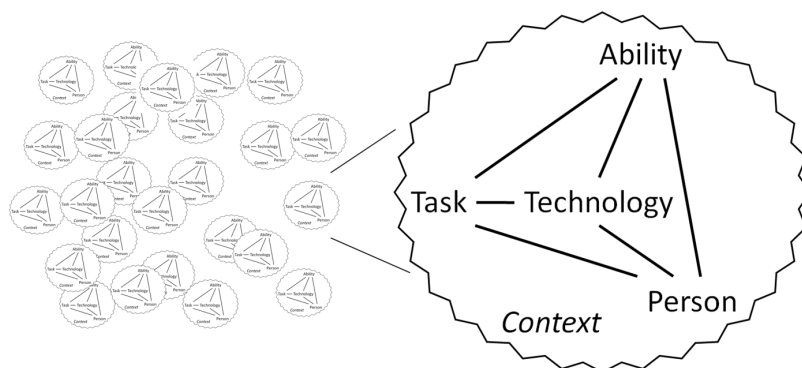


Figure 1.1: The PATTC Framework: The complexity of AT adoption and abandonment can be thought of as overlapping instances of the 5-way interaction between the person/user, (dis)ability, task/activity, technology, and the sociocultural-environmental context.

she herself has told them. If she has told them, the same rationalizations as before can apply. Such disclosure is not guaranteed and is perhaps unlikely. Case studies of people with RDs have found that many are reluctant to admit having difficulties with reading due to past experiences where they have been accused of faking, being lazy, or that reading disabilities just plain do not exist (Cory, 2005; Edwards, 1994). In addition to these direct responses, studies have found that associated stigmas can indirectly influence how people relate to a person with a reading disability (Cory, 2005; McDermott, 1993). As such, people with RDs tend to carefully control and limit who knows of their disability (Cory, 2005; Edwards, 1994; Pollak, 2005). The decision to use the TTS software in the public venue of the lecture is thus entwined in the complex social management of her reading disability.

This example only scratches the surface of the many sociocultural and environmental factors that influence AT adoption and abandonment. Some assistive devices are purchased through medical or health services, others through school systems. Each institution has different policies concerning funding and priorities (King, 1999). Individual users may have different responsibilities as well. In the United States, schools hold the responsibility for providing accommodations to students in grades K-12. In postsecondary education and employment, however, the disabled person is responsible for requesting and proving the need for accommodations (Cory, 2005). Finally, and perhaps most importantly, cultural views and stigmas vary across different disabilities and are likely to influence the actions of an individual with a disability (McDermott, 1993; Cory, 2005).

Understanding AT adoption and abandonment can be thought of as a five-way interaction that I refer to as the *PATTC* framework. I synthesized this model from my readings on the adoption and usage of assistive technologies (discussed in more detail in Chapter 4, Section 4). As shown in Figure 1.1, the model consists of a *person* with a specific set of (*dis*)abilities attempting to perform a *task or activity* with a specific *technology* framed in a particular sociocultural-environmental *context*. The interaction of the five components can be

instantiated many times in many ways due to the breadth and diversity of the components. Fortunately, there is considerable overlap through user profile; similar tasks and technologies; and common contexts. Still, the fact remains that AT adoption and abandonment is a complex, challenging topic for study.

3 Studying the Complexity

Studies of AT adoption have addressed this complexity in different ways. Early studies of AT adoption aimed at understanding these many instantiations and overlaps as a whole (Martin & McCormack, 1999; Phillips & Zhao, 1993; Riemer-Reiss & Wacker, 2000). Their work established a foundation from which guidelines could be developed for the design, evaluation, and recommendation of assistive technologies (King, 1999).

To provide deeper insights, more focused studies began to appear in which researchers constrained some of the components in the PATTC framework. Wehmeyer (1995, 1998) concentrated on adults with mental retardation but kept the tasks, technologies, and contexts unconstrained in his survey on AT use by adults with mental retardation. Dawe (2005, 2006, 2007a, 2007b) focused her efforts even further by constraining the technology and tasks in her research on the design and adoption of a personal communication device for young adults with moderate to severe cognitive disabilities such as Down syndrome and autism spectrum disorders. By placing constraints on the PATTC's components, Dawe and Wehmeyer delved deeper into understanding AT adoption and usage within their specific areas of interest. This deeper understanding then enabled them to design technologies to better meet their users' needs as well as allowing the researchers to explore more targeted interventions for promoting AT usage.

4 Overview of Dissertation

This dissertation is about understanding and supporting the adoption of assistive technologies by adults with reading disabilities, thus continuing in the same vein as the focused studies of Dawe and Wehmeyer. As with their studies, various components of the PATTC framework are constrained. Only reading disabilities are considered, and persons of interest are constrained to adults with RD, with a particular focus on adults enrolled in postsecondary education. Tasks are constrained to those involving reading and can range from the informal (e.g., reading the newspaper, surfing the web, enjoying a novel) to the formal (e.g., reading for university courses or work). Otherwise, no restrictions are placed on the technologies nor the sociocultural-environmental contexts. All possibilities for these two components are open for consideration. Through this mix of constraints and openness, a deep understanding of the complex factors that lead to the adoption and usage of ATs for adults with reading disabilities is obtained. These insights also provide direction for evaluating current ATs and provide recommendations for future design. A prototype AT based on these recommendations and some preliminary user evaluations are also presented.

Forming the central framework of the dissertation is *Value Sensitive Design* (VSD) (Friedman, Kahn, & Borning, 2006). An established design methodology, VSD includes and accounts for human values throughout the design process. To date, VSD has been applied to a wide range of technologies and topics, including browser security (Millett, Friedman, & Felten, 2001), urban planning and simulation (Borning, Friedman, Davis, & Lin, 2005), and groupware (Miller, Friedman, & Jancke, 2007). However, this dissertation is the first application of VSD to the design of assistive technology.

Framed as an interactional approach, VSD argues that while social systems and people do shape the development of technology, technology also shapes and influences the behavior of individuals and society (Friedman, Kahn, & Borning, 2006). To capture the complex dynamics at play, VSD uses a tripartite methodology (conceptual, empirical, and technical investigations) derived from many fields of study. Law, philosophy and ethics are brought in during the conceptual investigations. Research methodologies and models from the social sciences are utilized in the empirical investigations. Design, performance, and human factors knowledge from engineering and related sciences are involved in the technical investigations.

The interdisciplinary nature of VSD is particularly important given the many disciplines relevant to the research topic of this dissertation. Education and literacy studies provide the knowledge about reading disabilities and the reading process. Communication studies brings in the theories and methodologies of technology adoption and innovation diffusion. Disability studies gives insights into the social and cultural aspects of disability. Computer science and its sub-field of human-computer interaction address the technologies at play. Each discipline provides critical insights and knowledge, and all had to be brought together to produce the work presented here.

4.1 Contributions

The research contributions of this dissertation are listed in Table 1.1. Some of the findings add to the fields of assistive technologies and Value Sensitive Design. Primarily, though, this work provides an understanding of the many factors influencing the adoption of assistive technologies by adults with reading disabilities. Through the development of a value-stakeholder framework, it will be shown that the decision by adults with RDs to hide their disability from others is influenced by values of normalcy, literacy, and community. Technology usage reflects this dynamic, but the ATs currently available fail to address these values and the choice to not publicly disclose. Approaches for designing technologies that better support the values of the various stakeholders are developed, including a proposal for a system to help users with reading disabilities to navigate perceptions of normalcy across various social contexts.

4.2 Outline

Before engaging in the VSD process, the next three chapters provide relevant background information and discussions of related work. Chapter 2 provides a thorough foundation on reading disabilities. Assistive

Table 1.1: Summary of research contributions from this dissertation.

CONTRIBUTION	CHAPTER(S)
Applying value sensitive design to adults with reading disabilities, assistive technologies, and technology adoption	
<ul style="list-style-type: none"> Development and refinement of a value-stakeholder framework to describe factors influencing adoption of assistive technologies by adults with reading disabilities 	6–8
<ul style="list-style-type: none"> Analyses of online discussions about reading disabilities, technology, and society 	7
<ul style="list-style-type: none"> Interviews with young adults with reading disabilities about their literacy practices, social interactions, disability impact, technology usage, and values 	8
<ul style="list-style-type: none"> Value-based reviews of existing reading technologies 	9
<ul style="list-style-type: none"> Value-based recommendations for designing assistive reading technologies 	10
<ul style="list-style-type: none"> Proposal for socially-flexible reading tools that support users by promoting self-advocacy with the aid of meta-tools 	11
Insights about assistive technology design and adoption	
<ul style="list-style-type: none"> Identification, analyses, and discussions about the lack of assistive technologies for adults with reading disabilities 	3
<ul style="list-style-type: none"> Synthesis of the PATTC framework for understanding technology usage 	4, 5
<ul style="list-style-type: none"> Applying semiotic engineering to assistive technology design 	11
Contributing to and expanding the value sensitive design methodology	
<ul style="list-style-type: none"> Introduction of theme-value literature analysis as a tool for value identification in conceptual investigations 	6
<ul style="list-style-type: none"> Expansion of the concept of indirect stakeholders to include individuals who affect the usage of technology by the direct stakeholders 	6
<ul style="list-style-type: none"> Generalization of the value dams and flows methodology 	6

technologies for RDs and their studied effectiveness are then discussed in Chapter 3. Concerns regarding what technologies are commercially available and the level of research interest in technology-driven fields like computer science are also discussed. Following that, Chapter 4 discusses technology adoption and related theories and models. The chapter also focuses on studies of assistive technology adoption and provides arguments for the lack of research on AT adoption for reading disabilities. The PATTC framework is also looked at in greater depth.

The overarching research approach for the dissertation is presented in Chapter 5, and Value Sensitive Design is fully described. The different research activities presented in Chapters 6 through 11 are also introduced in relation to the VSD framework. An initial set of stakeholders and values are developed via a literature review in the conceptual investigation in Chapter 6. Analyses of the values and stakeholders reveal

the complex dynamics shaping AT adoption among adults with reading disabilities. Issues hypothesized to be of critical importance are detailed. Chapters 7 and 8 describe empirical investigations for validating and refining the value and stakeholder analysis. Online discussions about reading disabilities and technologies from message boards and newsgroups are analyzed in Chapter 7. Case studies of adults with reading disabilities and the technologies in their lives are presented in Chapter 8. Technical investigations then begin with value-based evaluations of existing assistive technologies in Chapter 9 and continue with the formulation of new AT design recommendations in Chapter 10. Using these guidelines, a prototype AT is proposed and described in Chapter 11.

In addition to a summary of the work and concluding remarks, Chapter 12 suggests several directions for future work. Additional studies to refine the value-stakeholder framework are discussed as well as implementation plans for the Calico system described in Chapter 11. Further applications of the work and findings are also commented upon, including related topics to which the findings and methodologies of this dissertation may apply.

NOTES TO CHAPTER 1

- 1 A running theme throughout this dissertation involves issues in selecting appropriate terminology. To start, my choice of the term “assistive technology” bears some discussion. Within the field of disability and technology, several adjectives beginning with the letter ‘a’ are frequently used when discussing technologies and people with disabilities—accessible, adaptive, and assistive. Although these terms may seem interchangeable, subtle differences exist.

Accessible technologies do not necessarily support or help people with disabilities. Accessible implies that a technology can be used by people with disabilities either directly or through an intermediary service or device. For example, a web browser is on the surface inaccessible to a blind user, but by providing various software hooks or application programming interfaces (APIs), screen readers can work with the browser to provide access. Thus, the browser is considered to be accessible.

Similarly, the term *adaptive* is sometimes used to refer to technologies that support users with disabilities. It is also used more generally to mean any technology that adjusts its function and interface to a user’s needs (Gajos, Czerwinski, Tan, & Weld, 2006). This can apply to technology for both non-disabled and non-disabled users, leading to ambiguity in usage of the term “adaptive technology.”

However, *assistive* is used to describe technologies that directly support and address the needs of users with disabilities. In the United States, assistive technology became an official term when it was legally defined in the Technology-Related Assistance for Individuals with Disabilities Act (1988):

The term “assistive technology device” means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.

More generally, the term “assistive technology” can refer to devices as mentioned above or to services that deliver and support the use of such devices.

I use the term “assistive technology” exclusively in this dissertation but not in the same connotation as above. My usage refers only to devices as this dissertation primarily pertains to tools for supporting reading. Services, when mentioned, will be explicitly stated as such.

- 2 *Abandonment*, also called *discontinuance*, is when a user makes the decision to purchase and use a technology for an extended period but stops using said technology well before the expected lifetime of usage (Rogers, 2003). The expected lifetime of usage is a key requirement. A person who stops using crutches after healing from a sprained ankle has not abandoned the crutches.

Substituting one device for another is also generally not abandonment. Replacing a hearing aid that has stopped functioning and upgrading to a newer version of software are not examples of abandonment.

However, switching to a new brand of hearing aid or software may be abandonment of the older brand, depending on the motivation and circumstances. For example, if the old software is obsolete or incompatible with a newer operating system, then the user really had no choice but to change. This would be a simple matter of *replacement*, not abandonment.

Adding to this careful consideration of terminology, abandonment is also different from *rejection*, which is the decision to not purchase and thus not use a technology. Understanding abandonment, replacement, and rejection are both critical components of technology adoption theory and are discussed in greater detail in Chapter 4.

- 3 Unfortunately, *Mainstream* is a magazine targeted towards people with disabilities and not a scholarly journal. As such, Tewey et al. (1994) fail to cite the studies or provide detail on the abandonment rates they reported. However, common sense and personal communications with Dr. Richard Ladner (professor of computer science and engineering, University of Washington) can suggest some possibilities. The 8% abandonment rate was likely for more life-critical technologies, such as breathing or feeding aids. The higher abandonment rates were likely for hearing aids, which have a reputation for poor acceptance among first-time users.
- 4 Blindness is generally recognizable in others due to common signs and traits, such as a usage of a white cane, dark glasses, or lack of eye contact and focus. To be fair, exceptions do exist. One notable example is Stephen Kuusisto. In his memoir (1998), Kuusisto relates how, despite being born legally blind, he actively denied and hid his blindness from others, even riding a bicycle well into his 20s. Although he often wore thick glasses that provided only minor help, only family members and a few close friends were privy to the extent of his vision problems. Kuusisto chose not to engage in any activities that would label him as a blind man until his 30s. Only then did he start using a cane and eventually received his first guide dog.

CHAPTER 2

READING DISABILITIES

As we drove home down the 405 that summer, I tried to think of all the parts of myself that I was ashamed of, that I thought didn't fit. I talked too fast, cursed, couldn't spell, couldn't sit still, mispronounced words, and interrupted people. I cried for a minute then told myself to stop. I decided, at twelve years old, as dramatic as this sounds, that I would be a soccer player, nothing more. Just be that dumb jock. . . . This was the only way I could envision my life.

— Jonathan Mooney, *The Short Bus* (p. 32)

This chapter provides critical background knowledge about reading disabilities. Reading disability is defined, and statistics on the prevalence of RDs are stated. An overview of the reading process is also provided to better illuminate how traits common to RDs affect the act of reading. The diversity of these traits, both negative and positive, are then described.

1 Definitions and Terminology

Many terms are used to refer to disabilities that affect reading. *Dyslexia* is perhaps the most well-known, but other terms used over the years include word blindness, phonological processing disorder, strephosymbolia (twisted letters), and visual stress (Edwards, 1994; Wolf & Boulton, 2007). Dyslexia is sometimes broken into different subtypes: auditory, phonological, and orthographic (Evans, 2001). Each term reflects changing scientific perspectives that emphasized or ignored different symptoms and traits (Pollak, 2005, Chapter 1). The meanings have been further shifted in disability legislation and educational policies by politicians and administrators. Popular notions, sometimes wildly inaccurate from what science tells us, have become ingrained in our daily lives (D. Mills, 2005). As each term brings with it a conflux of politics, histories, assumptions, and nuances, they are not interchangeable. Rather than selecting one to use consistently, I choose to use the more general, catchall term *reading disability* (RD). This choice does not restrict me to any one condition. At times, I will use a more specific term when referring to the work of others or quoting the term used by a person with an RD.

1.1 Defining Reading Disability

Still, defining reading disability is a complicated matter, due in part to a history of changing views as to underlying causes. As originally hypothesized by James Hinshelwood in 1895, a neurological deficit led to “word blindness” in individuals of otherwise fair intelligence. Debate and questions raged as to whether said deficit existed from birth or was the result of trauma (Edwards, 1994; Sandak, Mencl, Frost, & Pugh, 2004; Mooney, 2007).¹ Others suggested that the fault lay in the eyes and other sensory systems (Edwards, 1994; Evans, 2001). Perhaps, voiced another group, RDs are not the result of a defect or problem, but just an extreme learning style or multiple intelligence antagonistic to reading (Powell, Moore, Gray, Finley, & Reaney, 2004; Mooney, 2007) or constructed and exacerbated via social expectations (McDermott, 1993).

Despite the hundred plus years of debate, two elements have always been present in the definition of RDs. First, and perhaps the more essential of the two, the person exhibits profound difficulty in learning and performing the process of reading and related tasks (e.g., writing and spelling). Secondly, the person is provably intelligent but still experiences difficulty with reading even after tutoring and education is provided.

1.1.1 Definition and Diagnosis by Exclusion

Defining a reading disability is often accomplished by explaining what it is not. When a person, often a young student but occasionally an adult, shows marked difficulty with reading, the first course of action is to rule out other potential causes for the difficulty. For example, consider the RD definition used by Dickinson, Gregor, and Newell (2002, p. 97):

A disorder manifested by difficulty in learning to read despite adequate intelligence, and sociocultural opportunity

The first alternative explanation to rule out is the subject’s intelligence. Intelligence testing helps confirm if the cognitive potential is present for engaging in reading. Such testing is typically not limited to just general intelligence measures (i.e., IQ) and will often involve assessments of multiple skills and abilities. For example, the Weschler Intelligence Scale for Children (revised) gives measures of multiple skills, including vocabulary, reading comprehension, arithmetic abilities, memory, and spatial reasoning (Edwards, 1994). Such assessments better identify the person’s areas of difficulty, and it is not uncommon for a person with RD to show inconsistent levels of ability on the different skills. Edwards (1994, p. 5–9) provides an example of a dyslexic student who, despite being significantly below average in some reading and memory skills, scores in the top percentile on abstract reasoning, vocabulary, and judgment skills.

The second alternative explanation to exclude in Dickinson et al.’s RD definition is lack of sociocultural opportunity. By this, they mean that the person should have received at least some initial instruction in the unnatural² act of reading. Furthermore, unpracticed skills fade over time. Just as how learning French in high school but not using it until a trip to Paris twenty years later will be problematic, a person’s reading skills and

abilities will grow rusty and inefficient without regular practice. Simply put, a person needs the opportunity and encouragement to practice reading beyond the initial instruction.

The definition used by Dickinson et al. (2002) fails to exclude another potential reason for poor reading performance: poor vision. Many definitions of reading disabilities also recommend ruling out any potential visual impairments before labeling a person as having an RD (Evans, 2001). Being blind or having low vision is a sensory disability, not a reading disability.³ Additionally, vision problems like nearsightedness, farsightedness, and astigmatism can hinder the reading process by inducing physical strain and exhaustion when reading. Evans, a professor of optometry, has experienced and commented about multiple cases of children struggling with reading showing marked improvement after receiving proper vision care (2001).

1.1.2 Working Definition

Reasonable alternatives are thus always ruled out before diagnosing a reading disability. Although it may seem unscientific to define RD as poor reading performance for reasons not identified, remember that reading disabilities are best thought of as a syndrome of related conditions. Moreover, reading itself is a complex process and problems can manifest at any point or points in that process. Diversity is to be expected. This is why after ruling out other possibilities, additional neuropsychological exams are then administered to better understand the exact nature of the person's reading disability (Edwards, 1994; Peer, 2001; Ashton, 2001). Thus, the definition of reading disability used in this dissertation reflects both ruling out alternatives and the inherent diversity possible:

A reading disability is a syndrome of multiple conditions in which a person experiences difficulty with one or more aspects of the reading process despite possessing sufficient intelligence, learning, practice, and sensory capability.

1.2 Related Terminology

As shown in Figure 2.1, reading disabilities are a subset of several classes of disability. Although this dissertation focuses on RDs, these other classes occur frequently enough in the literature to warrant a brief coverage here. Working inward, this all begins with the concept of *disability*. As defined by the Americans with Disabilities Act (ADA) (1990) and the World Health Organization (Sears & Young, 2003), a disability is a physical or mental difference/impairment that negatively impacts one or more major life activities.⁴

One major subclass of disability is *cognitive disabilities*. Associated with the brain and its functioning, these disabilities affect aspects of learning, memory, emotions, thinking, sensory processing, socialization, and communication (American Psychiatric Association (APA), 2000; Dawe, 2006). They also range in degree of severity: mild, moderate, severe, and profound. Thus, a broad range of conditions are considered cognitive disabilities. Psychological conditions such as obsessive-compulsive disorder and depression are members of



Figure 2.1: Venn diagram showing the nested relationship of reading disability to specific learning disability to learning disability to cognitive disability.

this class. Cognitive disabilities also include conditions acquired after brain trauma or strokes, such as aphasia and amnesia. Most sensory disabilities are not cognitive disabilities, however, as the disability is usually in the sensory organ and not the brain / information processing behind the sense.

Of particular importance to the topic of this dissertation is the subclass of cognitive disabilities known as *learning disabilities* (LDs). Typically of mild to moderate severity, a learning disability affects the learning and maintenance of new skills (APA, 2000). LDs are often thought of as being of two types. General learning disabilities affect all areas of learning. Example of this type includes attention-deficit disorder (ADD/HD)⁵ as well as some forms of mental retardation, brain trauma, and autistic spectrum conditions.

Specific learning disabilities (SpLDs), on the other hand, only affect the learning of a specific set of skills (APA, 2000). A reading disability is an SpLD that impairs reading. Other SpLDs include dyscalculia (mathematical ability), dysgraphia (handwriting and composition), and dyspraxia (motor coordination). For the vast majority of people with SpLDs, their general abilities to think and act are within a range of normal expectations for their age. In fact, as discussed earlier, people with SpLDs typically show inconsistent ability levels on different cognitive tasks. However, if an individual has one SpLD, he or she is likely to also have other specific learning disabilities, though the degree of severity will differ. In particular, 80-90% of all people with SpLDs have been found to experience significant difficulty with reading (Kavale & Reese, 1992; Eden & Vaidya, 2008).

Not shown in Figure 2.1, RDs, LDs, and some cognitive disabilities are also members of the class of

hidden/invisible disabilities (Cory, 2005). As the name suggests, hidden disabilities are not readily apparent to others. Many disabilities have visual markers of the condition that broadcast their presence: wheelchairs, tics, white canes, hearing aids, etc. When a person with an invisible disability interacts with others, knowledge of the disability will only be made known if the person discloses the disability to somebody. One cannot simply look at a person and know that he or she has a reading disability. Thus, invisible disabilities allow a person to choose to pass as normal thereby avoiding any perceptions or stigmas associated with his or her disability.

Another classification scheme identifies people with *print* or *text access* disabilities as a group. With these disabilities, the primary issues of access concern written or printed text (Bookshare, 2010b). This disability class includes RDs as well as many visual disabilities. Some motor disabilities may be included if one considers that holding and turning pages of a book are issues of text access.

2 Prevalence of Reading Disabilities

The invisible nature of RDs provides a challenge in determining the number of individuals affected by them. The aforementioned vagaries of definitions and the usage of different terms to label the condition further complicate the task. One particular complication is determining at what point difficulty with reading is severe enough to warrant the label of a reading disability. Another difficulty is that statistics on disabilities may combine reading disabilities with other learning disabilities.

2.1 Statistics

Studies have revealed that upwards of 90% of individuals of all ages with learning disabilities experience significant difficulties with reading (Kavale & Reese, 1992). With these difficulties in mind, current estimates indicate that between 5 and 15% of the world's population has some form of an RD (Sands & Buchholz, 1997; Evans, 2001). More specific statistics regarding RDs among adults are available from educational institutions. In the 1990s, students with learning disabilities enrolling in U.S. postsecondary institutions were the fastest growing group of students enrolling with reported disabilities. A biennial survey found that the percentage of college freshmen reporting having a learning disability grew from 1% in 1988 to 2.4% in 2000, which represents approximately 27,000 out of 1.1 million undergraduates (Henderson, 2001).

Furthermore, the size of the RD population relative to other disability types is large. According to a 1999 NCES study, students with LDs comprised 46% (195,870 out of 428,280) of students registered with disability services at 2- and 4-year postsecondary institutions in the United States (L. Lewis et al., 1999). The next largest group, mobility disabilities, was one-third the size. However, another NCES study (Horn, Nevill, & Griffith, 2006) that surveyed a sample of 80,000 undergraduates and 11,000 graduate students in the U.S. found that 11.3% of students reported having a disability, of which 7.1% reported having a specific learning disability and 25.3% reported mobility-related disabilities.

The differing findings of the two NCES studies highlight some of the difficulties in gathering statistics on disability prevalence. Foremost is the difference between confirmed disability status used in the 1999 study versus self-reported identification used in the 2006 study. Some of the self-reports may be false, while some disabled students may not self-report. Flaws also exist in considering only students registered with disability services. Disabled students are not required to register; they have complete control over that decision. Thus, the raw numbers in the 1999 study probably undercounted the true number of students with disabilities. Moreover, studies have indicated that students with invisible disabilities, which include LDs and RDs, tend to avoid disclosing their disabilities and often avoid or delay registering with disability services (Henderson, 2001; Cory, 2005). This suggests that students with LDs were unlikely to have been counted accurately in either NCES study. Regardless of the actual numbers, students with RDs/LDs are clearly present in postsecondary education.

2.2 Languages

Variations of reading disabilities occur in all languages, even logographic languages like Japanese (Smythe, Salter, & Everatt, 2004). How the RD manifests, however, is dependent on the language and its complexity. With English and Greek, for example, the languages differ greatly in terms of orthographic depth—the complexity of the phonological mapping between letters and sounds. English has a notoriously complex mapping (e.g. *-ough* can be pronounced at least six ways), while Greek uses a simpler, regular mapping with very few exceptions (Seymour, Aro, & Erskine, 2003; Protopapas & Skaloumbakas, 2007). Thus, a person with an RD in English is more likely to experience difficulty with identifying and sounding out words due to the inherent difficulty within the language. For Greek individuals with RDs, word identification problems are less common. However, both English and Greek individuals with RDs experience slower reading speeds than the typical population (Protopapas & Skaloumbakas, 2007).

3 The Reading Process

A key to understanding reading disabilities is to understand the actual process of reading—from visual identification of letters on the page to comprehending a text in isolation as well as relative to previously read texts. Figure 2.2 shows a simplified model of reading broken into four component stages. Each stage

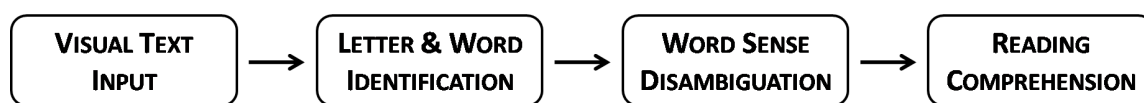


Figure 2.2: Diagram of the main stages of the reading process. For clarity, talkback from latter stages to previous stages is not shown.

depends on the outcomes of the previous ones. Thus, errors or difficulties experienced in one stage may lead the reader to return to a previous stage.

3.1 Visual Text Input

With the exception of haptic approaches like Braille, reading begins with the eyes. Light reflects off of the reading surface (page or screen), enters the eye, and triggers a series of chemical reactions that send nerve impulses to the visual cortex. The same events occur when we watch television, gaze at the stars, or look at a pony. Although the underlying sensory process is the same, several aspects make reading a unique visual task. Reading requires attention to a finely detailed scene composed of a series of similar shapes. These shapes are laid out in a regular fashion in what is essentially a two-dimensional format. Thus, reading contrasts sharply with most of the visual tasks we conduct in our daily lives (Everatt et al., 1999; Evans, 2001).

When it comes to how the eye moves during reading, one might think that the eye scans continuously across each line, inputting each character one by one. Eye tracking studies, however, reveal a punctuated process (Tinker, 1965; Rayner, 1983). The reading eye actually operates via repeated sequences of pauses (fixations) and movements (sweeps and saccades).

During a *fixation*, the eye is paused for 100–500 milliseconds, with an average of approximately 250 milliseconds (Rayner, 1983). This pause allows the eye to take in a set of characters—the *perceptual span*. Quantifying how many characters are found within the perceptual span is complicated. Only 4–5 characters are seen with perfect acuity, but surrounding text is also seen. Although seen with less acuity, some visual processing is applied to this surrounding text (Geiger & Lettvin, 1999).

After a fixation, the eye usually moves on to the next text. At the end of a line, a large motion known as a *sweep* occurs to move the eye to the start of the next line. Otherwise, the eye moves forward an average of 7–9 characters. This motion, called a *saccade*, takes only 20–30 milliseconds (Rayner, 1983). Not all saccades move forward in the text (to the right in English); the eye may engage in a *regression* to review previously read text. During sweeps and saccades, the visual system runs in a reduced capacity, omitting fine details that would blur due to the eye's motion (Pepper & Lovegrove, 1999; Evans, 2001).

3.2 Letter and Word Identification

The next stage of reading, as shown in Figure 2.2, begins the deciphering the inputted text via identifying letters and words. The actual process for how this identification occurs has been one of the most debated topics in the reading sciences (Perfetti, Zhang, & Berent, 1992). Multiple models for word identification exist (Harm, McCandliss, & Seidenberg, 2003; Perfetti, Liu, & Tan, 2005; Coltheart, 2006), but discussing and debating their relative merits is beyond the scope of this paper. Instead, only the *dual-route model* is highlighted due in part to its record of empirical support (Perfetti, 1999; Seymour et al., 2003; Coltheart, 2006) and, as shall be shown, its utility in understanding the nature of reading disabilities.

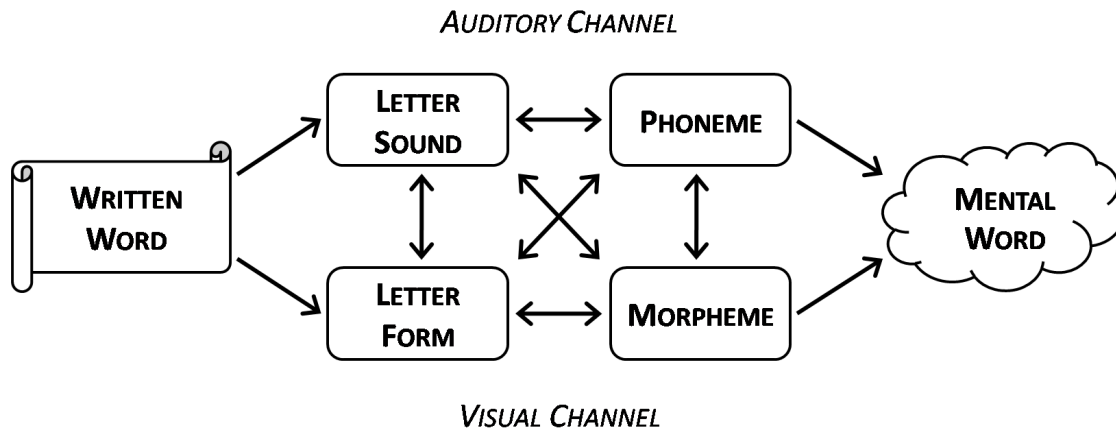


Figure 2.3: The dual-route model of word identification.

Figure 2.3 highlights the two key components of the dual-route model of word identification. First, words are identified through an incremental process in which the identification of letters and common letter groupings (e.g., “de-” and “-ing”) build up to word recognition. Second, two parallel processes work in conjunction: a visual channel and an auditory channel. The visual channel uses the shapes of letters and morphemes (groups of letters) to build up a notion of the word. The aural route simultaneously converts the symbols to simple letter sounds and more complex phonemes. For example, the word “greats” could be separated into the phonemes “gr-,” “-ate,” “-eet,” and “-s.” Note that the morpheme “eat” has two common pronunciations, hence the activation of both possibilities. Each morpheme and phoneme is associated with various words, and via the dual-route model, the most likely word is chosen.

Brain scans and studies of people with brain trauma have demonstrated that these channels exist and are processed separately in the brain (Coltheart, 2006). Although separate, the two processes show signs of intercommunication (Perfetti et al., 1992). *Reading fluency*, the ability to read both accurately and quickly, depends on proper functioning of both channels.

Despite their equal importance, the auditory channel has been shown to be the primary driver of word identification—an unsurprising result given language’s vocal origins (Perfetti et al., 1992). Still, some words are recognized quickly by the visual channel. Known as *sight words*, these words are those encountered frequently by readers (Ehri, 1997). Examples include articles, words of short length, and common verbs. Other sight words are words that fall outside of the language’s rules for spelling and pronunciation, thus posing a challenge for recognition by the auditory channel. Development of sight words is a necessary trait for becoming a fluent reader (Ehri, 1997).

Although not shown in Figure 2.2, difficulty with identifying the current word may trigger a regression saccade. This then allows for review and error-checking of previous letters and words. For long words in particular, misidentification of earlier letters and word parts will stymie and complicate word identification.

3.3 Word Sense Disambiguation

Reading does not stop with the deciphering of words, though. Reading comprehension begins with the association of meaning to identified words (see Figure 2.2). The challenge here is that in many languages, words often have multiple meanings or senses. *Word sense disambiguation* is the task of identifying the most relevant interpretation of the word given the context of the surrounding text. Consider the sentence: “The bank was flooded with patrons demanding quarters.” The word “bank” alone has at least eighteen distinct meanings (Table 2.1). Knowledge of grammar automatically rules out eight of the senses, however, as bank is used as a noun and not a verb.

However, grammar alone is not sufficient to completely disambiguate the senses of words. The W. Kintsch (1998) model of sense disambiguation and comprehension during reading consists of two phases: *construction* and *integration*. During the construction phase, a mental representation is formed of the text. Word by word, new propositions, sense interpretations, and relations are constructed and added to this representation base on the text and its grammar. At this stage, however, the model may contain inconsistent, contradictory elements due to the presence of multiple sense interpretations. The integration phase addresses these inconsistencies by calling upon the reader’s knowledge and experience relevant to the current understanding of the text. Using this information, the text representation is pruned by rejecting inappropriate parts while maintaining the most consistent and coherent ideas. Construction and integration repeat as more text is read.

Figure 2.4 shows a simplified example of Kintsch’s model in action. Four iterations of the construction-integration process are shown for the sentence: The bank was flooded with patrons demanding quarters. Initially, no distinction can be made of the word “bank.” Two likely senses for bank are conceptualized: side of a river and money institute. It is unlikely that both are simultaneously relevant, but both possibilities are included in the model. Next, the word “flooded” lends support to “side of a river” being the better interpretation given that flooding is more associated with water than an institution involving money. The word “patrons” reverses this support, making either of the two senses likely. Upon reading the word “quarters,” the reader’s mental understands that a large mass of people demanding 25-cent coins have entered the bank building.

An aspect of Kintsch’s model not shown in Figure 2.4 is the key role of memory. Sense disambiguation occurs via personal knowledge and the read text. However, the process is constrained by the limits of working memory. With each word and sentence, parts of the mental representation are shunted off to long-term memory in order to make room for the next piece of text. The few components that remain provide context that is used in the comprehension of the next sentence as well as retrieval cues to the information in long-term memory (W. Kintsch, 1998).

Additionally, Kintsch’s model suggests why sense disambiguation may break down. If an earlier word has been misidentified, the current working understanding of the text may be malformed or misleading. Poor or

Table 2.1: The 18 senses of the word “bank.” Retrieved from WordNet Search 3.0 at <http://wordnetweb.princeton.edu/perl/webwn> on March 21, 2010.

- noun**
1. sloping land (especially the slope beside a body of water)
 2. a financial institution that accepts deposits and channels the money into lending activities
 3. a long ridge or pile
 4. an arrangement of similar objects in a row or in tiers
 5. a supply or stock held in reserve for future use (especially in emergencies)
 6. the funds held by a gambling house or the dealer in some gambling games
 7. a slope in the turn of a road or track; the outside is higher than the inside in order to reduce the effects of centrifugal force
 8. a container (usually with a slot in the top) for keeping money at home
 9. a building in which the business of banking is transacted
 10. a flight maneuver; aircraft tips laterally about its longitudinal axis (especially in turning)
- verb**
1. tip laterally
 2. enclose with a bank
 3. do business with a bank or keep an account at a bank
 4. act as the banker in a game or in gambling
 5. be in the banking business
 6. put into a bank account
 7. cover with ashes so to control the rate of burning
 8. have confidence or faith in

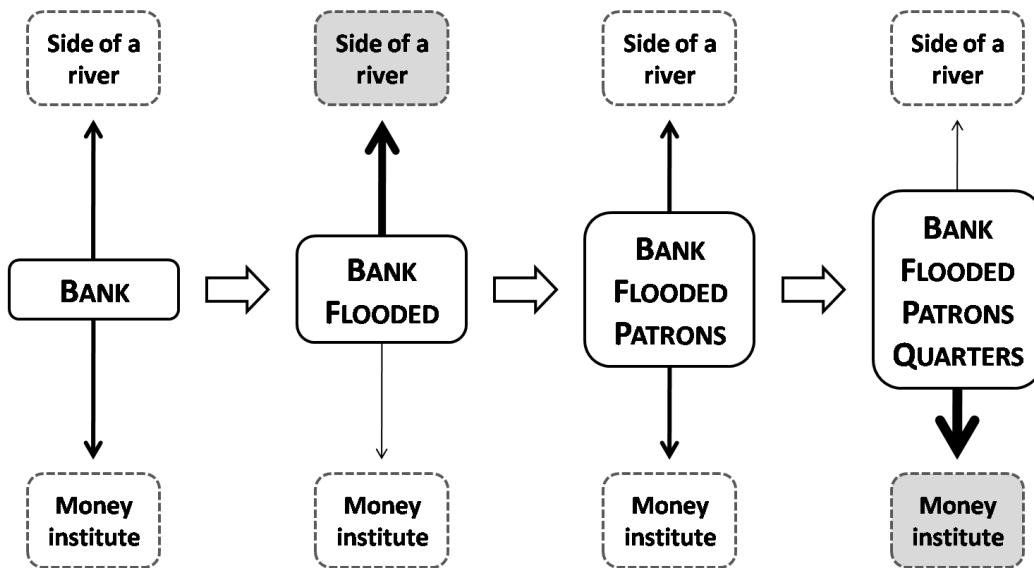


Figure 2.4: Mental model (based on W. Kintsch, 1998) held by the reader of the sentence: The bank was flooded with patrons demanding quarters. The reader’s mental model for the word “bank” after the construction and integration phases are shown. For clarity, only senses 1 and 2 from Table 2.1 are shown.

limited working memory may also lead to a poor mental model of the text. Additionally, the reader's own knowledge background relative to the text is critical. If the knowledge is lacking, the mental representation will not be able to reduce the level of coherency and will result in a larger mental representation to deal with. As more text is read, the size limit of working memory forces large chunks of this representation into long-term memory. Without this context, the interpretation of a word or sentence may become independent of the previous ones. Greater relevant knowledge will lead to the reader having a refined, well-developed text representation that stays in working memory. Such problems with sense disambiguation may lead the reader to reread previous text, thus reengaging the earlier stages of the reading process.

3.4 Reading Comprehension

Reading comprehension goes beyond understanding the meaning of individual words, however. Comprehension is not just about making sense of a text but also the ability to predict, summarize, question, and clarify parts or the whole of a text (Palinscar & Brown, 1984). Different reading tasks also demand different types and levels of comprehension. Some tasks concern finding a specific piece of information (Fraser & Schwartz, 1979). Others are about deep interpretation and meaning-seeking, such as in reading poetry (Peskin, 1998). Identifying an author's motivation and determining his or her credibility are other common tasks (Haas & Flower, 1988; Wineburg, 1991; Britt, Perfetti, Dyke, & Gabrys, 2000). Comprehension can also involve the comparison, contrast, and integration of multiple texts (Wineburg, 1991; Spoehr, 1994; Perfetti, Rouet, & Britt, 1999; Wiley & Voss, 1999).

The inherent vastness of what reading comprehension entails and requires cannot be discussed in full in the confines of this simple introduction. However, several factors are known to influence comprehension. As shown in the Kintsch model, relevant situational knowledge is a critical aspect for successful comprehension (Perfetti, Marron, & Foltz, 1996; W. Kintsch, 1998). An important aspect for acquiring such knowledge is through texts previously read by the reader. Novice-expert studies of reading skills in specific disciplines have shown that more experienced readers tend to recall and reference texts they are familiar with (Haas & Flower, 1988; Wineburg, 1991; Peskin, 1998).

Proper letter and word recognition skills are also strongly associated with efficient reading comprehension. Holmes (2009) showed in a study of adult readers that rapid and accurate low-level reading processes liberate resources for the crucial higher-level comprehension processing, ultimately resulting in more efficient text comprehension. Similarly, how a text is structured can influence the efficiency of reading as well as recall of the text. Different structures can benefit or hinder different reading tasks such as exam taking (Santos Lonsdale, Dyson, & Reynolds, 2006) and information searching (Fraser & Schwartz, 1979). More generally, as experts tend to organize data by forming conceptual neighborhoods (often hierarchical) of tightly-linked facts and concepts, texts that are structured similarly will tend to support recall (Spoehr, 1994).

Table 2.2: Summary of traits common to reading disabilities. Presence and severity of each trait is likely to significantly differ from individual to individual.

TRAIT	DESCRIPTION
Poor lateral masking	Difficulty filtering out surrounding text
More regression saccades	Repeated rereading of earlier text Potentially earlier onset of reading fatigue
Letter and word misidentification	Addition, substitution, or removal of letters Rearrangement of letters in a word
Rapid naming deficit	Slow visual recognition of letters and sight words
Phonological processing deficit	Slow recognition of phonemes Difficulty sounding out words
Comprehension difficulties	Rearrangement of words in sentences Difficulty disambiguating senses of individual words Fewer cognitive resources available for higher-level comprehension tasks
Memory issues	Less short-term working memory Slower recall Poor visual memory
Poor sequential processing	Difficulty following directions Skipping or repeating lines of text Problems remembering orderings
Visual stress	Movement and blurring of letters Headaches and eye strain Difficulty sustaining reading efforts
Writing difficulties	Poor spelling and proofreading skills Difficulty with logical organization
Attention issues	Increased comorbidity of ADD/HD Potential for distractibility and increased frustration Peripheral distractions when reading
Motor coordination difficulties	Increased comorbidity of dyspraxia Weaker fine motor control Poor body coordination
Social and psychological issues	Bullying and verbal / emotional abuse from others Low self-esteem, depression, and poor stress management Avoidance of or self-diminished performance with certain tasks
Visiospatial strengths	Strong spatial awareness Proficiency in abstract visualization tasks
Creative thinking skills	Increased lateral thinking skills Talents in art and design

4 Characteristics of Reading Disabilities

Now that a basic foundation about the reading process has been established, the specific characteristics of RDs can be discussed. As reading disabilities are a collection of conditions that affect a significant portion

of the population, one can reasonably expect a wide degree of diversity in how RDs manifest (Hammond & Hercules, 2003; Dickinson et al., 2002). A summary of these many traits is provided in Table 2.2, and this section provides coverage of these characteristics. Aspects specific to the reading process are presented first. Additional difficulties common to reading disabilities are also discussed as well as strengths and positive traits often found among people with RDs.

4.1 Difficulties with the Reading Process

The previous section detailed the reading process. This complex series of actions starts with vision and ends in high-level cognitive processing. Reading disabilities can impact every stage of this process. Moreover, each stage influences latter stages. When one reading specific reading challenge occurs, this will more than likely trigger a cascade of further difficulties.

4.1.1 Visual Input Issues

In terms of visual health, people with reading disabilities are very much like the general population (Evans, 2001). There is no evidence that people with RDs experience greater rates of nearsightedness, farsightedness, astigmatism, etc. Furthermore, despite earlier theories that RDs were a result of a mismatch between handedness and eye dominance (e.g., left-handed by right-eyed), crossed dominance is not more common among people with dyslexia than among the general population. There is, however, some minimal evidence to suggest that people with dyslexia require more physical effort to keep both eyes aligned correctly (binocular stability), which may produce blurry vision that could perhaps potentially negatively impact reading. As the many qualifiers in the previous sentence suggests, binocular instability is not viewed as a major contributing factor to RDs.

One identified difference in visual performance among people with RDs is in the capability to perform *lateral masking*. Lateral masking is the ability to filter out and ignore visual input outside of the primary region of visual focus. When reading, for example, a small section of text (a word or two) is placed in the foreground and seen in fine detail. The additional text to the left or right of this focus, however, is masked to reduce its clarity and any potential interference with the foreground. Geiger and Lettvin (1999) analyzed readers' ability to accurately recognize letters in the periphery of their vision. In ordinary readers, accuracy was highest near the center of the reader's gaze but dropped off quickly further from the center. For readers with dyslexia, though, accuracy remained higher further into the periphery. Thus, dyslexic readers have a reduced ability to mask and ignore surrounding letters when reading. However, this difference may not be an innate aspect of reading disabilities. Additional studies by Geiger and Lettvin (1999) showed that the differences in lateral masking could be influenced by the direction of fatigue and training. Notably, among dyslexic readers of Hebrew (which is read right-to-left), accuracy was maintained further into the left visual periphery than the right. Similarly, the accuracy was maintained further into the left periphery for for dyslexic readers of left-

to-right languages (e.g., English, Italian, and German). Geiger and Lettvin postulated that decreased lateral masking when reading may be an attempt at compensating for decreased reading performance.

Eye-tracking studies have also reported that people with RDs make more regression saccades than non-disabled readers (Rayner, 1983; Pepper & Lovegrove, 1999). These quick movements to previous text on a line have been shown to not be caused by improper eye muscle control, however. Instead, they are likely indicative of a need to reconfirm previously read text (Evans, 2001). Thus, the eyes of a reading-disabled reader engage in more overall movements than the typical reader.

Finally, going behind the eyes, the brains of people with reading disabilities also show some distinctive differences. Neuroimaging studies conclude that the brains of people with RDs more resemble those of beginning readers in that brain activity during reading is less distributed in both groups as compared to the distributed processing seen in more advanced readers (Bilger, Laginess-O'Neill, & Howes, 1998; Sandak et al., 2004). Thus, it is hypothesized that the reading processes in people with RDs use mental resources less effectively and are thereby less efficient at all stages of reading.

4.1.2 Letter and Word Misidentification

Misidentification of letters and words, often considered to be the hallmark trait of reading disabilities, can take many forms (Peer, 2001). Letters can be added or dropped from a word. Letter or words with similar shapes may be interchanged. Letters may be rearranged. These misidentifications significantly impact all of the reading process as word identification is an early and crucial stage of the process. Research into reading disabilities has largely focused on this stage of reading, and in doing so, two common performance deficits have been identified: a rapid naming deficit and a phonological processing deficit (Wolf & Bowers, 2000; Wolf et al., 2002). For many clinical definitions, a person with dyslexia is said to have one or both of these deficit (Wolf et al., 2002).

The *rapid naming deficit* refers to difficulty in the ability to quickly visually identify and name basic information signs such as letters or numbers. This deficit is most pronounced in the early stages of the dual-route model in Figure 2.3 (Letter Sound and Letter Form specifically). Despite its early place in the word identification process, this deficit does not intrinsically lead to misidentification due to calling a 'b' a 'd' or a '6' a '5'. The rapid naming deficit is primarily about the speed of reading.

To illustrate this distinction, Deeney, Wolf, and O'Rourke profiled a young boy with a rapid naming deficit but no other discernible reading disability. This nine year-old boy showed strong verbal skills and a well-formed vocabulary for his age. He would show remarkable slowness but high accuracy when reading—a distinct lack of fluency and automaticity. His awareness of being a slow reader would at time cause him to push himself to read faster, thus introducing more reading errors (misidentifying or skipping words). Thus, the rapid naming deficit is primarily about the efficiency of reading. It primarily impacts the recognition of

low-level elements of text (i.e., letters), but it can also limit the ability to achieve reading fluency due to the lack of acquiring sight words.

The *phonological processing deficit*, however, is more about processing than identification issues. Phonological processing is the ability to understand and manipulate the sound components of language. In reading, this includes translating individual morphemes into phonemes (see the dual-route model in Figure 2.3) as well as the ability to combine said phonemes into complete words. An individual with a phonological processing deficit experiences noticeable difficulty in performing these tasks in both speed and accuracy. Essentially, such an individual fails to develop the automaticity or fluency seen in average readers when it comes to sounding out words. Sarah Entine, a filmmaker with dyslexia, notes that as a child, the concept of letters making sounds was an alien notion to her and still is a difficult concept for her to grasp (Entine, 2009).⁶

As mentioned earlier in Section 2.2, the phonological mapping between letters and sounds does have some regular structure, though the complexity of the mapping does vary among languages. Readers with phonological processing deficits can thus develop strategies and rule sets to help with word identification. Unfortunately, words with irregular phonetic structures, of which there are many in English, can pose particular challenges. For example, the phoneme/morpheme “-eat” is usually pronounced with a long ē as in “eat” and “meat”. However, the word “great” is pronounced with a long ā even though the rules would suggest otherwise. Thus, a reader with a phonological processing deficit may misidentify the word as ‘greet’ instead.

Misidentification is also associated with a common misconception about reading disabilities—reversals. In English and many other orthographies, some characters can be flipped, rotated, or inverted to resemble other characters. A ‘b’ can become a ‘d’ through horizontal flipping, and either can become a ‘p’ or ‘q’ through a vertical transformation. Such reversals are often purported to be the main feature/cause of dyslexia: seeing letters backwards and/or upside-down (Harman, 1982; Gregor, Dickinson, Macaffer, & Andreasen, 2003; Entine, 2009). However, this reasoning is quite flawed. As Harman (1982) questions, why would the eyes of a dyslexic person only *occasionally* flip some characters and nothing else?⁷

The far simpler explanation is that reversals are a symptom, not a cause, of reading disabilities like dyslexia. Every reader has reversed letters at some point in their lives, and reversals are quite common in those learning to read. Even experienced readers may reverse a letter while reading, becoming more common when tired or rushing through a text (Harman, 1982). Most importantly, reversals occur during the process of word identification. A letter reversal will only occur if it results in an actual word. Quite simply, “bad” may become “dad,” but “different” will never be read as “bifferent.”

4.1.3 Word Sense Ambiguity

As previously discussed in Section 3.3, reading comprehension begins with determining the specific meaning or sense of the words. Moreover, word sense disambiguation can break down in multiple ways. An immediate

and obvious detriment is when a word is misidentified. An incorrect word essentially pollutes the working text model. Mental resources are wasted attempting to disambiguate the misidentified word. The invalid word also introduces irrelevant associations during the integration phase, further muddying the process. Unfortunately, recognizing that a word was misidentified does not instantly rectify the situation. Fragments of the erroneous word may persist in the reader's working model, falsely strengthening some concepts over others. Similar problems may occur when a word is accidentally skipped.

A person with an RD may experience further difficulties with sense disambiguation due to memory issues. Some people with RD report difficulties with memory and organizational skills, including the movement of short-term memory to long-term storage (Edwards, 1994; Raskind & Higgins, 1998; Mooney & Cole, 2000; Dickinson et al., 2002; Hammond & Hercules, 2003). Recall that Kintsch's model of sense disambiguation is constrained by the reader's working memory (W. Kintsch, 1998). Poor memory performance will hinder the reader's ability to maintain relevant information from previously read text, thus hindering the sense disambiguation process.

Furthermore, the sense disambiguation process is in part driven by the reader's knowledge relevant to the text. The more well read a reader is, the more efficient and effective the integration process will be (W. Kintsch, 1998). However, we know from longitudinal studies of reading behaviors, children who read less often than their peers continue to read less and less often relative to their peers as they reach adulthood (Cunningham & Stanovich, 1997). The struggles with early reading experienced by a child with an RD may very well lead to an aversion to reading and subsequent poor sense disambiguation. However, not all people with RDs become averse to reading. Jonathan Mooney, for example, was diagnosed with dyslexia in early childhood and graduated with honors in English literature from Brown University (Mooney, 2007).

4.1.4 Reading Miscomprehension

Misidentification and difficulty making sense of words in a text undoubtedly complicate and negatively impact reading comprehension in terms of both speed and accuracy. Venable (2003) identifies numerous ways in which word confusion can complicate understanding, including difficulties with metaphors, pronouns, sentence complexity, and inferring meaning from context. Memory issues may also influence comprehension, particularly in the recall of earlier sections in a large text or maintaining awareness of distinct components (i.e. characters or plot threads). Background knowledge and contextual information may also be lacking due to a hesitancy to engage in reading (although these can be gained through means other than reading).

However, recall that specific skills are needed for expert reading in a discipline (Haas & Flower, 1988; Wineburg, 1991; Peskin, 1998). How a reading disability may impact these higher-level skills, unfortunately, has not yet to be studied in detail. However, circumstances have enabled some critical issues to come to light. Due to disability education legislation in Britain, schools are required to include students with disabilities in

the general classroom (Peer & Reid, 2001). In high school courses, however, a certain phenomenon started to be observed: a decline in the academic performance of students with dyslexia who had performed well previously (equivalent to their non-dyslexic peers) with the aid of accommodations. Cory (2005) noted that some American college students similarly experienced a drop in their performance despite believing that they had successfully addressed their learning disabilities in high school.

One potential explanation may be understood in terms of available cognitive energy and resources. With accommodations, the dyslexic students were able to perform the same as their peers but were also applying nearly the whole of their available cognitive resources to doing so. When new reading tasks arose in the more difficult high school courses, they lacked the spare resources possessed by their peers to engage in the new activities. Time and practice may help streamline the resources to better address these difficulties. Different forms of accommodations may also help. Still, the full impact of RDs on higher-level reading comprehension activities is an open question.

4.2 Other Common Difficulties

Not all difficulties associated with RDs are specific to reading, however. Various other elements of cognition, physical ability, and social interaction may also be affected.

4.2.1 Memory Issues

As previously reported, many individuals with RDs report memory difficulties (Raskind & Higgins, 1998; Dickinson et al., 2002; Hammond & Hercules, 2003). Short-term memory is particularly affected, meaning people with RDs tend to keep less in short-term memory and thereby slowing recall. Visual memory can also be affected, with some individuals reporting getting lost in a text and having difficulty finding one's place after looking away for only a short instance (Dickinson et al., 2002; Newell, Carmichael, Gregor, & Alm, 2003). These short-term and visual memory issues also have an impact on interface design. Users with RDs have reported getting disoriented by complex menu systems and having difficulties recalling the locations of commands (Keates, 2002).

4.2.2 Writing Difficulties

Given writing's intimate ties to reading, people with RDs unsurprisingly also experience many challenges in writing (Edwards, 1994; Raskind & Higgins, 1998; Peer, 2001; Hammond & Hercules, 2003). Studies have shown that spelling errors made by people with RDs are notably different from those made by the general population (Pedler, 2001; Bourassa & Treiman, 2003). Errors are often based more in phonological confusion than the accidental transposition of letters due to typing mistakes. Examples of such errors due to the phonological processing deficit (mentioned in Section 4.1.2) include "jerney" for "journey" and "clene" for "clean." Additionally, Bourassa and Treiman (2003) found that dyslexic writers often exhibit a lexicality

effect in which real words are preferred over non-words. For example, while a non-dyslexic writer might misspell “severe” with the typo “seveer,” the lexicality effect would lead to a dyslexic writer using the real word “server.” Another example of the lexicality effect would be writing “secede” for “succeed.”

Proofreading itself can thus be problematic for those with RDs. Despite their designed intention to aid writers, spellcheckers are often not helpful. A spellchecker will suggest several potential corrections, requiring that the user to not only identify similarly spelled words but to also interpret what they mean. Both tasks may be of significant difficulty to a person with a reading disability. Pedler (2001) has detailed the many shortcomings of spellcheckers when it comes to spelling errors atypical of those made by people without RDs.

The writing composition process is another area of potential difficulty for people with RDs. Organizational skills are commonly reported to be poor among people with RDs, and this can carry over into arranging arguments in writing (Raskind & Higgins, 1998; Hammond & Hercules, 2003). The linearity of written prose has often been suggested as particularly daunting (Hammond & Hercules, 2003; Entine, 2009).

4.2.3 Sequential Processing

More generally, sequential and linear processing difficulties have also been reported among people with RDs (Raskind & Higgins, 1998; Peer, 2001; Hammond & Hercules, 2003). Sequential processing takes place with tasks involving a specified order. Thus, a person with an RD may find it difficult to follow a list of directions such as a recipe. Accidentally skipping or repeating lines of text when reading can also occur.

Remembering the relative positions of list elements may also pose a challenge. For example, while a person with an RD may recall all seven parts of biological classification (kingdom, phylum, class, order, family, genus, and species), she may not be able to remember if class comes before or after family. Similar difficulties with the alphabet and its order are also common.

4.2.4 Visual Stress

Although RDs are viewed primarily as being neurological in origin, some visual difficulties are associated with RD (A. J. Wilkins, Jeanes, Pumfrey, & Laskier, 1996; Jeanes et al., 1997; Evans, 2001; A. Wilkins, Huang, & Cao, 2004). Among these is the notion of visual stress (also referred to as Meares-Irlen syndrome and scotopic sensitivity syndrome). During reading, some readers report perceptual effects such as color, movement, and blurring of letters. Prolonged reading usually exacerbates these effects and can lead to headaches and difficulty in sustaining reading.

In general, visual stress is diagnosed by ophthalmologists or optometrists (Evans, 2001), although both a screening questionnaire (Singleton & Trotter, 2005) and computerized assessments (Singleton & Henderson, 2007) are being developed. Studies suggest that an estimated 20–30% of the general population experience visual stress to some degree, although there is some evidence that visual stress is more common among people with RDs (Kriss & Evans, 2005; Singleton & Trotter, 2005). Thus, a growing view is that visual stress is a

separate condition but one that strongly influences reading disabilities.⁸

The biological underpinnings of visual stress, however, are still not understood. Neither is it understood why certain color overlays (see Chapter 3, Section 1.3) appear to successfully accommodate those with the condition (Jeanes et al., 1997; Evans, 2001; A. Wilkins et al., 2004). However, several theories have been proposed (Evans, 2001, see Appendix 7 for a review). One theory regarding the cause of visual stress is that some people are sensitive to the pattern glare formed by regularly-spaced lines of black-on-white text. The sharp contrast between black and white is viewed as a primary factor, but some studies have found that simply ameliorating contrast does not account for all visual stress (Jeanes et al., 1997). Irlen proposed a scotopic sensitivity disorder as an explanation, although critics note that the scotopic visual syndrome is specific to low-light vision and not visual functions associated with reading (Irlen, 1991; Evans, 2001). Deficits in the magnocellular visual system are another potential explanation. This visual system is about transient vision such as detecting changes in peripheral vision, gathering coarse details, and detecting flicker. The rapid movements of the eyes during reading rely on the magnocellular system to help clear away any previous image and determine the current span of text to read. As noted by Evans (2001), studies suggest that upwards of two-thirds of all people with dyslexia show magnocellular deficits, and dyslexia is considered synonymous with magnocellular deficits by some. However, the magnocellular deficit does not detect color and thereby does not explain why color overlays reduce visual stress.

This lack of a clear biological explanation has unsurprisingly helped lead to dissent regarding the legitimacy of visual stress as an actual condition. For example, at the Third World Congress on Dyslexia in 1987, the plenary speaker, Isabelle Liberman, made the statement that “Vision has nothing to do with developmental dyslexia,” although she specified no evidence to support such an extreme position (Cornelissen, 2005). The American Optometric Association has even issued a statement of caution regarding the diagnosis and treatment of visual stress and suggests that it is actually due to various already known visual disorders (G. J. Williams, Kitchener, Press, Scheiman, & Steele, 2004). However, the results of an earlier literature review by Evans (2001) contradicts with this viewpoint. As this controversy is ongoing and unlikely to be resolved in the near future, I choose to consider visual stress and its potential accommodations (see Chapter 3, Section 1.3) as elements to be relevant to reading disability and technology usage.

4.2.5 Attention

If an individual has one type of learning disability (specific or general), then one is statistically more likely to have one or more additional LDs as well (Semrud-Clikeman et al., 1992). One particularly common disability class comorbid to reading disabilities are the various attention deficit disorders. Although some estimates have placed the co-occurrence rate as high as 90%, more recent estimates suggest that among people with RDs, 15–30% or 25–40% also have some form of ADD/HD (Willcutt & Pennington, 2000; Eden & Vaidya, 2008). The

prevalence rate of ADD/HD in the general population is only 3-17% (Eden & Vaidya, 2008).

People with ADD/HD have varying degrees of difficulty with impulsivity, hyperactivity, and attention in their daily activities (Mooney, 2007; Eden & Vaidya, 2008). For example, a person with impulse issues may decide to take on an action without consideration of the consequences. Avoidance of reading tasks until near a deadline may be one result of impulsivity (Mooney & Cole, 2000). Hyperactivity can also lead to strong emotional reactions and, in the case of RDs, may increase feelings of frustration with one's reading ability. Finally, attention issues may result in distractions during reading, leading to repeated scanning of the same text. Frequent breaks during reading may hinder complete comprehension of the text due to memory decay.

Vision during reading may be complicated due to ADD/HD as well (Klein & D'Entremont, 1999; Pollatsek, Rayner, Fischer, & Reichle, 1999; Evans, 2001). As mentioned earlier in Section 4.1.1, dyslexic readers show a reduced ability to ignore letters in periphery. More generally, the ability to control what is being attended to during a fixation while reading may be more difficult for poor readers (Klein & D'Entremont, 1999). The presence of ADD/HD will likely further exacerbate this situation. As noted by Evans (2001), the surrounding text may even distract the eye enough during saccades that the eyes are led to focus on the wrong section of text.

4.2.6 Motor Coordination

Clumsiness and poor fine-motor control are also common among people with reading and learning disabilities (Dickinson et al., 2002; Peer, 2001). If poor coordination is severe enough to significantly impact a person's daily life, the person is said to have the specific learning disability known as developmental dyspraxia. Among people with specific learning disabilities (such as RDs), dyspraxia has a comorbidity of 50% (Smits-Engelsman, Wilson, Westenberg, & Duysens, 2003). Thus, about half of all people with RD will have some degree of fine motor control or body coordination issues. During reading, dyspraxia may increase the difficulty of certain small physical tasks such as turning the thin pages of a book or using a hand / pointer to follow along a line of text.

Dyspraxia may also impact computer usage. Fitts's Law is a predictive model from motor psychology that describes the time necessary to move a pointer to a target based upon the target's size and the distance to the target (MacKenzie, 2003). This law is often used to model the use of a mouse or digital pen on a computer. Smits-Engelsman et al. (2003) compared the performance of children with and without developmental dyspraxia on a Fitts's Law-based task. Participants used a digital pen to perform a series of target acquisition tasks for various target sizes (22, 44, and 88 mm). The observed movement patterns of both the control and experimental groups (32 children each) were accurately modeled by Fitts's Law. However, significant differences in certain task behaviors were identified. For example, the children with dyspraxia undershot or overshot the target more frequently than the control group. This missing occurred more often

as well with the smaller targets. The experimental group was also found to exert greater and more variable pressure on the pen's tip.

An additional impact of dyspraxia is its visible nature. Unlike most of the other aspects associated with RDs, clumsiness and awkward movements are readily visible to others. Involvement in sports and other physical activities may be impaired. Peer (2001) suggests that this lack of physical finesse may mark dyspraxic students as targets for bullying and mockery.

4.2.7 Social and Psychological Issues

Peer's suggestion goes beyond bullying, however. The impact of a reading disability is not limited to how and how well the individual performs various tasks; having an RD can impact an individual's emotions, self-image, and interactions with others. In her case studies of young men with dyslexia, Edwards (1994) found that having dyslexia elicited additional burdens beyond academic difficulties. In struggling with reading while others appear to have little or no difficulty, the students experienced severe amounts of self-doubt, low-confidence, and feelings of isolation. Many of them reacted to these troubles in negative ways: behavioral problems, extreme sensitivity to criticism, and psychosomatic pain. A more recent study by Alexander-Passe (2006) confirms how low self-esteem, depression, patterns of avoidance, and stress management issues negatively impact the lives of teenagers with dyslexia. Reading-related tasks are likely to trigger anxiety, although may be attenuated by the audience and expectations placed on the reader (Tsovili, 2004). Riddick (1995) additionally argues that these social and psychological issues are secondary characteristics that arise as the person ages and interacts with society.

More generally, interactions with others can be troublesome for people with RDs. Due to misconceptions about what a learning disability is, some people doubt the existence of LDs or assume that the person is merely lazy or unintelligent. Edwards (1994) notes that many of the students in her study had been teased or ridiculed by their peers. In interviews with college students with learning disabilities, Cory (2005) found that when several of them told professors of their disability, the students were informed that such disabilities do not really exist and that they needed to just try harder. This attitude may not be uncommon; articles in the *Chronicle of Higher Education* have been written by professors questioning the legitimacy of requests for accommodations by students with LDs (W. M. Williams & Ceci, 1999; Zirkel, 2000).

The knowledge that a person has a learning or reading disability can also lead people to lower their expectations for that person. In a case study of an individual child with LD across several learning environments, McDermott (1993) found that the child's ability to perform various tasks was directly affected by the expectations of the people around him. When people around him expected him to read poorly, he did. Otherwise, he still struggled but performed much better. As McDermott describes it, only when a proper unsupportive environment was present would the learning disability "acquire" the child into being disabled.

Given these negative associations of having a reading disability, it is of no surprise that some individuals avoid acquiring the RD label (Edwards, 1994; Cory, 2005). As the body shows no outwardly visible evidence of the person having this disability, an RD (as well as any LD) is considered to be an invisible or hidden disability. This allows a person with an RD to potentially pass as “normal,” thereby avoiding the stigmas associated with the disability. However, passing as “normal” does come with some costs. Studies of success for people with LD have found that acceptance and recognition of one’s disability is correlated highly with achievement (Spekman, Goldberg, & Herman, 1992; Gerber, Ginsberg, & Reiff, 1992). If hiding one’s disability reflects not accepting its reality, then one’s chances for future success could be limited. Furthermore, seeking out support and help from others requires disclosing about the disability to others. In studying the experiences of college students with invisible disabilities, Cory (2005), found that students with hidden disabilities are very strategic in choosing when and to whom they come out to in regards to their disability. Many, due to past negative experiences, will delay registering with disability services until a crisis necessitates it. Unfortunately, this is often too late to avoid poor or failing grades for that academic term.

4.3 Strengths Associated with Reading Disabilities

After the long list of difficulties associated with reading disabilities presented above, one may conclude that having an RD is an all-out negative experience. However, positive aspects may arise from having a disability as well, such as enhanced peripheral vision among many of the congenitally deaf (Bavelier, Dye, & Hauser, 2006). Acknowledging strengths may provide opportunities for compensating and accommodating the negative aspects of a reading disability.

Many individuals with RDs show prowess with tasks involving spatial awareness and visualization skills (Dickinson et al., 2002; Cottrell, 2003). Some also show particular strength with creativity and lateral thinking (West, 1997, 2001; Cottrell, 2003; Powell, Moore, Gray, Finley, & Reaney, 2004) as well as in art and music (Edwards, 1994; West, 1997, 2001). In fact, the prevalence of students with dyslexia and other RDs in design schools and art programs has led some to directly associate creativity, artistry, and visual thinking as universal strengths among individuals with RDs.

For example, Thomas West (1995, 1997) argues that many great minds (e.g., Leonardo da Vinci and Albert Einstein) throughout history have had undiagnosed learning disabilities and this different neurology enabled them to visualize information through innovative means, transcend common forms of thought. Although he does cite some neurological evidence that visual talents are associated with verbal difficulties, West has the advantage of cherry picking his historical examples to confirm what he wants to include. Moreover, the accuracy of RD diagnoses in historical figures is questionable. Although Einstein is often popularly considered to have had dyslexia, biographical studies do not support this position (Pais, 2005). Similarly, the diagnosis of Leonardo da Vinci as dyslexic is derived only from his surviving writings, and writing samples alone are not

considered enough for making a diagnosis of RDs (Edwards, 1994).

Although many with RDs are drawn to artistic or other creative careers, one should be careful about drawing any causation. While it may be that individuals with RDs have natural talent in the arts, it might also be that said fields emphasize verbal tasks to a lesser degree, thereby posing less frustration and difficulty for those with RDs. Moreover, it is risky to place expectations of superior performance on an entire population. In fact, specific studies of visual abilities among people with dyslexia (Winner et al., 2001) found that not only did the RD population not show superior visual skills, a significant portion showed deficient performance compared to the general population. A more moderate perspective to take is offered by Powell, Moore, Gray, Finley, and Reaney (2004): while a person with an RD may not show savant-like visual abilities relative to the general population, said abilities may be a relative strength in regards to all of his or her abilities.

5 Chapter Summary

This chapter has provided a comprehensive overview of reading disabilities. As has been demonstrated, reading disability is not a single condition but a cluster of related issues that impact reading ability. RDs impact individuals in varied and diverse ways and, importantly, can involve and affect more than just the act of reading. Moreover, scholarly debate and study about what RDs are and what causes them is ongoing.

NOTES TO CHAPTER 2

- 1 This debate as to whether reading disabilities are present from birth or acquired later is essentially moot nowadays. Both types are generally recognized now: developmental (from birth) and acquired (Edwards, 1994; Elkind et al., 1996). Distinguishing between the two can be difficult given that reading abilities are not identifiable at birth, usually only being diagnosed in the school years. Generally, an RD is considered acquired when a noticeable change in reading ability follows a recent brain injury (e.g., stroke, infection, or trauma).

In this dissertation, the RDs under consideration are almost always developmental though not necessarily identified in childhood. Instances of acquired RDs are explicitly noted.

- 2 Given the ubiquitous nature of reading in our lives, it is easy to forget that reading is not a natural, innate aspect of humanity. Early hominids evolved language as a means of more expressive communication for coordinating tasks such as hunting, gathering, and communal living. Such utterances, either through sounds or gestures, were ephemeral in nature. Only millenia later did humans begin to record and reuse their words in a more permanent fashion (M. J. Adams, 1990; Wolf & Kennedy, 2003). How this recording was accomplished has also evolved from pictograms to logographs and orthographic symbols mapped to syllables and sounds.

Additionally, what we mean by literacy today is very different from what it was over a century ago. At the beginning of the twentieth century, basic literacy in the United States consisted of knowing one's ABCs and being able to read certain chosen pieces of literature, like the Gettysburg Address, the Preamble to the U.S. Constitution, essentially from memory. Reading comprehension was not an aspect of literacy and was not emphasized until mechanization in World War I necessitated the need for people to be able to read instructions and apply them (Bransford, Brown, & Cocking, 2000, p. 133) This reading for a purpose has further evolved into reading for meaning, identifying symbolism, and other various forms of interpretation.

Simply put, written language and the act of reading it are both constructs of human civilization. These constructs are in-progress and constantly evolving.

- 3 The reader may wonder if it is possible for a person to be both blind and have a reading disability? This is a definite possibility, as injury or disease could lead to a born-seeing individual with RD becoming legally or functionally blind. Whether a congenitally blind person could also be reading-disabled is more difficult to answer. Part of the difficulty lies in that reading is typically defined as the process of decoding the meaning of an established set of *visual* symbols (e.g., letters in English, logographs in Japanese, musical notation). If we adjust the definition to *non-auditory* symbols, then we can ask if

readers of tactile languages like Braille can experience difficulties due to having a reading disability.

The literature on this topic is sparse but reveals that some struggling Braille learners show signs of developmental dyslexia. Early work by Arter (1998) provided evidence that cognitive impairments similar to dyslexia led to slowed learning of Braille among some students. She hesitated to make a definite conclusion given her perception of a lack of a consistent definition of dyslexia. Further study by Greaney and Reason (1999) found evidence of a phonological processing deficit in a struggling reader of Braille. As of this writing, I am aware of two studies beginning to explore the presence of dyslexia among some of the congenitally blind (Coppins & Barlow-Brown, 2006; Anneli & Pol, 2009).

Although the evidence is preliminary, it does seem possible for a person to be born both blind and reading-disabled. Remember, however, the latter of the two disabilities will only become present when learning or interpreting a non-visual language like Braille. When it comes to challenges in interpreting a visual language, a blind person is not reading-disabled; the problem is the inaccessibility of the text.

- 4 What necessarily constitutes a major life activity is an area of much debate and legislation (ADA, 1990; ADA Amendments Act (ADAAA), 2008). Certain tasks, such as taking care of basic health needs, receiving an education, and being able to work are generally considered to be major life activities. Still, debate can and does occur. Does this mean that all jobs must be achievable for any person regardless of (dis)ability? Is participation in sports and hobbies a major life activity?

These questions are beyond the scope of this dissertation and have been debated and discussed deeply by many others. For my work, I take a simple perspective and consider any major life activity to be an activity a person wants to do. I do keep an element of pragmatism and expect some level of within reason in these desires. Strawmen such as inclusive design meaning the blind should be able to drive cars (Newell & Gregor, 2000) distract from the goals of providing access and opportunity.

- 5 The classification of ADD/HD as a general learning disability is an example of the vague boundaries between disability classes. ADD/HD definitely impacts learning, especially in rigorously structured classrooms (Mooney & Cole, 2000; Mooney, 2007). However, the condition also affects aspects of life beyond learning. In various discussions with other disability scholars, I have found mixed opinions on whether ADD/HD is an LD or not. As the condition is not a primary focus of my work, I choose not to enter into this debate and note that my choice to list it here as a general learning disability is not hard and fast. The bottom line is that ADD/HD is a cognitive disability that can and does affect learning.
- 6 In her film *Read Me Differently*, Entine demonstrates her ongoing struggles with phonological processing by reading a Dr. Seuss book aloud to her niece and nephew. Seuss's rhyming prose invariably

contains many nonsense words that must be properly decoded to fit the intended rhythm and rhyme scheme. Although the works of Dr. Seuss are much beloved by many (including myself), one has to wonder about the experiences of a child with a reading disability attempting to read *Green Eggs and Ham* or *The Cat in the Hat*. Although such books are targeted for children's reading levels, they do require advanced phonological processing skills.

- 7 When I started looking at ATs for dyslexia, I originally thought that dyslexia was all about letter reversals. This misconception was quickly corrected once I began to read about dyslexia and related conditions. My earlier misconception is shared by many others in society, which raises the question as to why reversals have become so strongly tied to dyslexia in the public's eye. The line of reasoning offered by Harman (1982) is clean, direct, and, in hindsight, quite obvious. However, this argument has not penetrated the public sphere.

Although I have no evidence for as to why the public conception of dyslexia has evolved as such, I can hypothesize a few potential reasons. First, the image of a backwards letter is entrenched in our popular culture as the scrawls of someone of limited writing ability, be they a young child or an uneducated buffoon. Struggling with reading is similarly associated with youth or lack of education.

Second, reversals are relatable. Unlike most other disabilities, it is difficult to empathize with people with RDs. Although the experiences are not the same, a "normal" person can wear a blindfold to emulate blindness, sit in a wheelchair to experience physical barriers, etc. To struggle with reading, however, is fairly alien. One may read articles from a highly-specified field or a foreign language they are barely fluent in, but these reading acts may be overcome through study and effort. They lack the sense of the self being at fault. Reversals, though, can at least offer a phenomenon to relate to.

These two hypotheses are just that—hypotheses. Understanding why reversals are the public conception of reading disabilities requires not only following the history of popular depictions of dyslexia and other RDs in media and public discourse but also popular conceptions of disability, reading, literacy, and likely much much more. That is another dissertation in itself.

- 8 Acknowledging visual stress as a component to reading disability does introduce some complications to the working definition of reading disability in Section 1.1.2. As discussed earlier, ruling out vision problems is a key aspect to the exclusionary diagnosis process. Visual stress is a vision problem that can hinder reading, so it should not be considered as part of the RD umbrella. However, given that visual stress has been strongly associated with RDs both historically and in the current day, the legacy is worth continuing. Its inclusion is just as important as understanding other comorbid conditions, such as ADD/HD and dyspraxia.

CHAPTER 3

ASSISTIVE TECHNOLOGIES FOR READING DISABILITIES

The poem is filled with fragments of foreign languages, ancient Greek, odd line breaks, and so on. The machine attacks it like someone with a gun at his head. The voice is metallic and fuzzy, a robot on bennies. It reads and reads and reads and reads. It's practically air-starved as it heads for the end of the page. Another decade will pass before this machine can read Eliot, and it will be another decade before I unfold the white cane.

— Stephen Kuusisto on his interactions (circa 1980) getting a Kurzweil reading machine to read *The Waste Land* by T. S. Eliot, *Planet of the Blind* (p. 113)

Given the previous chapter's discussion of the many ways in which reading disabilities manifest themselves, one would expect that the relevant assistive technologies would show a similar degree of diversity. As revealed in this chapter, this is not the case. This chapter, presented in three parts, provides an overview of the assistive technologies for reading disabilities. The first part discusses past and current research efforts. Next, concerns are raised regarding a lack of diversity in the AT recommendations by reading disability experts and a lack of interest in ATs for RDs research in the field of computer science. Finally, several hypotheses that may explain these concerns are presented.

1 Overview of Assistive Technologies for Reading Disabilities

Although reading disabilities impact more than just reading performance, this chapter and the remainder of the dissertation focuses mostly on assistive technologies that support the reading process. Technologies for supporting writing, organization, managing one's daily life, etc. are all important. However, the outstanding aspects of RDs relate to the problems with reading performance. Compounded with the diversity seen in RDs, one would expect there to be an extensive, diverse array of technologies specifically aimed at aiding and supporting the reading process. In reviews of various ATs for postsecondary students with learning disabilities, however, R. B. Lewis (1998) and Raskind and Higgins (1998) both discussed multiple tools for supporting writing, organization, and mathematics. Their lists of tools specific for help with reading contains essentially

one item: technology for hearing text read aloud. The same is true of a more recent survey of several AT options by C. K. Lewis (2007) that also focuses primarily on writing supports. As shown in this section, further review of the research literature shows that, despite nearly 10 years between the publications of these three studies, the research on assistive technologies for RDs has remained largely unchanged.

1.1 Text-To-Speech Software

Prior to the availability of personal computers, books-on-tape were a common approach for addressing print disabilities. Such audiobooks were recordings of a person reading a text aloud. Preparing an audiobook is a lengthy process. Applications such as ReadPlease (ReadPlease, 2005), and Kurzweil 3000 (Laga, Steere, & Cavaiuolo, 2006; Kurzweil Educational Systems, 2006) use text-to-speech (TTS) technologies to programatically convert digital text into audio. In regards to reading disabilities, books-on-tape and TTS allow the listener to utilize the oral fluency used to comprehend spoken language (Sands & Buchholz, 1997). This approach bypasses the phonological processing deficit found in RDs by using the reader's unhindered aural ability to understand language. By the same reasoning, reading speed increases because the primary causes of labored reading are bypassed through the speech synthesis.

Computer speech was first used as an assistive technology in the 1970s with reading machines for the blind. As noted in the chapter's opening quote, Stephen Kuusisto (1998), legally blind since birth, encountered a Kurzweil reading machine at the University of Iowa during his time there as a masters student in the late 1970s and early 1980s. Although his experience was poor, the technology has improved significantly in the ensuing decades. Voices with different genders, accents, and vocabularies are now available. Tools for correcting the pronunciation of specific words (often needed for technical vocabularies) are provided in some systems. Moreover, users of TTS (and even with the earlier books-on-tape) found that, with practice, they could become comfortable listening to text read at faster than normal speaking rates. Thus, many systems allow the user to increase or decrease the speed at which the text is read. Text-to-speech systems also do not require the user to listen to the entire text and, instead, can read aloud a specific word, line, paragraph, or page as requested by the user.

Although the initial application of TTS was for blind readers, the potential of computer speech to support other types of readers quickly became of interest. By the mid-1980s, the effectiveness of TTS systems in early reading instruction began to be studied. Olson and Wise pioneered such efforts and gave particular focus to struggling and reading-disabled students (R. K. Olson, Foltz, & Wise, 1986; R. K. Olson, Wise, Ring, & Johnson, 1997; Wise, Ring, & Olson, 2000; R. Olson & Wise, 2006). Additional efforts over the years have investigated and refined the usefulness of text-to-speech for supporting readers with RDs and LDs (Farmer, Klein, & Bryson, 1992; Elkind, Cohen, & Murray, 1993; Elkind et al., 1996; Sands & Buchholz, 1997; Elkind, 1998/2001; Hecker, Burns, Elkind, Elkind, & Katz, 2002). In addition, many studies have looked at

utilizing TTS in general reading education and remediation (Weinberger, 2004; R. Olson & Wise, 2006). This emphasis on reading education positions TTS more as an educational technology than an assistive technology. Thus, although the body of literature on TTS is vast, few studies look at its effectiveness beyond the reading classroom. One of the few exceptions is the study by Elkind et al. (1996) that investigated long-term use of the BookWise software by adults in their homes and workplaces. Text-to-speech has even been applied to non-traditional reading tasks such as computer programming (Wilson, 2004). Another variant of TTS investigated if whether eye-tracking could be used to automatically detect when the reader struggled with a word and thus automatically proffer the spoken version (Sibert, Gokturk, & Lavine, 2000).

In general, evaluative studies have generally confirmed the effectiveness of TTS systems for reading-disabled users (Elkind, 1998/2001; Hecker et al., 2002; Disseldorp & Chambers, 2003; Weinberger, 2004; Lange, McPhillips, Mulhern, & Wylie, 2006; Iowa Department of Education, 2007). Generally, studies show that reading rate and accuracy improve when using TTS systems, and, to a lesser extent, reading comprehension is better. For example, one BookWise study involving middle school students showed that most reading-disabled students who used the TTS software improved both their reading rate and reading comprehension (Elkind et al., 1993). However, some students' comprehension actually decreased. Further investigation suggested that those students did not possess strong enough auditory skills to find the system helpful. In a follow-up study with adults using the same system, reading performance also benefited from use of the system, and the improvements were again dependent on the user's auditory skills (Elkind et al., 1996). In both these studies by Elkind et al., they found that the level of improvement was correlated with the severity of the reading disability. Readers who struggled the most typically benefited the most.

However, it is important to recognize that text-to-speech is not a panacea. In a study investigating the use of TTS for teenagers with severe reading disabilities, Farmer et al. (1992) found no significant improvements with use of the system. As noted by the researchers, the findings had several possible explanations. The participants may have been poor auditory learners, thus making TTS an inappropriate accommodation (a finding noted in later studies by Elkind et al. (1993) and Sands and Buchholz (1997)). Farmer et al. (1992) also proposed that the available digital voice technology in 1992 may have limited the effectiveness. The latter is still an ongoing issue, as computerized speech still lacks many of the nuances of human speech. Unlike listening to an audiobook or a person reading aloud, digitized speech lacks the intonations, elisions, and emotional engagement with the text.

1.2 Optical Character Recognition

For text-to-speech to work, the computer needs access to the text to be read. Although digital texts are becoming increasingly more common (Bookshare, 2010a), many texts are still in printed, bound form. Procuring a digital version of a text can be a complicated, difficult process. For books for educational

purposes, legislation (Kentucky Postsecondary Textbook Accessibility Act, 2003; Supplemental instructional materials for students with print access disability, 2004) mandates that publishers provide accessible electronic equivalents in a timely manner. Official standards have been established for the formatting of these texts and include the DAISY standard for digital talking books (NISO, 2005) and the NIMAS standard for accessible instructional materials (National Center on Accessible Instructional Materials, 2006).

Still, it is often the end user who has to digitize the text. While one can manually type up a text for use in a TTS system, a more scalable approach is to digitally scan in the text and apply optical character recognition (OCR) to convert the scanned page images into text. However, the scanning process can be time-consuming as it typically needs to be done 1–2 pages at a time (Laga et al., 2006). OCR is also highly sensitive to the resolution and background color of the text being recognized (Bigham, Kaminsky, Ladner, Danielsson, & Hempton, 2006).

Not all TTS systems (e.g., ReadPlease) come with OCR built-in, though. Even if OCR is included as in Kurzweil 3000, the hardware needed for scanning is often separate from the system. Some commercial efforts have looked at integrating the scanning, OCR, and TTS systems into a single device. For example, the ReadingPen (WizCom, 2010) allows users to scan in individual words or lines of text and hear them read aloud. The Intel Reader (Intel, 2010a) instead uses a camera to capture entire pages of text at a time and then uses a built-in display to show and read the text aloud.

1.3 Color Overlays

In contrast to the sophisticated digital technologies used in TTS systems to accommodate the phonological processing deficit, the typical accommodation for visual stress is much simpler: colored transparent sheets laid over the text. These sheets may cover the entire page or may be smaller ones that require the user to move along the text while reading. Eyeglasses with color-tinted lenses are another option. All versions work by changing the background color of text from white to another color, which results in readers with visual stress reporting less difficulty with sustaining reading and fewer incidences of headaches and eye strain (Evans, 2001). Meares, a school teacher, first noted this when she observed that some of her students who struggled with reading complained of visual difficulties performed better on days when the worksheets were printed on other than white paper or when read through a tinted plastic or glass sheet (Irlen, 1991; Evans, 2001). Around the same time, Irlen defined a syndrome around similar observations and noted that the color of an overlay could further affect reading performance.

Subsequent research has shown that use of overlays can improve both reading rate and word identification accuracy (Jeanes et al., 1997). Interestingly, it has also been shown that the optimal color for an overlay differs from person to person and that individuals are sensitive to even slight hue changes. Thus, the optimal color for an overlay for a specific person must be carefully selected (Jeanes et al., 1997; A. Wilkins, Sihra, & Smith,

2005; Smith & Wilkins, 2007). Systems like the Wilkins Intuitive Colorimeter have been developed to help optometrists and ophthalmologists with this identification process (Jeanes et al., 1997; Evans, 2001). Less formal diagnostic tools are also available. For example, Intuitive Overlays (2010) provides a testing pack for educators that consists of a set of overlays (2 sheets each of 10 provided colors), the Wilkins Rate of Reading Test (A. J. Wilkins et al., 1996), and instructions for administering the test with the overlays. Due to the limited number of colors and the lack of formal training, the recommended color may not be optimal for the individual but should still improve reading performance.

Whether a teacher or eye doctor will administer these tools, though, is uncertain. As mentioned in Chapter 2, Section 4.2.4, visual stress is not accepted by some in both the reading sciences and optometry / ophthalmology communities (G. J. Williams et al., 2004; Cornelissen, 2005). In addition to the aforementioned reasons for the distrust, such as the lack of a biological model, perhaps the innate simplicity of the color overlay has helped stoke the controversy. The benefits of overlays preceded the formal defining of visual stress—they solved a problem that was previously unknown. Moreover, Irlen went ahead with the overlays and established Irlen Institutes to disseminate color overlay treatments. Her work, however, lacked scientific rigor and often made unwarranted claims. Additionally, the diagnostic procedures and screening instruments were kept proprietary and high costs were often charged to patients. This combination of poor scientific backing, lack of openness, and the suggestion of profit as a main motive¹ provided many reasons to doubt the existence of visual stress and the value of overlays.

In the last decade, however, better scientific research has been conducted on visual stress and overlays. Double-blind, masked studies and other studies controlling for novelty and placebo effects have been conducted that show the efficacy of overlays (Jeanes et al., 1997; Evans, 2001; Kriss & Evans, 2005). Specific studies have determined how many different overlay tints are needed and what the color precision needs to be (A. Wilkins et al., 2005; Smith & Wilkins, 2007). Other fine-tuning, practical questions have been investigated, such as how large should an overlay be relative to a page of text (Waldie & Wilkins, 2004; Smith & Wilkins, 2007). Unfortunately, the researchers in these efforts, such as Evans and Wilkins, are ophthalmologists by training and typically publish their findings more in journals their field. Some of their findings are beginning to be disseminated in education and reading publications, however.

1.4 Text Windows

One of the oldest and simplest ATs used to support reading is a text window. A text window is a piece of cardboard with a small window cut-out to limit the amount of text seen at a time (Pepper & Lovegrove, 1999). The window can range in size to show only one or two words at a time to one line of text or more. This approach is believed to help reduce interference from the surrounding words and thereby improve reading speed and accuracy.

Pepper and Lovegrove (1999) studied the efficacy of this approach empirically in a lab setting. Using a computer screen, participants with dyslexia were presented with several conditions. As a control, the participant read from a screen where the complete text was shown. In one experimental condition, one word at a time was flashed briefly on the screen with the word located where it would be in the complete text. The other experimental condition also flashed one word at a time, but the word was centered vertically and horizontally on the screen. Pepper and Lovegrove found that both speed and accuracy improved significantly in the two experimental conditions showing only one word at a time. Although the best performance was actually with one word centered on the screen, revealing one word at a time just as with a text window showed significant improvement as well but to a lesser magnitude. While their findings suggest single-word displays may be a viable accommodation, one should note that they did not assess reading comprehension.² Given that some studies have shown that text layout affects and shapes recall and understanding (Frase & Schwartz, 1979; Wylie & McGuinness, 2004; Walker, Schloss, Fletcher, Vogel, & Walker, 2005; Santos Lonsdale et al., 2006), such accommodations may reduce comprehension performance while improving other aspects of reading.

1.5 Word and Line Highlighting

Related to the text window, many TTS systems include a feature for highlighting the word and lines of text as they are read aloud. Users typically can customize the color of highlighting. While the main purpose of the moving highlight is to help the reader follow along with the digital voice, the highlight may additionally prevent rereading or accidentally skipping words or lines. This latter potential is in some ways independent of the TTS and suggests that an automated, moving highlight may be a potential form of accommodation. Any specific studies of such a tool are unknown, although the idea is similar to one of the experimental conditions in the aforementioned study by Pepper and Lovegrove (1999). Similarly, the intersection of color overlays for visual stress and highlight colors appears to have not been studied. Although some overlays are made smaller than a full page for reasons of portability, these are larger than a single line. Thus, it is an open question as to whether highlight colors interact with visual stress.

1.6 Electronic Dictionaries

Another assistive tool often recommended for people with RDs is an electronic dictionary (Raskind & Higgins, 1998). These specialized, portable devices allow the user to look up unfamiliar words on demand. Some require the user to type in the word to be looked up, although OCR-based reading pens with dictionaries also exist (WizCom, 2010). Dictionaries are also included in some TTS systems like Kurzweil 3000. Studies suggest that the use of dictionaries may improve reading comprehension among students with LDs (Lange et al., 2006). However, the study by Lange et al. also included TTS systems, thereby obscuring the actual effect of the dictionary alone. Given that a dictionary may present multiple definitions for a single word, the tool itself may just introduce further difficulties with sense disambiguation. Similar concerns have been raised over

the efficacy of spellcheckers for dyslexic users (Pedler, 2001).

1.7 Typography

Most of the aforementioned ATs are more about augmenting the reading process or the reader. Another approach is to augment what is being read, namely looking at how printed text is presented to the reader. Unfortunately, once a book is printed, the typography is essentially fixed. Small exceptions do exist such as changing the background color with an overlay or enlarging the text with a magnification lens. This is not in all respects a bad thing, as typesetting has evolved as one of those rare blends of both art and science (Tinker, 1963, 1965; Sutherland, 1988, 1989; Knuth, 1999). Over the centuries, printers have crafted and selected font faces, font sizes, interline spacings, margins, etc. that have best met the needs of readers in terms of both reading and aesthetics.³ Such efforts work towards supporting the typical reader. This leads one to ponder whether different typographic choices may be better for atypical readers, such as those with RDs.

This reasoning is perhaps what led to the creation of the Read Regular font (Frensch, 2003b, 2003a; Lantin, 2003; Curtis, 2005). Frensch, a dyslexic student working on her masters in art and design, sought to design a typeface that intrinsically addressed letter recognition issues associated with RDs. Interviewing others with dyslexia, she identified font features that were viewed as particularly difficult for people with dyslexia (Frensch, 2003a). Some of the design choices included additional spacing in the kerning between letters as well as longer spacing between words and lines. Serifs were generally avoided, and the visual weight of letters was balanced out to avoid the implication of movement. Most specifically, Read Regular makes similar letters visually distinct. For example, the letter 'b' is drawn in single motion while the 'd' is drawn as a distinct circle and vertical bar. This theoretically avoids letter reversals and misidentifications.

One other important element to Read Regular is that it was designed to look like any other, normal font. As noted in a newspaper article by Lantin (2003), previous attempts at making a dyslexia-friendly typeface led to fonts that were distinctive in their lack of aesthetics and easily identified as serving a special need. Frensch's font does not mark its users as disabled, making it a viable choice for all readers. In fact, because even non-dyslexic children commented favorably about its readability, Chrysalis Books, a British publishing house, decided to print their children's books using only Frensch's fonts ("Chrysalis Books uses Frensch font", 2005; Curtis, 2005). Unfortunately, the Read Regular family of fonts does not appear to have been made available publicly or even commercially aside from a few select book publishers.

Does Read Regular really improve reading performance among people with RDs? Although Frensch reportedly conducted user testing, no formal, peer-reviewed assessments have been published. Unfortunately, this is also the case for studies of the interaction of typography and RDs in general. In one of the few studies published, O'Brien, Mansfield, and Legge (2005) investigated the effect of print size on reading speed (correct words / minute). They found that both dyslexic and non-dyslexic children exhibited the same pattern. For

the range of font sizes they tested (the height of a lowercase x ranged from 0.037 cm to 0.582 cm), reading speed increased with font size until reaching a plateau. The critical point at which the plateau began, however, occurred slightly though significantly later with the dyslexic participants. This suggests that enlarging the size of text may help to some extent with letter and word recognition. This finding also occurred in a similar study by A. Wilkins, Cleave, Grayson, and Wilson (2009). Although not specifically about reading disabilities, A. Wilkins et al. found that larger type sizes improved both the reading speed and reading age (ability to deal with increasingly more difficult texts) among children 7–9 years of age. The greater font size is thought to increase the distinctiveness of letters, thereby making letter and word recognition easier and thus freeing cognitive resources for comprehension tasks. This benefit is limited, however, as eventually increasing the font size will lead to diminishing returns and perhaps even worse reading performance (Tinker, 1963, 1965).

Another investigation of typography and RDs is the SeeWord project out of the University of Dundee (Dickinson et al., 2002; Gregor et al., 2003) in Scotland. This project developed a front-end for Microsoft Word to meet the needs of people with dyslexia and other reading disabilities. While the major contributions of SeeWord concern computer user interfaces for the RD user population, one small study looked at personal renderings of text. Six high school students with RDs used the system to customize the font style, font size, line spacing, text color, and background color of text to provide what they personally thought was most supportive for reading. When compared to reading black text on a white background, five subjects made approximately 50% fewer errors when reading text aloud with their customized renderings. This improvement was not significant, however, as the sixth subject made 54% more errors with his customized rendering. Despite selecting a format he felt would promote good reading, this last participant would have been better off reading from black text on a white background. This suggests that users may not be the best judges when it comes to fine-tuning accommodations, especially those with a large parameter space as offered by SeeWord.

In other explorations of SeeWord's potential, the developers included a feature that colored reversible letters like 'b' and 'd' differently in the belief that the colors would help prevent the user from confusing similar looking letters or words. In a think-aloud study with users with RD, the participants found that this coloring did not really help with word confusion, but the sporadic coloring helped break up the text and reduced their feelings of getting lost in the text (Newell et al., 2003). Despite the promise suggested by early studies, the SeeWord project has been inactive for several years now due to lack of funding (personal communication, Dr. Peter Gregor, June 2007). A few projects similar to SeeWord have also been explored, such as web tools that allow users to reformat a website's layout to their preferred typographic style (Hanson & Richards, 2004; Seeman, 2004). However, these systems have not gone beyond research efforts.

Personalized typesetting, however, is becoming more realizable. Karow (1998) recognized that digital typesetting and high-quality printers were becoming common and affordable enough such that booksellers

would eventually be able to print books on demand. A person could perhaps purchase a book's content and then have it printed and bound in the font, dimensions, and colors of his choice. Such technology has recently been realized with the Espresso Book Machine (On Demand Books, 2010). This technology was forged for the purpose of reducing the cost of books by eliminating the hefty price of shipping. Potentially, systems like the Espresso could allow a person with an RD to purchase books rendered in an optimal typography for her reading needs. This has yet to be explored, though, and there still exists the challenge of identifying an individual's optimal typography.

1.8 Diagnosis Tools

A final area of technology development for people with reading disabilities is not about accommodations per se. Alongside the developing assistive technologies, there has been a parallel interest in the development of screening and diagnostic technology for identifying individuals with reading disabilities. The neuropsychological examinations needed for identifying a person as reading-disabled are both expensive and time-consuming. When a person without RDs undergoes such an exam, that effort and time is in a sense wasted as those resources could have been better used to identify a person who could benefit from a diagnosis. Such an automated screening process would mean diagnostic exams could be made more efficient by only administering them to the most likely candidates.

One such screening process, the Dyslexia Adult Screening Test (DAST), is a series of short performance tasks that assess various aspects of reading performance (A. G. Harrison & Nichols, 2005). DAST is targeted at screening adults for dyslexia, with a particular interest in identifying postsecondary students who may not have been identified while in the K-12. system. A series of studies on its validity and reliability suggest that DAST does hold promise, but several critics argue that it is not currently rigorous enough for clinical usage (A. G. Harrison & Nichols, 2005; Singleton, Horne, & Simmons, 2009).

Another criticism is that DAST is administered by a trained professional; greater efficiency would be achieved with an automated assessment performed on a computer. Computer-based screening does not rely on trained personnel, and multiple people can easily be screened at the same time. Tests on the computer can also be made to be adaptive by using the test taker's ongoing performance to tailor the assessment and ideally shorten the overall testing time. Singleton et al. have been exploring the use of computers and adaptive testing in assessing reading skills for both children and adults (Singleton, Thomas, & Horne, 2000; Singleton et al., 2009). Their efforts have led to the development of an adaptive test that achieves reliable levels of sensitivity for clinical work. Protopapas and Skaloumbakas (2007) have developed a similar screening system for dyslexia among Greek children.

Other types of screeners and performance measurers have been developed as well. A computer-based screening system for visual stress has been prototyped (Singleton & Henderson, 2007). The Watch-me!-Read

uses speech recognition to measure the reading development of children reading text aloud (Nix, Fairweather, & Adams, 1998; S. M. Williams, Nix, & Fairweather, 2000). This technology was primarily designed as a tool to help develop early reading skills and not for reading disability detection. However, its performance analysis statistics could be repurposed towards detection. Still, such systems are limited in that they just screeners and performance measurers. They do not give a definitive diagnosis and do not tell how the identified reading difficulties may best be addressed.

2 Commercial Options, Research Efforts, and the Lack Thereof

Although the previous section appears to list a wide range of assistive technologies for RDs, the actual scope is quite narrow. OCR, highlighting, and dictionaries are often bundled together with TTS systems. The typographic examples are not commercially available. Moreover, consider again the vast diversity of traits associated with RDs. TTS systems address word recognition, overlays address visual stress, but where is the support for visual memory, attentional issues, comprehension, etc.? It is my opinion and experience that there are essentially none commercially available. The ATs available to the reading-disabled public are essentially variants of either text-to-speech or color overlays. Moreover, there is a lack of research interest regarding RDs and ATs in fields like computer science where new technologies are constantly being developed and explored.

To demonstrate this scarcity in commercial and research efforts, this section describes two review studies I conducted. The first is a compilation of the technologies recommended by major organizations that support and provide information about RDs and LDs. The latter then looks at the incidence of RDs mentioned in computer science research over the last few decades.

2.1 Reading Disability Experts and Assistive Technology Recommendations

For a person to start using a technology, that person needs to first know that the technology exists. Thus, a key influence on what assistive technologies are used by adults with RDs are the recommendations made by experts. These recommendations not only have the weight of professional support but also reflect what products are available commercially.

2.1.1 Leading Reading Disability Websites

To gather the recommendations of disability experts, six RD/LD websites were analyzed. Listed in Table 3.1, these are the websites for major organizations involved in research, education, and advocacy work regarding disabilities.⁴ Publications referred to those pages, and may themselves have contributed to the websites' contents. Thus, these sites are viewed in high esteem by many and seen as both informative and trustworthy.

In September 2009, I searched each of the six websites for recommendations, statements, or comments about assistive technologies or the use of computers for supporting people with RDs/LDs. When possible, I used a site's search engine to find pages mentioning "computers," "accommodations," or "assistive

Table 3.1: AT recommendations from leading RD/LD websites as collected in September 2009.

<p>LD Online</p> <p>Leading website and information storehouse that serves parents, teachers, and other professionals who work with learning disabilities and ADHD. Contains multiple articles written by experts that are regularly updated to reflect the most recent research and practices.</p> <p><i>Recommends:</i> audio/visual recorders, audio books, electronic dictionary, laptop, OCR, online reference materials, personal organizers, portable word processor, reading pen, speech recognition, spelling/grammar checkers, TTS, visualization tools, word prediction software, word processor (14 total)</p>	<p>http://ldonline.org/</p>
<p>Disabilities, Opportunities, Internetworking, and Technology (DO-IT)</p> <p>DO-IT is an organization dedicated to bringing people and information together to promote the success of people with disabilities in higher education and professional careers. This includes specific interest in supporting people with disabilities in the fields of science, technology, engineering, computing, and mathematics.</p> <p><i>Recommends:</i> audio/visual recorders, audio books, brainstorming software, magnification, OCR, personal organizers, speech recognition, spelling/grammar checkers, highlighting, TTS, word prediction, portable word processor (12 total)</p>	<p>http://www.washington.edu/doit/</p>
<p>Learning Disabilities Association of America (LDAA)</p> <p>The LDAA provides support to people with LDs and their parents, teachers, and other professionals through providing practical information and resources targeted at local, state, and national levels.</p> <p><i>Recommends:</i> personal organizers, audio/visual recorders, spelling/grammar checkers, TTS, portable word processor (5 total)</p>	<p>http://www.ldanat1.org/</p>
<p>The British Dyslexia Association (BDA)</p> <p>As a UK national organization, the BDA campaigns for positive change in the lives of people with dyslexia through ongoing efforts in legislation, education, information dissemination, and research.</p> <p><i>Recommends:</i> color overlays, brainstorming software, audio/visual recorders, highlighting, personal organizers, portable word processor, reading pen, speech recognition, spelling/grammar checkers, TTS, typography, word prediction software, electronic dictionary (13 total)</p>	<p>http://www.bdadyslexia.org.uk/</p>
<p>International Dyslexia Association (IDA)</p> <p>The IDA supports and disseminates research on understanding and treating dyslexia and related LDs to educators, researchers, parents, and those with dyslexia.</p> <p><i>Recommends:</i> none</p>	<p>http://www.interdys.org/</p>
<p>National Center for Learning Disabilities (NCLD)</p> <p>NCLD works to ensure that every child, teenager, and adult with LDs has the information and opportunity to succeed in school, work, and life.</p> <p><i>Recommends:</i> typography, portable word processor (2 total)</p>	<p>http://www.nclld.org/</p>

Table 3.2: List of technologies recommended by RD/LD websites. Counts show how many of the six sites recommended each technology.

TOOLS (READING)	SUGGESTIONS	TOOLS (OTHER TASKS)	SUGGESTIONS
Audio books	2	Audio/visual recorders	4
Color overlays	1	Brainstorming software	2
Electronic dictionary	2	Laptop	1
Highlighting	2	Personal organizers	4
Magnification	1	Portable word processor	5
OCR	2	Speech recognition	3
Online reference materials	1	Spelling/grammar checkers	4
Reading pen	2	Visualization tools	1
TTS	4	Word prediction software	3
Typography	2		

technologies.” Multiple, independent passes were made on each site to generate lists of recommended technologies. These passes were combined and then reduced for clarity. Specific details of this process are described in Appendix A.

2.1.2 Assitive Technology Recommendations

Nineteen technologies were recommended across the six sites, as shown in Tables 3.1 and 3.2. Actually, one should say *five* sites since the International Dyslexia Association’s website did not mention a single technology. Although some of their pages mentioned accommodations, said pages only mentioned that technology solutions may be one means of providing accommodations. Instead, the IDA’s website focuses more on pedagogical interventions and reading remediation practices.

The other sites, fortunately, did mention and recommend various types of technologies. However, the technologies mentioned do not really go beyond those recommended in the decade-old reviews by R. B. Lewis (1998) and Raskind and Higgins (1998). The only “new” technology mentioned was more discussion of portable computer tools such as the reading pen and the recent ubiquity of laptops in the classroom. Some discussion of typography did appear, although this was often focused on websites and configuring a web browser to make the font larger or to force color styles to avoid contrast issues. More intensive typographic interventions, such as SeeWord or the ReadRegular font were not mentioned.

More distressing, however, were the tasks that the technology recommendations addressed. As shown in Table 3.2, the websites rarely mentioned tools for supporting reading. Text-to-speech systems were mentioned by four sites, but other reading support technologies were rarely mentioned. Instead, the sites more readily recommended tools for supporting writing, notetaking, and organizational skills. Just as in the reviews by R. B. Lewis (1998) and Raskind and Higgins (1998), the RD/LD websites recommended a wider array of

technologies for tasks other than just reading.

2.1.3 Summary of Expert Recommendations

The scope of this survey is limited to only six websites. Other opinions and recommendations likely exist, but these sites were chosen for their reputation and standing. These sites are regularly updated with news of current research and practices. Teachers, parents, disability advocates, and many others turn to these pages for reliable information.

Unfortunately, the information sought in this survey was found to be lacking. The experts, as suggested by the six websites, are only able to offer a limited set of technologies for supporting reading tasks. Otherwise, the assistive technologies that benefit users with RDs/LDs target other task types, such as writing and managing one's daily responsibilities. Multiple conjectures may be made as to why the suggestions for reading tools are so narrow. One possibility may be that the experts are unaware of other approaches, although the scope and diversity seen on the sites makes this unlikely. Another explanation, perhaps, is that the experts are recommending the only ATs available. In other words, the transfer of researched technologies to commercial products has been stagnant over the last ten years.

2.2 Computer Science Research Involving Reading Disabilities

Such technology transfer requires that new ATs for RDs are being developed and explored. One field where one would expect such research to be occurring is computer science (CS). To identify the extent that this is actually the case, I analyzed a major database of computer science research papers to determine the frequency and depth that RDs appear in the CS literature.

2.2.1 Motivation

Before discussing the search and its findings, the motivation for focusing only on computer science papers requires some explanation. Looking at the level of research interest in RDs in a technology-driven field like computer science can offer some insight about the lack of diversity seen in commercially-available ATs. Clearly, a review of only CS research will not find all of the work on ATs for RDs. Many of the papers cited earlier in the chapter were from education-related journals, not computer science publications. However, the goals of research in education and computer science are different. The education research is about helping the reading process in people with RDs. Meanwhile, in computer science, the focus is on how *technology can be used* to reach that goal. While the education research might touch on and explore a technology, CS research nearly always places the technology at the forefront. A consequence of this shift in emphasis is that novel, innovative uses of technology are more likely to occur from computer science research.

To be fair, this means that a fair portion of researched technologies may be solutions looking for a problem to solve. An idea for a new interface needs a motivation or problem space to work in, and sometimes, disability

accommodations are suggested. From the targeted end user's perspective, said technology may not address a real problem and could be wildly inappropriate. Said technology could also turn out to be helpful. Either outcome is not really that important, however, as the focus was always on demonstrating the technology. To be clear, not all research starts out this way, nor do I wish to besmirch any efforts that explore technology space. Such studies are valuable for demonstrating the possibilities of new technologies. Moreover, when the "problem" being addressed involves a disability, this demonstrates that the researchers are at least cognizant of the disability to some extent. This provides insight about the awareness of the disability within the field.

More importantly, reading disabilities offer many interesting problems for CS researchers to investigate. For assistive technology and human-computer interaction (HCI) researchers in general researchers, the fairly large prevalence of RDs in the population (7–15%) creates a sizeable user subgroup in which to explore usability and access issues (Sands & Buchholz, 1997). The recent boon in electronic reading devices like the Kindle (Amazon, 2010) and the Nook (Barnes & Noble, 2010) adds further motivation and opportunities. Moreover, the sheer amount of reading-related tasks performed by members of an information society further suggests the need for HCI research regarding reading from digital devices. The research potential goes beyond HCI topics, however. Developing tools to supporting reading tasks such as word sense disambiguation and comprehension invoke classically challenging natural language programming problems such as automated word sense disambiguation (Navigli, 2009) and reading level detection and text simplification (Schwarm & Ostendorf, 2005; Petersen & Ostendorf, 2009). From this perspective, one would expect that research involving RDs would appear to some degree in the published literature.

2.2.2 Searching the ACM Digital Library

Thus, to identify the awareness of and interest in technologies that address reading disabilities within the computer science community, a search of the research literature was conducted. The ACM Digital Library (<http://portal.acm.org/dl.cfm>) contains all articles published by the Association for Computing Machinery and related organizations. Thus, it is a major storehouse of CS research. On August 17, 2009, the digital library was searched for all papers containing the search terms listed in Table 3.3. Four separate searches were performed: RDs only, LDs only, RDs and LDs combined, and disability in general. For the RD search, both dyslexia and reading disability were used as search terms. The LD search was included given the aforementioned overlap of reading difficulties with LDs. Other terms related to reading disability were not used as search terms, however. Finally, a last search just concerning disability was performed as a baseline given that not all papers in the ACM digital library concern disabilities.

2.2.3 Analyzing the Returned Publications

In Table 3.3, the results of the RD + LD search accounted for 0.1% of all papers (286 / 255,808) in the digital library. Given that computer science is a broad field with multiple topics, it is more realistic to compare the

Table 3.3: Summary of literature search on the ACM Digital Library (<http://portal.acm.org/dl.cfm>) conducted on August 17, 2009. Search terms and results shown for the four searches are shown.

SEARCH	TERMS	RESULTS
Reading Disability	dyslexia OR dyslexic OR dyslexics OR “reading disability” OR “reading disabilities” OR “reading disabled”	161
Learning Disability	“learning disability” OR “learning disabilities” OR “learning disabled”	151
RD + LD	<i>all previous terms</i>	286
Disability (baseline)	disability OR disabilities OR disabled	6,621
Total Documents Searched		255,808

Table 3.4: Descriptions of the labels developed through open coding that were applied to the 286 RD + LD search results from the ACM digital library.

CATEGORY LABEL	DEFINITION
Acquired Cognitive Disability	Paper concerns RDs/LDs acquired via disease or trauma
Assistive Reading Technology	Paper discusses technology for supporting reading for users with RDs/LDs but is not a Deibel or SeeWord paper
Brief Mention Only	Search term mentioned in text with no further details
Deibel	Paper written by myself
Diagnosis	Paper describe a system for diagnosing a disability
Experiment Control	Study participants screened as to exclude RDs/LDs
In Poor Taste	Refers to RDs or LDs in a negative way
Includes Other Disabilities	Paper discusses various disabilities, including RDs/LDs.
Non-Reading LDs	Paper addresses an LD (ADD/HD, dyscalculia, etc.) but does not address any aspect of reading
Not a Paper	Returned reference refers to conference proceedings, calls for participation, workshops, tutorials, etc.
Participant Has RD/LD	Paper is not about RDs/LDs, but a study participant has an RD/LD that impacts the involvement in the study
Position Paper	Paper serves to inform others about or express a philosophical view involving RDs/LDs
Possible Application	Paper suggests that a technology designed for other purposes may be useful for people with RDs/LDs
RDs as an Example	Paper on a different topic uses RDs/LDs as an example or motivation
Referenced Paper	The only search hit is citation in the bibliography that includes a search term
Related Work Only	RDs/LDs only mentioned in related work section of paper
Search Error	Hit due to search engine idiosyncrasy or a paper’s nonstandard use of terminology
SeeWord	Paper is from the SeeWord project (Gregor et al., 2003)
Severe LD	Paper is primarily about severe LDs (e.g., autism or mental retardation)

Table 3.5: Occurrence of labels among the 286 ACM search results. Since multiple labels could be applied to a search result, the numbers sum to greater than 286. Indented, italicized sections show counts for other labels applied to the tags *Assistive Reading Technology* and *Possible Application*.

LABEL	COUNT	LABEL	COUNT
Acquired Cognitive Disability	3	Position Paper	10
Assistive Reading Technology	18	Possible Application	35
. <i>Includes Other Disabilities</i>	9 <i>Brief Mention Only</i>	20
. <i>Position Paper</i>	1 <i>In Poor Taste</i>	1
Brief Mention Only	111 <i>Includes Other Disabilites</i>	3
Deibel	4 <i>Related Work Only</i>	1
Diagnosis	5	RDs as an Example	10
Experiment Control	7	Referenced Paper	43
In Poor Taste	7	Related Work Only	4
Includes Other Disabilities	34	Search Error	5
Non-Reading LD	3	SeeWord	5
Not a Paper	25	Severe LD	14
Participant Has RD/LD	8		

number of results with only the disability baseline search. The RD + LD papers account for only 4.3% of all papers involving disability (286 / 6,621). These raw numbers suggest that among CS researchers whose work involve disabilities, their interest is elsewhere. This is somewhat surprising since, relative to other disabilities, RDs/LDs are not rare and, in some contexts, are the most common disability type (L. Lewis et al., 1999).

To further explore the search results, an open coding analysis was performed on the 286 search results. Open coding (Taylor & Bogdan, 1998) is a methodology for labeling qualitative data in which a categorization system is developed during data analysis in lieu of using a predefined set of categories. While reading through the search results, I developed different tags for categorizing the papers. Through three passes over the results, categories were created, split, merged, and removed until I settled on the 19 labels described in Table 3.4. Complete details of the coding process are described in Appendix B. The breakdown of the codes across the RD + LD search results is shown in Table 3.5. At least one code was applied to each search result, although some search results were tagged with up to three codes when appropriate.

These labels provide several insights about the search results. The first is an observation that a significant portion of the results fell outside of the search's intended scope: research on technologies for supporting users with RDs. Mishits due to problems with searching (*Search Error*) were rare. However, a surprising 43 of the search hits occurred only because the paper's references used one of the search terms (*Referenced*

Paper). Other reasons for a paper falling outside the intended scope were due to a focus on different disability types (*Acquired Cognitive Disability*, *Non-Reading LD*, or *Severe Learning Disability*). Some search hits interestingly came from researchers who screened their participants for RDs as a means of reducing variance in reading or writing performance measures (*Experiment Control*). Another surprise came from 8 papers that were technology evaluations. Although the studies did not concern disability or ATs, the researchers commented on how a participant's reading disability provided additional issues and insights (*Participant has RD/LD*). In total, 83 of the results were found to fall outside of the search's intended scope.

A second insight of from the coded results suggests that the CS researchers are aware enough of RDs to include brief mentions of them in their publications; 111 papers were tagged with the code *Brief Mention Only*). Unfortunately, those brief mentions are exactly that—brief. Over half of the papers that suggested the studied technology could also be of benefit to people with RDs only said so in passing (20 of the 35 papers labeled *Possible Application*). No follow-up studies exploring these conjectures appeared in the search results.

Moreover, the papers involving actual research about ATs and reading-disabled users are quite rare; only 18 papers were labeled as *Assistive Reading Technology*. Half of these papers discussed RDs within broader discussions of ATs and accessibility issues. Although these papers do show an awareness of RDs by the researchers, broader disability efforts are unlikely to address the complexity and diversity within RDs alone. Among the papers exclusive to RDs/LDs, two did not address typical forms of reading and instead focused on programming (Powell, Moore, Gray, Finlay, & Reaney, 2004; Wilson, 2004). Three other papers were about TTS systems (Elmer, 2000; Sibert et al., 2000; Disseldorp & Chambers, 2003). Two of these papers did push the bounds of the technology, however, by adding eye-tracking (Sibert et al., 2000) and speech recognition (Elmer, 2000) to the basic TTS approach.

A final revelation from the search results is the lack of continued research efforts by the same researchers. For most of the search results, the authors appeared only once. Even when an author did appear on more than one paper, those papers were typically about separate, unrelated projects. Only two exceptions were found among the results. The first was a series of papers discussing the SeeWord project (Dickinson et al., 2002). The second were my own publications.

2.2.4 Summary Of ACM Search

In all, the search of the ACM digital library shows that while there is some awareness of reading disabilities among computer science researchers, this awareness primarily only appears in publications in short, passing references. Only a few publications reflect actual research aimed at exploring technologies specifically for supporting users with RDs. As technology researchers, computer scientists are not pushing the boundaries of reading technologies with reading disabilities in mind.

These findings, however, do not and cannot generalize to all technology-driven fields. Still, the fact that a

major field like computer science engages in very little active research on ATs for RDs is a bit worrisome. At the very least, what could be a rich source of new, innovative approaches to assistive reading devices is absent. Without research, technologies cannot transition from the laboratory to public, mainstream usage.

3 Understanding the Dearth in Research

If new AT concepts are not being proposed, tested, and promoted by technology researchers, it is unsurprising that RD/LD experts can recommend only a limited set of reading support tools. Given the critical importance of reading in today's information age and that reading disabilities are far from uncommon, one should naturally question why reading assistive technologies are as limited and few as they are. This section proposes and discusses several hypotheses that potentially address this question.

3.1 Reading on Computers

Starting from a technology viewpoint, a major challenge for ATs for reading disabilities is the available hardware. When it comes to computer-based assistive devices for reading disabilities, this invariably means that the user will be reading text displayed by a computer. Even if the reader is using TTS, she is likely to still visually follow along with the text as most TTS systems incorporate highlighting of the current word and line being read aloud.

Consider the years of the TTS studies mentioned in this paper: Farmer et al. (1992); Elkind et al. (1993, 1996); Sands and Buchholz (1997). At that time, computers were mostly desktop systems. While laptops did exist, they were notoriously expensive and bulky. Reading on a desktop computer locks the person to one location and a limited set of postures. Additionally, these desktop computers most likely used CRT monitors for the display. Earlier studies of reading on computers found that the flicker rate on these monitors interfered with reading performance (Mills & Weldon, 1987; Muter, 1996; Dyson & Kipping, 1998).

Technology advances have changed what reading on a computer entails. Portable computers such as laptops, PDAs, and tablet computers no longer restrict the reader to a single, fixed location. Posture options have also increased, although reading from a laptop still requires a posture not typically associated with the act of reading. Similarly, the evolution of display technologies away from CRT displays to LCD displays has increased the visual quality of electronically displayed text and has helped eliminate negative factors like flicker rate. Other studies have also determined important factors in the design of electronic reading devices (Gujar, Harrison, & Fishkin, 1998; B. L. Harrison, 2000; Waycott & Kukulska-Hulme, 2003).

Moreover, a reading technology need not be a computer anymore—just a digital device. With the recent explosion of e-book readers such as the Kindle (Amazon, 2010) and the Nook (Barnes & Noble, 2010), the idea of dedicated electronic reading devices is not only realized but apparently popular among consumers. Moreover, other portable electronic solutions are now becoming available. Smartphones with large touch

displays such as the iPhone (Apple, 2010b) are potential venues for displaying text to be read. Tablet computers are also becoming more popular, whether they be the equivalent of a laptop or of a more limited functionality like the iPad (Apple, 2010a).

Previous AT efforts were thus stymied by the limits of technology at the time. The discomfort, awkwardness, and limitations of reading from desktop and laptop computers discouraged research and innovation for the primary reason that users were likely not interested. The reading devices that have recently become available may drastically change this situation, though.

3.2 Difficulty with Reading Disability Empathy

For the potential of these new reading devices to be explored however, technologists must still research the possibilities. One potential barrier to this may be the ability to understand what it means to have a reading disability. An able-bodied person can simulate the effects of having certain types of disabilities. Ear plugs and blindfolds can impair a person's hearing and vision. A person can use a wheelchair or crutches to navigate around a building. The many types of color blindness may be simulated through image processing (Jefferson & Harvey, 2006). Although such simulations are by no means equivalent to living with a disability, such experiences allow designers opportunities to empathize with users.

However, how do you simulate a reading disability? Papadopoulos, Pearson, and Green (2008) and the Accessibility Research Centre (2009) have developed a few online simulations of dyslexia and visual stress for increasing awareness of accessibility issues among designers. However, the researchers are the first to admit that their simulations do not capture the actual RD experience. For dyslexia, the simulations reverse letters or change words to common misidentifications. Unlike such mistakes made by a person with dyslexia, though, these text effects are permanent and cannot be corrected through rereading. Similarly, the visual stress simulations introduce pattern glare and movement, but such effects are ongoing instead of transitory and dependent on time, stress, and level of effort.

Unlike sensory disabilities where there is a clear point where ability breaks down, RDs affect an entire process in multiple ways of varying degree. A reading disability does not stop reading from taking place; it makes it more difficult. Such difficulty and struggling with reading is likely a distant memory for many technology researchers since they likely achieved reading fluency years ago. Empathizing and relating to users with RDs is a more formidable challenge for designers. Although this is purely conjectural, I suspect that the extreme difficulty for designers to put themselves into the shoes of people with reading disabilities has helped to hinder technologists from exploring this AT space.

3.3 Emphasis on In-School and Early Learning

To be fair, not all technologists have been hindered so. There is after all research on ATs for RDs, most of it published in education research journals as those cited earlier in this chapter. Unfortunately, this is

problematic for technology development. Education research places great emphasis on early childhood and in-school learning. Thus, most of the AT work has understandably targeted early reading skills as motivated by longitudinal studies showing how performance differences between successful and struggling readers widen over time (Cunningham & Stanovich, 1997). Early intervention can help narrow and perhaps prevent this gap. This focus has two unfortunate consequences, however.

First, as mentioned in Chapter 2, Section 3.4, reading comprehension skills continue to develop after the basics of reading are learned. Disciplinary-specific skills are honed. Because of this, it is unreasonable to believe that the same ATs used when a person is “learning to read” are going to be as applicable and helpful when the person is now “reading to learn.” For advanced readers with RD, fundamental reading skills like word identification are still important tasks for ATs to support. After all, breakdowns in word identification impact comprehension. However, the same ATs should also offer support for the more advanced reading tasks these users experience. A focus on AT for early reading skills development fails to provide such support.

The second consequence is due to focusing on learning to read and, by association, reading in schools. Quite simply, reading does not take place only within the walls of a school. Reading can occur in the workplace (as studied by Elkind et al. (1996)), at home, and essentially anywhere for reasons ranging from pleasure to education to work. With this in mind, consider a “successful” implementation of the Kurzweil 3000 TTS system in a school (Kurzweil Educational Systems, 2005a, 2005b). Such an implementation involves the software being installed on computers in a lab. However, a student who uses these computers is typically only at school for 6–7 hours a day for 5 days of the week. The software is not available to the student outside of those times. As Laga et al. (2006) points out, unless the student has a personal copy of the software, informal reading outside of school will be unassisted. Although the AT has been successfully adopted and integrated into the school environment, the student has not been able to adopt and integrate it into her reading practices. An AT should be able to support reading in the various locales where the user engages in reading.

3.4 A Medical Model Approach

Additionally, overemphasis on early reading education may also explain the nearly tunnel vision focus on using text-to-speech. In disability studies, the *medical model* views a disability as an imperfection or problem that needs treating or fixing (Clough & Corbett, 2000; N. Matthews, 2009). This is in contrast to the *social model* which views that the problems and challenges experienced by a person with a disability come from the inaccessible design of products and environments, not the person or the disability (Clough & Corbett, 2000; N. Matthews, 2009). Under the medical model, poor phonological processing is recognized as a key problem in people with RDs, and, logically, interventions should address the problem by either supplanting or treating the deficit. This intent is strongly suggested in the TTS studies as many have discussed TTS not as an accommodation but a tool for remediation and improving the phonological processing of the user (Farmer et

al., 1992; Sands & Buchholz, 1997).

There are numerous problems with using the medical model to direct assistive technology research. By its nature, the medical model focuses on the disability and ignores socio-environmental context (Clough & Corbett, 2000). Moreover, attempting to replicate what “normal” readers do imposes unnecessary limits on possible approaches. In discussing new directions for telecommunications research, Hollan and Stornetta (1992) use an analogy about crutches and running shoes:

The crutch is designed specifically to make the best of a bad situation—to let someone hobble around until they are back in shape. On the other hand, shoes are to correct some of the problems of our natural condition, and in the case of athletic shoes, to enhance our performance.

(Hollan & Stornetta, 1992, p.120)

This analogy is also relevant to AT design. Just as Hollan and Stornetta argue that the focus on perfectly mimicking face-to-face communication constrained and limited telecommunication research, this medical model approach of trying to make a reading-disabled person “normal” also limits AT research. Instead of building reading “crutches” that repair reading deficiencies, one should design reading “running shoes” that enhance reading performance rather than just repair individual deficiencies.

3.5 Absence of User Needs and Demands

However, there might not even be a need for such “running shoes.” Quite possibly, the lack of research and tool diversity are really non-issues. The current existing assistive technologies may meet all the needs of reading-disabled users. Another possibility is that other technologies may have been repurposed to support reading, and the experts are not yet aware of or have not recognized their usage as ATs.

To explore such questions, another scholarly perspective is required. One needs to understand how knowledge of a technology arrives to users and how and why said users decide to adopt the technology into regular usage. The next chapter discusses technology diffusion and adoption and reviews studies of AT adoption and usage.

4 Chapter Summary

Assistive technologies for reading disabilities were described in this chapter. Although past research has generated some diversity in the available technologies for supporting the reading process, text-to-speech systems are the predominant tools available. Reading disability experts are able to recommend a greater number of tools for non-reading support, and computer science research on reading support tools was shown to be rare. Hypotheses were presented for explaining the dearth in both available ATs and technology research.

NOTES TO CHAPTER 3

- 1 There is quite a bit of inconsistency in viewing high costs and profits as a motivation for distrust and skepticism. Both well-intended or malicious quackery has great cultural and historical weight. From snake oils and cure-alls from decades ago to the new age, holistic healing fads of the modern age, a collective cynicism has developed. Evans (2001) touches on many of the false treatments offered for visual complaints throughout history and notes that a common theme is that the treatments were never free. Thus, demanding compensation for some treatments or aid is suspect, yet we are inconsistently willing to pay for doctor visits, prescription medicines, and other treatments or forms of help.

Moreover, the economics of assistive technologies often lead to high prices. Due to small consumer populations, any company that invests in the research and development of ATs often need to charge high prices to recoup expenses and achieve a profit. Scale and mass production are often not available to ameliorate costs and prices. Charging high prices may suggest false promises, but they might also be necessary for the ATs to even be available.

- 2 It is not surprising that Pepper and Lovegrove (1999) did not assess reading comprehension in their study. Both are psychologists who specialize in the cognition of human vision. Comprehension is outside of their sphere of research. This highlights again one of the challenges faced in researching reading disabilities. As mentioned before in Chapter 2, Section 4.2.4, there exist both a visual theory and phonological theory of dyslexia and other RDs. Accepting that both contribute to explaining RDs requires straddling multiple disciplines. Unfortunately, most research and its publications stays within its discipline. Visual factors papers will refer to the neurology of the eye and vision while phonological factors papers focus on comprehension and other elements of reading science. Both types of papers properly apply their areas of expertise, but they also invariably omit other aspects. Fundamentally, reading is both a visual and a phonological activity and thus naturally straddles multiple disciplines. Solid, excellent research needs to do the same.
- 3 The science and art of typography have not necessarily worked in accord over the years. The scientific exploration of how choices in typography affect reading performance began centuries after mass printing of books became possible and popular. As such, the craftsmen of type possessed a strong legacy and felt that they did not need scientists intruding upon their craft. Sutherland (1988, 1989) chronicles one of the more glaring examples of this divide in her study of the influence of the work of Miles Tinker. Tinker, a psychologist specializing in human vision, amassed a gigantic body of experimental data on how various elements of typography affect the legibility and readability of print (Tinker, 1963, 1965). He pioneered methods of how to assess reading performance, empirically verifying and comparing the

reliability and validity of multiple measures. Yet, as Sutherland noted, he faced great resistance and animosity from the typesetting community. As such, the true impact of Tinker's efforts on the printing industry was likely minimal. His work, instead, lives on through those doing scientific work on reading and printed text.

Although this tale of science and art is a fascinating side journey, it does hold important testament to the challenges of conducting research and effecting science-based change in a long-established domain. While one can certainly draw parallels with the scientific study of traditional healing practices (e.g., acupuncture), I myself see similarity in the work in this dissertation. The struggle to consider visual components of RDs is one such area. The challenges of doing multidisciplinary work across different academic cultures is another.

- 4 In the interest of full disclosure, I am an active member and participant in the DO-IT organization, and one of my committee members, Dr. Sheryl Burgstahler, is the director of DO-IT. I am also a paying member of the International Dyslexia Association, although I am not actively involved. My membership is primarily for access to IDA publications.

CHAPTER 4

[ASSISTIVE] TECHNOLOGY ADOPTION

Jo: Doesn't exactly look like second grade literature.

Jimmy: Why would I wanna read that stuff... it's boring and stupid.

Jo: Yeah, I guess you're right.

— *Sparks: An Urban Fairytale* (Marvit, 2002, p. 55)

Most technologies, including but not just assistive technologies, are designed to improve the lives of their intended users. Evaluation studies might say that a tool increases some measurement of reading performance by 25%, but the truth is that the tool provides no benefit if the target users fail to use it. One might even define success of a technology as the product of its potential benefit and its likelihood of being adopted.

This chapter provides background on the technology adoption process and the factors that promote or hinder adoption. Given the focus of this dissertation, specific focus is given to AT adoption. The first section provides an overview of one of the dominant models of technology adoption—Roger's diffusion of innovations. Next, several adoption models developed specifically for understanding AT adoption are discussed. The third section gives an overview of adoption studies of assistive technologies. Finally, I present my PATTC framework as a means of understanding the many influences on [assistive] technology adoption.

1 Rogers's Diffusion of Innovations

Understanding how ideas and technologies diffuse or spread among people has been studied in many fields. To explain the factors that promote or hinder the acceptance of a technology, several models have been proposed, such as the Technology Acceptance Model (Venkatesh & Bala, 2008) and the Lazy User Model (Tetard & Collan, 2009). Perhaps the leading and most influential model, however, is Everett Rogers's *Diffusion of Innovations* (2003). Although several researchers preceded him, Rogers (2003) is viewed as the pioneer of technology adoption research. Studying rural and agricultural sociology, his doctoral dissertation in 1957 was on the usage patterns of a new weed spray among Iowan farmers. For his related work section, he reviewed other studies of how groups adopted a new technology or idea. Despite these studies coming from fields as

varied as medicine, agriculture, and marketing, he found multiple commonalities. From this, he formulated an overarching, theoretical framework. This section provides a description of his framework.

1.1 The Notion of Innovation

One of Rogers's key insights was in not just focusing on technology or commercial products. Instead, he developed the concept of *innovation*, which he defined as any object, idea, technology, or practice that is new. An innovation can include tangible, physical objects such as a new device or medicine. An innovation may also be intangible, such as a new design methodology or pedagogical technique. Furthermore, the notion of an innovation's newness can be relative to both place and population. An innovation may be cutting edge communication technology among Silicon Valley businessmen. However, a well-established technology or practice, such as the use of antibiotics, may be new in a developing world context such as some regions in Africa. E-mail and instant messaging, though well-established among most age groups in the United States, may be completely new to a group of senior citizens. By defining innovation in this way, Rogers effectively dissolved the barriers between disciplines and could openly consider adoption studies from multiple fields. With such a broad scope, the commonalities in findings from various studies are much more potent. Rogers's model thus readily generalizes and has wide applicability.

1.2 The Innovation-Decision Process

One of the general findings of Rogers's literature review was what he termed the *innovation-decision process* (Rogers, 2003, chapter 5). Shown in Figure 4.1, the innovation-decision process describes the steps an entity goes through in deciding whether to adopt an innovation. The entity involved may be a solitary individual or a group such as a community or company. Note that for my research, I generally focus on the decision process of an individual with RD deciding whether or not to use a technology to support some element of the reading process. Thus, the following discussion on the process is conducted with that focus in mind.

1.2.1 Knowledge

The innovation-decision process begins with the *Knowledge Stage*. One cannot begin the adoption process without knowing about the innovation. In this stage, a person first becomes aware of the technology. Perhaps she sees someone use the technology in real life. She may also see said technology advertised on television or read about it in a magazine or on the web. A peer or mentor may inform her about it as well.

1.2.2 Persuasion

A person moves into the next stage, the *Persuasion Stage*, when she moves beyond simple awareness of the technology. She begins to show interest in the technology and seeks out information about the technology: costs, features, user reviews, etc. It is at this point that she begins to consider herself as a potential user of the technology and begins to actively consider whether or not to adopt the technology into her regular activities.

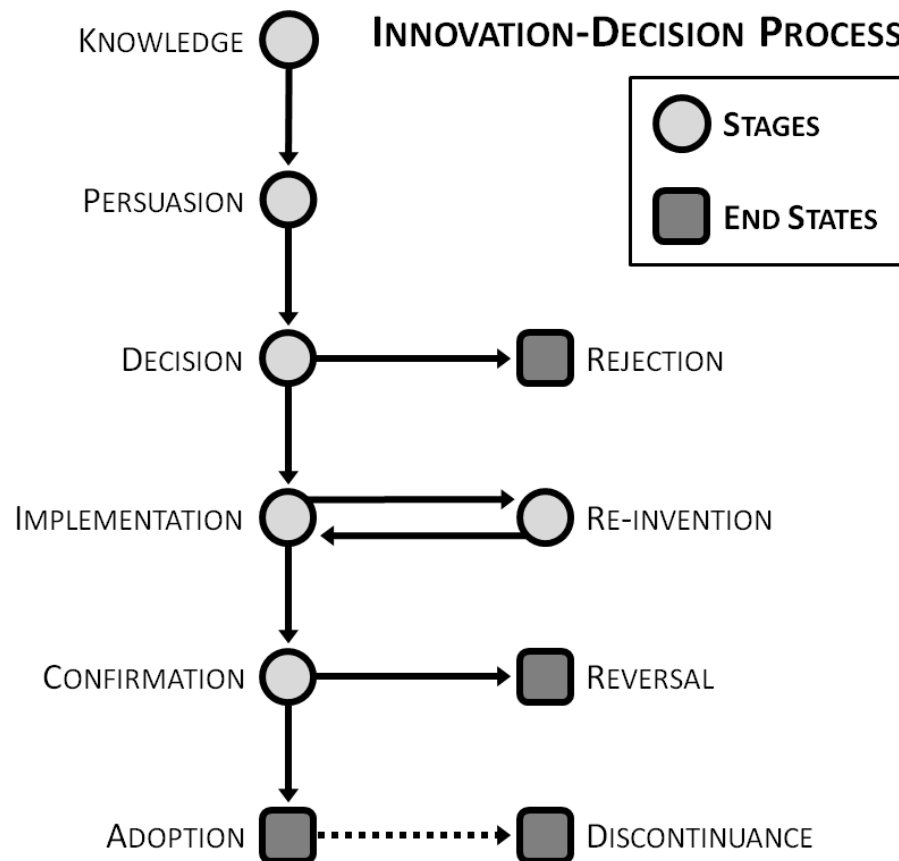


Figure 4.1: Rogers's innovation-decision process of technology adoption.

1.2.3 Decision

At the *Decision Stage*, a person makes the choice to reject or adopt the technology. This personal process involves the weighing of advantages, disadvantages, costs, benefits, and trade-offs. The decision to not adopt, *rejection*, is an active choice to not acquire the technology or ever use it. Otherwise, the person begins to use and integrate the technology into her daily life.

Although this stage is perhaps one of the most critical for understanding technology adoption, it is perhaps one of the most difficult to study. As Rogers points out, the process of deciding occurs silently and invisibly to the outside researcher; one can rarely capture the exact moment of decision. Instead, the researcher can only access the adopter's reflections and retrospectives of the decision to adopt or not, sometimes months or years later. Such data is, of course, fraught with validity concerns.

1.2.4 Implementation

The task of integrating the innovation into regular use is called the *Implementation Stage*. This can be a slow, time-consuming process. For the person involved, changes to her usual habits and practices may be necessary. The technology is also being evaluated at this time to see if it meets expectations. Further information about

the technology may also be sought in order to improve usability and usefulness of the technology.

During this stage, re-invention may occur. *Re-invention* refers to the process by which a person adapts or modifies a technology to better meet her needs and improve its overall compatibility. This modification may also involve using the technology for a task different from the technology's original intent. For example, in an AT study by Dawe (2006), parents repurposed a memo-recording device as a communication aid for a non-verbal teenager with autism.

Rogers comments that the importance and ubiquity of re-invention was overlooked by himself and other technology adoption researchers for many years (Rogers, 2003, p. 17). Once aware of the concept, researchers found that many adopters re-invent the technology to some degree. Moreover, technologies that are more readily repurposed were found to be adopted more quickly than less flexible technologies. As will be discussed in Section 3, issues of re-invention have been noted in some AT adoption research as well (Martin & McCormack, 1999; Riemer-Reiss & Wacker, 2000; Dawe, 2006). Definitions of assistive technologies often include re-invention as well:

Any item, piece of equipment or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. (Martin & McCormack, 1999, p. 414)

1.2.5 Confirmation

Once the processes of integration and re-invention have completed the final stage, *Confirmation Stage*, has been reached. At this point, the person finalizes their decision regarding the adoption of the technology. One option is exactly that—*adoption*. At this point, the person is committed to using the technology to its fullest potential it can serve in her life. Another option is a *reversal* of the original choice to use the technology. This is essentially a delayed rejection.

1.2.6 Discontinuance

After the adoption of a technology, the person does not always continue to use the technology, though. After an initial period in which the technology is used, the person may abandon the technology. Such *discontinuance* can occur in several ways. Some technologies face *obsolescence* in that they cease working or have a limited expectation for the duration of their use. For example, crutches given to a person with a sprained ankle are expected to be abandoned once healing has completed.

Another form of discontinuance is *replacement*. If a broken technology is substituted with a new version, this is one form of replacement. A technology may be also abandoned in order to replace it with a newer or older version. Upgrading a computer with the latest software or purchasing a newer model cell phone are examples of this type of replacement discontinuance.

The final type of discontinuance is perhaps the most regrettable. *Disenchantment* rejection, also called abandonment, is when the user becomes dissatisfied with the technology and quits using it. Although the decision to stop using may be conscious, the user may instead just gradually use the technology less and less until it is forgotten. At the heart of it, disenchantment discontinuance means that the adopter's entire effort of learning, deciding, and implementing the innovation into her life has been ultimately for naught. She has wasted her time, resources, and efforts.

1.3 Influences of Adoption

The innovation-decision process explains how an innovation becomes adopted, rejected, or abandoned. It does not, however, explain why one technology may be adopted over another. Rogers's diffusion of innovations proposes five factors that shape the rate and likelihood of adoption. Some factors are inherent to the innovation, while others concern the adopters themselves and their usage of the innovation.

1.3.1 Relative Advantage

For a person to choose to use a technology for a specified task, it should provide some form of benefit for the task concerned. To be more specific, the innovation should demonstrate a *relative advantage* over other options, ideally including the technology currently used for the task. Better technologies will be adopted, plain and simple. However, what defines "better" is rarely a single, simple statistic. Increased performance, cheaper costs, increased social standing, or even a wow factor may all contribute to the sense of relative advantage.

1.3.2 Compatibility

Another factor is the *compatibility* of the innovation with the user's life and practices. An adopted technology will be integrated into one's life and therefore must mesh well. This compatibility may be of a technical basis, such as software or hardware compatibility issues with a computer. Any interruption to one's workflow should also be minimal. Additionally, the technology should not cross one's value or belief system. For example, if a person is against the mistreatment of animals, any medication tested on animals would be incompatible.

1.3.3 Complexity

When deciding to adopt an innovation, the inherent difficulty of using the technology is a major concern. *Complexity* refers to the sense of difficulty that the user has in using and understanding an innovation. The learning curve associated with learning how to use a technology is considered. Also considered are traditional human-technology interaction notions of usability and affordances as espoused by Norman (2002) and others. Complexity goes beyond these elements, though. A potential user must also understand why the innovation is appropriate or beneficial. The level of such an understanding need not be to an extreme depth but should at least convince the user of the innovation's value. In a case study of an attempt to promote the boiling of water in a Peruvian village, germ theory was used to motivate the adoption of boiling water. However, the

villagers had difficulty accepting germ theory as the cause of illness. Thus, they overwhelmingly rejected water boiling as they failed to understand the motivation to do so (Wellin, 1955; Rogers, 2003).

1.3.4 Trialability

A fourth factor in promoting the adoptability of an innovation is the opportunity for a potential user to experience using the innovation itself. Such *trialability* covers opportunities such as test drives, demonstration units, and simulations. The user gets the chance to try the technology without having to fully commit to purchasing or adopting it. Trials can be great sources of information searched for and needed during the Persuasion and Implementation stages. In particular, trials directly limit or prevent forming inaccurate assumptions about the technology.

1.3.5 Observability

The fifth and most critical factor that shapes innovation diffusion is *observability*. Observability refers to how visible the use of the technology is to those around. For a person to adopt a technology, seeing, hearing about, or otherwise knowing that other individuals are using that technology dramatically encourages adoption. Observing a technology stimulates awareness of the innovation and conversations among one's peers.

Rogers found evidence for the power of observability when he plotted the number of adoptions over time. Consistently, these plots revealed a normal Bell curve, while plots of the cumulative number of adoptions over time showed a sigmoid or s-curve. Examples of these curves are shown in Figure 4.2, and both reflect how knowledge and observability shape the rate of diffusion. Adoption is slow in the beginning as awareness of the technology is limited. As more and more people use the technology, the public becomes more aware of the technology and thus the rate of adoption increases until the technology is in common use and has saturated the market. At this point, the number of adoptions drops off as there are fewer and fewer new consumers available.

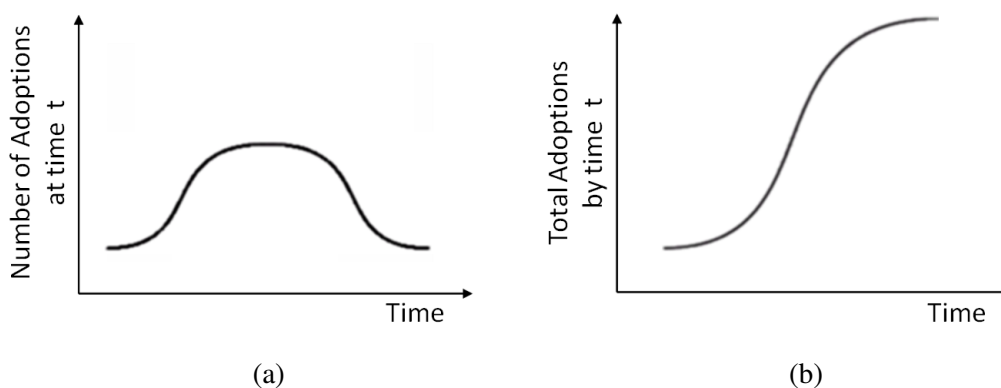


Figure 4.2: Example plots of adoption over time. (a) Bell curve of adoption frequency. (b) S-curve of cumulative adoptions.

1.4 Communication Channels

For Rogers, the power of observability encouraged research on what makes an innovation more readily noticed. Mass media is a major influence on the public's awareness of new innovations. The people we interact with on a regular basis are another. Some are complete strangers, but we might notice them using the newest cell phone or MP3 player. Others are much closer to us—friends, family, and coworkers. Our technology choices are influenced by their choices and recommendations. Thus, understanding the diffusion of an innovation is greatly facilitated by understanding the communication channels and social networks involved.

As such, many diffusion studies identify who talks to who and how adoption spreads through the identified social network. Some individuals are more influential than others. Known as *change agents*, these persons are often highly connected within the network or are held in high esteem by their peers. Change agents may also hold a position of power, such as in the case of a manager or director position. Regardless, when a change agent decides to adopt or reject a technology, his peers will likely follow suit.

The nature of the connections between members of a social network also influences the likelihood of diffusion. Power dynamics can force an adoption or rejection of a technology. While an employee might prefer to use an Apple computer, a company's decision to use exclusively IBM computers would override his personal choice. A person may also weight the value of a peer's recommendation based on how similar they are to each other. Termed by Rogers as levels of *homophily* and *heterophily*, a person is more likely to accept and pursue a technology when recommended by peers who share similar attributes (homophily) rather than peers who differ on multiple attributes (heterophily).

1.5 Implications of Rogers' Model

Because of its scope and scholarly reputation, Rogers's model is important for consideration in the study of AT adoption among people with reading disabilities. Unfortunately, the implications for the work in this dissertation are not encouraging. The key to the diffusion process is the growing awareness of the technology among the intended user population. This awareness can come from seeing others using the technology or being told about it. This is a troublesome point when it comes to reading disabilities. As discussed in Chapter 2, Section 4.2.7, individuals with RD tend to avoid disclosing their disability and engage in tactics to hide their disability from others (Cory, 2005). As such, they are perhaps unlikely to be seen using an AT or talking with other users with RDs about an AT. Thus, diffusion could be greatly constrained by this restricted amount of communication.

Still, an understanding of the communication channels involved in ATs for RDs adoption is warranted given the concerns about a lack of communication. However, it is important to not just consider individuals with RD in the network. Other people with knowledge about or interest in ATs (e.g. parents, teachers, and disability and AT specialists) will have potential influence in such a network. Figure 4.3 shows how a social

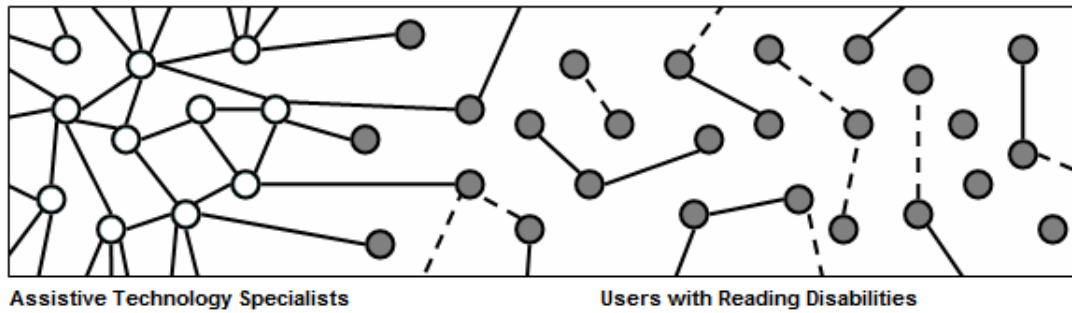


Figure 4.3: A possible social network involving AT specialists (white nodes) and users with RDs (gray nodes). An edge between two nodes indicates that the two communicate with each other. A dashed edge between two users with RDs indicates that communication occurs but one or both is unaware of the other's disability.

network of AT specialists and users with RD could appear. Due to professional organizations, mailing lists, and other means, the AT specialists are likely well connected, meaning that knowledge of new ATs will likely spread quickly among them. However, the individuals with RDs are less connected and only a few talk with the AT specialists as suggested by the hesitancy of college students with RD to register with disability services (Cory, 2005). Adding further complexity is the possibility that two peers may both be reading-disabled yet may not have disclosed this to each other.

Even if such communication issues can be addressed, Rogers's model suggests that finding an adoptable technology may be difficult. Reading, particularly from typeset materials such as books and magazines, has been around for several centuries now. Books and literacy have become embodied in our culture, and the technology has been refined over the years. However, encultured technologies can easily resist change. as evidenced in the history of the QWERTY and DVORAK keyboard layouts (Rogers, 2003, p. 8–11). The QWERTY keyboard was designed intentionally to slow down typists in order to prevent jamming. However, the advancement of technology eliminated the problem QWERTY was designed to address, leading to the development of keyboard layouts like DVORAK that improved typing efficiency, error rates, and risks for repetitive stress injuries. Despite its superiority, though, DVORAK keyboards have not become standard due in part to inertia from users hesitant to change established practices. Any new reading technology will thus have significant hurdles to overcome if it is to be adopted. Just providing a superior relative advantage will not be enough given how readily compatible current approaches are and reading's established legacies.

2 Models of Assistive Technology Adoption

Although Rogers's model of the diffusion of innovations is well-regarded and has been shown to generalize across multiple fields, specific models of AT adoption have also been developed (see Edyburn (2002) for an overview). By focusing solely on assistive technologies, these models can better identify and highlight

Table 4.1: King's (1999) essential factors for assistive technologies.

FACTOR	DESCRIPTION
Device transparency	User-friendliness and how open usage is to new users
Cosmesis	Aesthetic attributes of a device and the user's opinions towards them
Natural interface mappings	The device's interface should follow culturally-expected patterns
Affordances	Qualities afforded by the materials used in a device's design
Learned or taught helplessness	Internalization of difficulties experienced with a device as a personal failure
Feedback loops	Manipulation of the device should result in communicative feedback to the user
"In the head" versus "in the world" knowledge	Recognizing that knowledge of how to use a device may be conveyed by a device or expected as common knowledge
Constraints of AT use	Limitations placed on the device usage due to physical, sensory, cultural, or other reasons
Forcing and fail-safe functions	Features to prevent harm or device misuse
Error prevention	Features that prevent or limit mistakes by the users or help insure successful usage of a device

issues that are critical to AT adoption. This section presents four frameworks that attempt to provide a general description of the actions, processes, and players involved in the adoption of an assistive technology. Since none of these models were designed specifically with reading disabilities in mind, their relevance and applicability to RDs is also discussed.

2.1 King's Essential Human Factors

King's essential human factors is not a model per se, but a collection of properties that he has identified as important for consideration when promoting adoption and avoiding abandonment (King, 1999). As an expert in alternative and augmentive communication systems, King has worked extensively in the disability services sector for several decades. As such, he directly witnessed the many negative effects of AT abandonment. Not only did he see the time and effort he spent working with a client to select, configure, and deploy an assistive device be wasted, King also saw how such AT failures led to helplessness and depression in his clients. Over the years, he developed a set of best practices that positively influence ongoing use of an AT.

Table 4.1 lists the ten factors he identified. Some are well-established concepts from studies in human-technology interaction: device transparency, natural interface mappings, and "in the head" versus "in the world" knowledge. This is unsurprising given that King acknowledges how the work of Norman (2002) and other usability specialists contributed to the development of his list of factors. Moreover, this influence helps emphasize that assistive technologies and "normal" technologies are not completely different entities.

Other factors such as forcing functions, fail-safes, and error prevention are of greater relevance for ATs

than other technology types, however. As King notes, an electric wheelchair that accelerates too quickly or unexpectedly could cause the user injury. In such cases, the user's disability would make it difficult to rectify the situation. Similarly, if a communication device is too unwieldy or breaks too easily, the user may lose his ability to interact with others. Such examples highlight how assistive technologies often address critically important user needs and thus induce higher stakes when it comes to poor performance and errors.

However, two factors—learned helplessness and cosmesis—are, in my opinion, particularly insightful for AT designers. In the case of learned helplessness, technology failures and user difficulties can affect anyone's self-esteem when it comes to technology usage. For people with disabilities, though, an assistive device is often presented as absolutely necessary for engaging in life and to be successful. An AT recommendation is usually also the product of a lengthy selection process and framed as the best choice for that user. If the technology is found to not be helpful or too difficult to use, the user may internalize the failure as being due to himself and not the technology. After all, the technology was chosen just for him and without it, he cannot function in life. He must be beyond hope. Clearly, great care must be taken when recommending ATs.

As for cosmesis, King points out that people with disabilities have personal styles and tastes just like everyone else. He recounts the case of “Jane,” a young woman with cerebral palsy. Despite great success with an initial trial of a new communication tool, she refused to have it mounted on her wheelchair. The technical staff proposed mounting it on an chrome and black articulated frame that they would attach to her wheelchair. Jane adamantly refused as this would clash horribly with the style of the new chair she had just gotten in her favorite shade of purple (King, 1999, p. 196–198). Technologists often focus on the outcomes of using the technology; their views limited to how helpful a device may be. It is all too easy to forget that an AT integrates with the user's life, and life is more than just performance. Style might not be crucial for performance, but should always be considered. After all, we offer multiple options for eyeglasses, automobiles, and other technologies that we do not typically think of as assistive devices.¹

In summary, King's list of essential human factors for assistive technologies does provide insights for AT designers. While these insights reflect King's many years in the field, that itself is a limitation. King has worked primarily in the area of speech pathology. His clients and the motivating examples he uses come typically from people with communication disabilities and serious physical disabilities such as cerebral palsy and muscular dystrophy. The direct applicability of his factors to other disability types, namely reading disabilities, is thus uncertain.

2.2 Baker's Basic Ergonomic Equation

One of King's other contributions to understanding AT adoption is his promotion of the heuristic known as *Baker's Basic Ergonomic Equation*. Original formulated by Baker (1986), this equation is a way of thinking about alternative communication systems and what makes a person decide to go through the process of using

the device to communicate. He reasoned that the likelihood of using a communication device was a function of the time it took, the person's motivation, and the effort (both cognitive and physical) involved:

$$\text{Likelihood of Usage} \propto \frac{\text{Motivation}}{\text{Time} + \text{Physical Effort} + \text{Cognitive Effort}}$$

The basic premise is that the longer and harder it is to say something with the device, the higher the user's motivation must be if he or she is to use the device to convey a message.

Although Baker proposed this equation specifically for the domain of alternative communication systems, King (1999) realized it could be applied to AT usage in general: the longer and harder it is to perform a task with the device, the higher the user's motivation must be if he or she is to use the device to complete said task. King, also an expert in alternative communication systems, modified the equation by separating linguistic effort from cognitive effort:

$$\text{Likelihood of Usage} \propto \frac{\text{Motivation}}{\text{Time} + \text{Physical Effort} + \text{Cognitive Effort} + \text{Linguistic Effort}}$$

Here, cognitive effort refers to the thinking, sensing, procedures, configuration, and memory that a user must do or have to use a device. Linguistic effort refers to the symbolic/semiotic interpretation required by the user when interacting with the device.²

In general, Baker's Basic Ergonomic Equation appears applicable to assistive technologies for reading disabilities. Elkind et al. (1996) did identify motivation as a key factor in successful usage of their TTS system. The equation, however, is incomplete in some regards. However, consider again the students with invisible disabilities in the study by Cory (2005). These were students enrolled in college with a clear motivation to receive an education and achieve future career goals, yet many chose to avoid seeking out help or support, due in part to their desire to control the impact of being labeled as having a disability. Refusing to use an assistive device is one form of control, so it seems appropriate to include a perception of stigma due to using the device in the equation. Another aspect missing from Baker's equation is a perception of the necessity of the device for completion of the task. For example, consider a person with paraplegia and a person with a reading disability. Without some form of assistance, the person with paraplegia is for all practical purposes immobile. However, even without an assistive device, a person with a reading disability can usually still read, albeit slowly and problematically. Thus, the necessity of using an AT could be less for that individual.

Even with these limitations, the Baker's equation provides insights into the factors that influence the use of an assistive device. Moreover, one can address these limitations by adding further elements into the equation. I propose just such an enhanced version as described in Appendix C. Still, given that both Baker and King work primarily with alternative communication systems, it is enlightening to see how their approach readily generalizes to other types of ATs.

2.3 Kintsch and DePaula's Adoption Framework

Unlike King's factors and Baker's equation, other efforts have developed full models of the assistive technology adoption process. One of these is the framework proposed by A. Kintsch and DePaula (2002). Working from previous AT adoption studies, A. Kintsch and DePaula put forth a four-stage cycle that describes key elements of a successful adoption process: development, selection, learning, and integration. Additionally, they frame these stages in terms of four stakeholder groups: the users, caregivers, AT specialists, and AT researchers and developers. This framing is particularly notable in that, for each stage, they discuss what information each stakeholder group should communicate to the others.

Unfortunately, A. Kintsch and DePaula place great emphasis on the role of caregivers in the adoption process. For example, they are careful to mention the importance of including both the user and the caregiver in the selection stage as well as the importance of trial periods. The learning stage, however, overemphasizes the role of the caregiver. In this phase, while the user is learning how to use the device, the caregiver is also learning how to customize and maintain the AT. It is unclear as to why only the caregiver and not the user is assigned such duties. A. Kintsch and DePaula also state that the caregiver should only help the user learn the device once the caregiver has himself become comfortable with the AT. Perhaps it is poor phrasing on their part, but this places the caregiver in the role of a gatekeeper and goes against their idea of the learning phase being a shared event of understanding.

This adoption framework can thus be said to overprivilege the role of the caregiver and begins to devalue the independence of the AT user. This goes against a major goal of assistive technologies: to improve the independence of people with disabilities (King, 1999). Moreover, the assumption that a caregiver is always present is unsupported when people with invisible disabilities are considered. The idea of having a friend, family member, or mentor to occasionally seek support from is frequently reported in the literature (Adelman & Vogel, 1990; Gerber et al., 1992; Spekman et al., 1992; Cory, 2005). Complete reliance on another person, however, is not. Thus, this framework is not appropriate to all disability types. By making a clear distinction between the user and caregiver roles, they inadvertently constrain the applicability of their model to disabilities where having a caregiver is the norm and maintaining an assistive device. In regards to reading disabilities, the user is not expected to be in charge or capable of customizing or neither is the case.

2.4 Scherer's Matching Person and Technology Model

Another framework developed for understanding the adoption and usage of ATs is Scherer's *Matching Person and Technology* (MPT) model (Scherer, 2005; Scherer, Jutai, Fuhrer, Demers, & Deruyter, 2007). Developed for rehabilitation professionals, the MPT framework is about understanding the myriad characteristics that positively and negatively influence AT usage. Although originally developed for assistive technologies, the MPT approach has been expanded for understanding technology usage in schools, the workplace, and health

care (Institute for Matching Person & Technology, 2010).

Scherer separates the influencing factors into three main classes: milieu, personality, and technology. *Milieu* refers to the environment and sociocultural context in which the user lives. Aspects of milieu include available resources (both financial and informational), social support structures, and the current stress levels and time commitments of the user and his social supports. Pertinent features of the user's psyche comprise *personality*. The user's cognitive abilities, comfort with change and technology, self-esteem, and optimism are included here. Characteristics of *technology* include relative advantage, ease of repair, financial cost, cost effectiveness, and adaptability.

The above three factors are not that novel given the previous discussions in this chapter. However, what makes the MPT model fairly unique is that it has been instrumented. Protocols, instruments, and assessments have been developed and validated for rehabilitation and disability service personnel to utilize in their work (Institute for Matching Person & Technology, 2010). One instrument is the *Survey of Technology Use*, which is used to develop a profile of the user's attitudes towards technology. Another assessment, the *Worksheet for the MPT Model*, is a protocol to identify user needs and goals and then match them with available technologies.

The efforts by Scherer and the Institute for Matching Person & Technology to validate such instruments does lead to a weakness of the MPT model, at least when it comes to reading disabilities. Like King (1999), Scherer's work has mostly focused on one disability type: severe mobility issues due to spinal injuries or congenital conditions such as cerebral palsy (Scherer, 2005). The MPT assessments even specifically describe assistive technologies as only "products for persons with physical disabilities designed to enhance independence and functioning (examples are wheelchairs, adapted utensils, communication devices)" (Institute for Matching Person & Technology, 2010). The implications of physical disabilities, particularly acquired paraplegia and quadriplegia, are radically different from those of RDs. The differences in the visibility of the disability, the impact on one's life activities, and the nature of accommodations and ATs all raise different issues when it comes to AT adoption and usage. To properly apply the MPT framework to RDs would require extensive reshaping and revalidation of the provided instruments.

3 Studies of Assistive Technology Adoption

In addition to the previously discussed models and frameworks, specific studies of AT adoption and usage have been conducted. Continuing the pattern of the research on ATs for RDs being limited in scope and effort, very few studies have been conducted on assistive technology adoption among users with reading disabilities. Despite extensive reviews of the literature, I am aware of only one research study that directly examines factors leading to AT adoption exclusively by individuals with RDs: Elkind et al. (1996). Other studies have focused on different disability types or considered a wide range of disabilities that might or might not include RDs.

Table 4.2: Descriptions and findings of the assistive technology adoption studies discussed in this paper. Studies marked with an * indicate that the study included participants with RDs/LDs.

Assistive Technology Adoption Studies	
1	<p>Phillips & Zhao (1993)</p> <p>Mail and phone survey of 227 adults with physical disabilities and their current and past technology usage.</p> <p><i>Findings:</i> - 507 of 1732 (29.3%) devices reported as abandoned - Factors of abandonment: user not included in selection process, poor device performance, procurement difficulty, and changing needs of the user</p>
*2	<p>Elkind et al. (1996)</p> <p>Study of 8 adults with RDS using the BookWise TTS system for several months at home and/or work. One subject's RD was due to brain injury.</p> <p><i>Findings:</i> - 4 of 8 had positive experiences with the software - Factors that promoted adoption included: motivation to improve job, perceivable gains in reading performance, and ease of digitizing texts</p>
*3	<p>Jeanes et al. (1997)</p> <p>Multiple studies of long-term usage of color overlays by K-12 students for treatment of visual stress. All participants were diagnosed as experiencing some visual stress when reading.</p> <p><i>Findings:</i> - 14 of 66 students still using overlays after 10 months - Longitudinal analysis controlled for placebo / novelty effects</p>
4	<p>Wehmeyer (1995, 1998)</p> <p>Piloted mail survey of families caring for persons with mental retardation.</p> <p><i>Findings:</i> - Only 10% of respondents used AT despite expected benefits - Cost and lack of information were main reasons for non-use</p>
5	<p>Martin & McCormack (1999)</p> <p>Survey of AT abandonment in Ireland among 17 individuals with physical disabilities.</p> <p><i>Findings:</i> - 35% abandonment rate (out of 46 devices) - High abandonment rate (86%) among users aged 20 to 30 - Males less likely to adopt new AT after initial abandonment</p>
*6	<p>Riemer-Reiss & Wacker (2000)</p> <p>Survey of 115 adults with disabilities to identify factors leading to AT discontinuance. Based directly on Rogers's diffusion of innovations. 7.4% of the 115 participants were identified as having learning disabilities.</p> <p><i>Findings:</i> - 32.4% abandonment rate with 6.4% of AT never used even once after being purchased/acquired - Significant predictors of adoption: relative advantage, compatibility, and user involvement in selection process</p>
*7	<p>Koester (2003)</p> <p>Longitudinal study of 8 disabled users new to using speech recognition software. One participant had specific disabilities with reading and writing.</p> <p><i>Findings:</i> - 7 of 8 participants had abandoned software after 6 months - Reasons for abandonment: slowness, unclear if accuracy improved despite training, and technical issues</p>

Table 4.2: (continued from previous page)

Assistive Technology Adoption Studies (continued)	
8	<p>Dawe (2006)</p> <p>Technology-focused interviews of 12 families and 8 teachers of adolescents with moderate to severe cognitive disabilities.</p> <p><i>Findings:</i></p> <ul style="list-style-type: none"> - Importance of including stakeholders beyond family - AT configuration and maintenance should embrace simplicity - Most of the AT used were repurposed technologies
9	<p>Shinohara & Tenenberg (2007)</p> <p>Embedded case study and technology biography of a young, blind woman.</p> <p><i>Findings:</i></p> <ul style="list-style-type: none"> - Workarounds can be inefficient but preferable by the user - Sensitivity to how technology can mark a user as disabled - The small <i>n</i> allowed for the study of a broad range of tasks and technologies
*10	<p>Comden (2007)</p> <p>Personal communications with Dan Comden, the manager of the Access Technology Lab at the University of Washington, regarding usage of ATs by students with RDs on campus.</p> <p><i>Findings:</i></p> <ul style="list-style-type: none"> - Near (if not) zero usage of TTS software provided by the university by students with RDs - Students might be using freeware TTS systems on their personal computers
*11	<p>Deibel (2007b, 2008)</p> <p>Study of experiences of four university students with disabilities taking computer science courses and includes one student with an RD taking a computer animation course.</p> <p><i>Findings:</i></p> <ul style="list-style-type: none"> - Experiences with human readers and books-on-tape made the unnatural flow of digital speech distracting and unhelpful
*12	<p>Johnson (2009)</p> <p>Personal communications with Dr. Kurt Johnson, professor of Rehabilitation Medicine at the University of Washington, regarding failed attempts to study AT usage (circa 2001) by students with RDs on campus.</p> <p><i>Findings:</i></p> <ul style="list-style-type: none"> - Abandoned planned studies when research team failed to find any college students with RDs who consistently used ATs
*13	<p>McRitchie (2010)</p> <p>Personal communications with Karen McRitchie, Academic Support Manager at Grinnell College, IA, regarding the recent deployment (2008-9 school year) of Kurzweil 3000[®] at her university.</p> <p><i>Findings:</i></p> <ul style="list-style-type: none"> - Despite informing learning-disabled students of the software, monitoring of the software license usage found that no students ever used it.

The methodologies used by these studies are also quite varied. Despite the different disability concentrations and study designs, however, the findings are generally consistent with each other.

3.1 Overview of Studies

As an overview of that research, Table 4.2 lists ten research studies and three personal communications on AT adoption. The three personal communications (10, 12, 13) focus nearly exclusively on RDs/LDs. Half

of the research studies involve people with learning or reading disabilities, but the collection represents a complex range of disabilities including physical disabilities, sensory disabilities, mild to severe cognitive disabilities, etc. The range of assistive technologies considered in the studies is too vast to list here. Different methodologies and study sizes are also represented.

3.1.1 Personal Communications

Although they lack the rigor of an actual research study, the three personal communications provide some insights that I have not readily found in the research literature because they have not or are unlikely to ever be published. For instance, Johnson (12), an assistive technology researcher, attempted to study technology usage among reading-disabled college students. He had to abandon the study before it even began when he failed to find any participants who used ATs more than rarely. Similarly, both Comden (10) and McRitchie (13) hold positions as technology providers at universities with a focus on ATs and disability support. Their years of work experience is a source of valuable information similar to what motivated King to develop his essential human factors framework (1999). The key difference is that they have not published these findings. Thus, including the personal communications taps into knowledge not readily or currently seen in the published literature.

3.1.2 Survey Studies

Of the entries in Table 4.2, the earliest published study is the seminal (1993) work by Phillips and Zhao (1). This study was one of the first large-scale, quantitative studies of the reasons behind AT abandonment. Its use of a structured survey for administration by mail or telephone served as a model for other studies in the table: (4) Wehmeyer (1995, 1998), (5) Martin and McCormack (1999), and (6) Riemer-Reiss and Wacker (2000). Typically, the participant or a caregiver is asked to list assistive technologies, indicate whether or not the technology is still in use, and then answer a series of questions indicative of factors believed to be relevant to adoption and abandonment (e.g., cost, complexity, involvement of user in selection, etc.). Various statistical methods are then utilized to identify correlations and predictive factors of abandonment.

The studies by Wehmeyer (1995, 1998), however, are an exception. Wehmeyer was interested in exploring the usage of technologies by individuals with moderate to severe mental retardation. Instead of asking if technologies had been abandoned, he asked participants whether or not specific types of AT were being used and if not, would using such a device be potentially beneficial and if so, why is one not being currently used? This shift allowed him to identify barriers to adoption instead of predictors of abandonment after adoption.

3.1.3 Specific AT Studies

While the survey studies typically looked at a wide range of assistive technologies, other studies in Table 4.2 focus more on specific AT and the issues of adoption associated with them: (2) Elkind et al. (1996), (3) Jeanes et al. (1997), and (7) Koester (2003). The typical approach in these studies is to identify a set of users who

benefit from the technology, train the users, configure the device for the user if necessary, and then let the user use the technologies for an extended time. Follow-up observations then determine if the AT is still being used and why the technology was or was not abandoned. The findings are then used to inform and facilitate future deployments of the technology.

Such studies are usually smaller in size than the survey studies; each of the Elkind et al. (1996) and Koester (2003) studies involved only 8 participants. The various studies reported in Jeanes et al. (1997) have *n*'s of 30 or higher, but those studies were not primarily about adoption. Instead, the studies they conducted were aimed at addressing the controversies associated with overlays as discussed in Chapter 3, Section 1.3. The larger study sizes and long-term usage were thus used to improve the statistical power of their studies and control for potential biases such as placebo and novelty effects.

3.1.4 Qualitative Studies

The remainder of the studies reviewed in Table 4.2 are qualitative in nature. These studies typically take the form of case studies: (8) Dawe (2006), (9) Shinohara and Tenenberg (2007), and (10) Deibel (2007b, 2008). In these studies, the goal is to develop a descriptive picture of some aspect of the participants' lives. Shinohara and Tenenberg's technology biography of a single blind individual, Sara, recounts the varied ways that Sara relates to the world through the tasks and tools that she uses. The deep description provides a realistic context for designers of ATs for blind individuals to think about. Dawe (2006) provides a set of rich perspectives and insights about the multiple stakeholders involved in selecting an AT for a person with a cognitive disability. She would later use this knowledge to inform the design of remote communication assistive device as part of her dissertation work (Dawe, 2007b).

3.2 Insights

Of all the studies in Table 4.2, Elkind et al. (1996) is the only formal study that looked primarily at reading disabilities (with the exception of the one person with an acquired RD) and investigated factors surrounding the adoption of an AT. While informative, the experiences of Comden and McRitchie working with students with RDs and Johnson's attempts at conducting RD technology research are anecdotal and need further confirmation. My studies (Deibel, 2007b, 2008) were about the experiences of students with disabilities taking computer science courses, not AT adoption. It just happens that one of my participants had an RD and commented about his dislike of TTS software. Jeanes et al. (1997) did look only at participants with an RD (visual stress) and measured long-term usage of color overlays, but their reasons were not from an adoption research perspective. However, they were able to determine that the magnitude of improvement in reading performance due to using an overlay was positively correlated with long-term usage of an overlay.

A weakness of studies that consider more than one disability type is that the results are often not reported by the different types. Any nuances particular to a disability group are lost. Thus, although studies like

Riemer-Reiss and Wacker (2000) and Koester (2003) included subjects with LDs or RDs, the lack of reporting the effects due to different disability types makes it difficult to determine how applicable the findings really are to that group. In contrast, the study by Elkind et al. (1996) presents separate findings for each participant and clearly identifies which participant had acquired dyslexia instead of a developmental RD. It is thus possible to tease out the nuances due to disability type.

To gain a perspective on what aspects of the AT adoption research space have been covered, consider the two plots shown in Figure 4.4. In both plots, the studies from Table 4.2 are distributed along axes representing the range of AT and disabilities considered. Figure 4.4(a) plots the studies according to the number of disability types versus the number of AT considered. Its companion, Figure 4.4(b), plots the same studies according to how much the study focuses on reading disabilities versus the number of AT considered in the study. Together, these plots show that with the exception of the Riemer-Reiss and Wacker (2000) study (6), research on AT adoption among users with RD have focused narrowly on only a few technologies. Little is known in general about AT adoption for this user population as evidenced by the sparsely vacant upper-right corner of Figure 4.4(b).

Despite all this, the findings from the Elkind et al. (1996) and Jeanes et al. (1997) are fairly consistent with those of the other studies. A significant performance increase noticeable by the user is generally a predictor of continued usage (Phillips & Zhao, 1993; Elkind et al., 1996; Jeanes et al., 1997; Martin & McCormack,

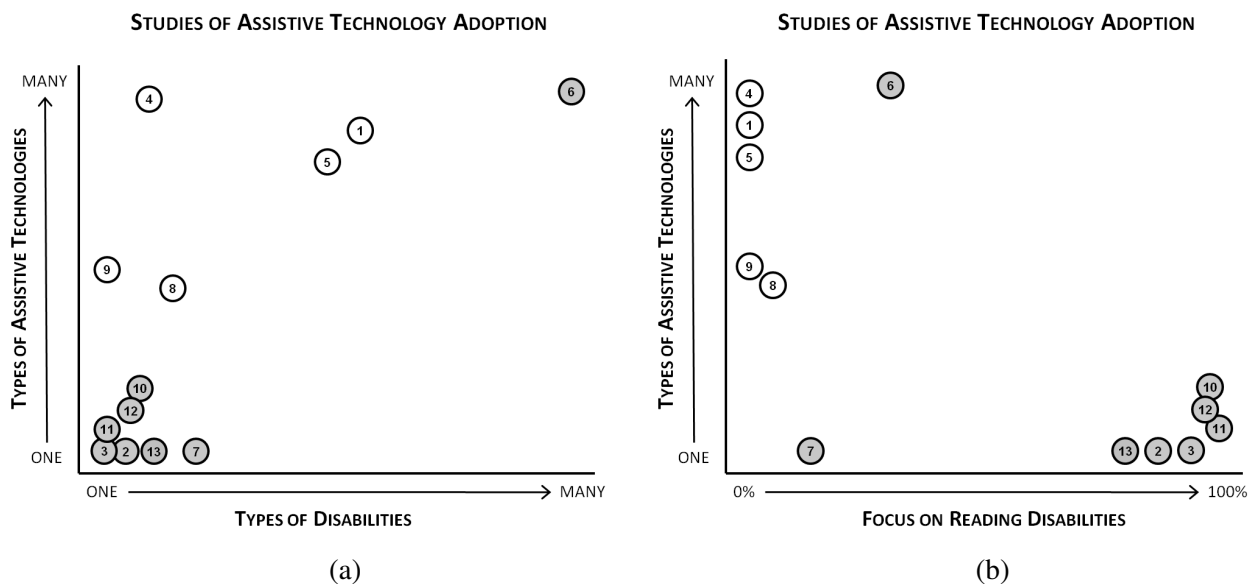


Figure 4.4: Distributions of previous research studies on AT adoption. Numbers correspond to the studies listed in Table 4.2. A greyed circle indicates the study involved participants with LDs or RDs. (a) Plot showing number of disabilities versus number of ATs in the study. (b) Plot showing focus on reading disabilities versus number of ATs in the study.

1999; Riemer-Reiss & Wacker, 2000), and if the AT integrates well with the user's environment and lifestyle, adoption is more likely to occur (Elkind et al., 1996; Martin & McCormack, 1999; Riemer-Reiss & Wacker, 2000). However, other significant factors like the importance of considering the opinion of the user in the selection process (Phillips & Zhao, 1993; Martin & McCormack, 1999; Riemer-Reiss & Wacker, 2000) and the importance of the AT being easy to repair and maintain (Phillips & Zhao, 1993; Martin & McCormack, 1999; Riemer-Reiss & Wacker, 2000; Dawe, 2006; Shinohara & Tenenberg, 2007), have not been explored in these RD studies. Moreover, there is little knowledge on what technologies (both assistive and those repurposed to be assistive) users with RDs actually use to support the reading process, unlike with blind individuals (Shinohara & Tenenberg, 2007) and users with mild to moderate cognitive disabilities (Dawe, 2006). Similarly, unlike the data collected by Wehmeyer (1998) for adults with mental retardation, there is a lack of data on this user group's perceptions of the possible benefits of technology.

One notable aspect of this overview is that only two of the ten AT adoption research studies included any consideration of adoption models. Riemer-Reiss and Wacker (2000) frame their study of AT discontinuance exclusively around Rogers's (2003) concepts of technology diffusion: relative advantage, compatibility, etc. Dawe (2006) references Rogers (2003) and A. Kintsch and DePaula (2002) and uses both to highlight important aspects of the adoption process that her study needed to include.³ Both studies benefited from the insights of the referenced adoption models.

In summary, these thirteen assistive technology adoption studies reveal that the research involving people with reading disabilities has mostly been concerned with the adoption and usage of particular technologies. In these few studies, the researchers were the ones who introduced and provided the technologies to the users. Thus, there have been no "in the wild" studies of assistive technology usage among people with reading disabilities. An "in the wild" study is a study that looks at technologies that a person has adopted on their own volition and not because a researcher introduced the person to the technology. Nor are there studies about the repurposing of "regular" technologies for this user group. While other AT adoption studies have identified factors that influence the AT adoption process, the lack of knowledge about what technologies are currently used by individuals with RDs makes applying such findings a questionable academic exercise.

4 The PATTC Framework

Finally, in the process of reviewing the literature cited in this chapter, I developed a framework for understanding the multiple factors that influence the adoption and usage of an assistive technology. Introduced at the beginning of this dissertation in Chapter 1, the *PATTC* framework is shown in Figure 4.5. This framework has two purposes. First, it provides high-level insight into how various factors interact to promote technology usage. Second, it provides a means for understanding and making methodological decisions

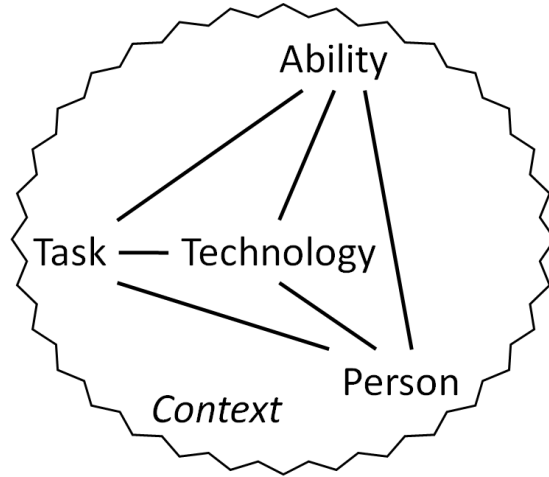


Figure 4.5: The PATTC Framework: The complexity of AT adoption and abandonment can be thought of as overlapping instances of the 5-way interaction between the person/user, task/activity, technology, (dis)ability, and the sociocultural-environmental context.

for research studies. Moreover, although it was first framed for understanding AT usage, the framework generalizes readily to all technology types.

4.1 Description

As shown in Figure 4.5, the PATTC framework consists of a five-way interaction. First and foremost is the *Person*. At the basic level, the inclusion of person reiterates the importance of involving the user as emphasized in user-centered design approaches (Newell & Gregor, 2000; Nettet & Large, 2004). Moreover, person entails the qualities and attributes of the user that impact technology selection. Demographics such as age, location, economic status, and maybe even gender or ethnicity are such factors. This is similar to the Person component in Scherer's MPT model (2005) discussed earlier in this chapter.⁴

Next is *Ability*. This includes disability but is purposefully broader to encourage considering the strengths and weaknesses of the user. The separation of ability from person is perhaps controversial, given that disability is considered by many as a component of one's identity (McDermott, 1993; Edwards, 1994; Cory, 2005; Mooney, 2007). Such separation is also often associated with the medicalization of disability, an act that may ignore the human involved (P. Williams & Shoultz, 1982; Clough & Corbett, 2000; Mooney, 2007). However, from a design standpoint, being able to discuss a disability separate from a person is advantageous. Each and every disability (and all abilities as well) is defined by a collection of symptoms and traits. Although the nature and severity of these will differ from individual to individual, the general symptoms and traits form a foundation for discussion by suggesting what tasks could be affected and what contexts may be troublesome. Moreover, how the disability or ability personally manifests is still captured in the framework through the interaction between person and ability.

The third component of the PATTC framework is *Task*. This encompasses all tasks and activities that any person might engage in. The range of tasks is constrained by the interaction with the person. One person with a reading disability may want to read newspapers while another may desire to earn a PhD—the tasks are thus shaped by the person. Additionally, the three-way interaction of person, ability, and task helps identify how the person's strengths and weaknesses interact with their desires.

Technology's role in the framework is fairly straightforward. Like the technology component in Scherer's framework (2005), this component includes the available technologies and their abilities. Compatibility and relative advantage is noted in the interactions with the other components. Notions of accessibility also occur here. The two-way interaction of ability and technology would highlight general barriers such as a sight impairment and visual-only feedback. Adding in person would further refine the accessibility issue. For example, the person with limited sight may be able to discern visual feedback if presented at a large size.

The final component is the most critical—*Context*. The usage of a technology will take place in different places at different times. The importance of a task will vary by this context. As noted in the discussion of Baker's Basic Ergonomic Equation (Baker, 1986; King, 1999) earlier in the chapter, the motivation to perform a task may vary. Getting help from medical personnel would usually be of higher importance than asking the price of book at a store. Context also shapes how an ability and task interact. Compare hearing in a noisy bar versus a quiet coffee shop. Finally, the interaction of person and context is where personal values and desires come into play. While a technology may be perfectly appropriate for use when alone, concerns about stigma and appearance may discourage its use in view of others. As Scherer (2005) noted, the milieu matters.

4.2 Motivating Example: Eyeglasses

To illustrate the usefulness of the PATTC framework, consider the history of eyeglasses. As noted earlier, eyeglasses are assistive devices. In fact, they are probably the most successful ATs of all time given their ubiquity and generally high rates of adoption and continued usage. Glasses have a long history as well. Although there are records of eyeglasses being used in China as early as the first century, C.E., there is no evidence that these were used for correcting vision. Instead, glass lenses appear to have been worn by scholars for protection when reading texts believed to be dangerous or cursed. The earliest usage of glasses for vision correction dates to the thirteenth century in Italy where they were used for farsightedness (Ilardi, 2007; Fleishman, 2010)

One potentially surprising fact about the development of eyeglasses is that the modern frame with rigid ear pieces were not invented until 1725. However, there was little motivation to make it easier to wear glasses for extended periods of time. Glasses were to be used only when needed (Ilardi, 2007; Fleishman, 2010), and the technology reflected this desire. The monocle, the pince-néz, and the lorgnette were all designed to be pulled out, used, and put away. There were only three exceptions of groups of people who regularly wore their

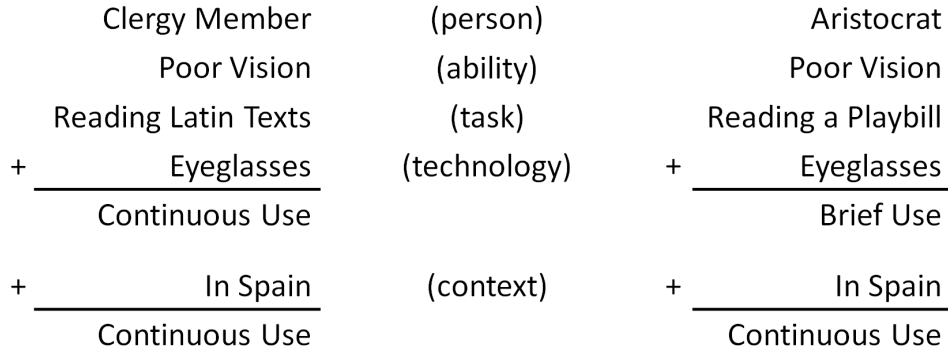


Figure 4.6: Historical usage of eyeglasses and the PATTC framework.

glasses. The first two were the clergy and academics as their careers necessitated long periods of reading.⁵

The third exception were the Spanish. Embracing an attitude radically separate from the rest of Europe, the Spanish viewed the wearing of glasses as a sign of nobility, power, and intelligence (Ilardi, 2007). Larger lenses were associated with higher social ranks and class. To support the wearing of lenses for long periods, they often used ribbons or cloths that either looped behind the ears or the back of the head.

So how does the history of eyeglasses motivate the use of the PATTC framework? As shown in Figure 4.6, the framework captures the various factors that historically influenced how eyeglasses were used. In an unspecified context, an aristocrat would use glasses only fleetingly for quick tasks like reading a playbill. A clergy member, however, would regularly use his glasses. Put both individuals in Spain, though, and both will use their glasses on an ongoing basis.

4.3 Applying the Framework

The example with eyeglasses shows one of the potential uses of the PATCC framework. By listing out the various factors and the usage outcomes, one can determine the relative importance and impact of each factor and their interactions. The PATTC framework is thus a means for analyzing and understanding technology usage that has previously taken place.

Although not instrumented like Scherer's MPT model (2005), the PATTC framework is also useful as a tool for predicting potential technology usage. As previously mentioned, the framework can help identify accessibility barriers. Boundaries of usage can also be explored by adjusting a factor. For example, consider an adult with an RD managing loans at a bank and that the technology is a tool for improving the usability of the spreadsheet used for calculating loan rates. If everything is kept the same except for the task, then the tool will likely support tasks beyond calculating loan rates for most uses of the spreadsheet application. Similarly, if we change the context to other finance-related jobs, the tool will likely still be used. Essentially, one can conceptual multiple instantiations of PATTC of differing distances from each other and potentially

overlapping. Such a distribution can help reveal when and why a technology is used or not used.

Finally, the framework is useful for defining and constraining the problem space. For example, Wehmeyer (1995, 1998) concentrated on adults with multiple forms of mental retardation but kept the tasks, technologies, and contexts unconstrained when he surveyed AT usage in his target population. Wu, Baecker, and Richards (2005) only considered adults with anterograde amnesia and specifically focused on a PDA-based orientation technology to support memory rehabilitation at a medical clinic. Wehmeyer thus explored a wide problem space while Wu et al. focused on a specific problem. By specifying, constraining, or keeping open each PATTC component, one shapes the direction research will take.

5 Chapter Summary

This chapter discussed theories, models, and studies of general and assistive technology adoption. Although the models and studies suggest general factors about what supports an AT being adopted, studies specifically about AT adoption among people with reading disabilities are essentially nonexistent. Additionally, existing models such as Rogers's diffusion of innovations suggest several challenges for the diffusion of ATs regarding reading disabilities.

NOTES TO CHAPTER 4

- 1 Of course, eyeglasses are assistive devices—the most successful ATs of all time. Poor vision to any degree is a disability and can greatly impede many life activities. The appropriate solutions, eyeglasses or contact lenses, have become so universal that we just no longer equate them with wheelchairs, white canes, and other typical tools for disabled individuals. Glasses are not fully accepted by everyone, though. Insults such as “four-eyes” and the association with glasses and nerdiness are still prevalent. Many people will remove their glasses for photos, despite wearing them the rest of their waking hours.
- 2 What actually distinguishes cognitive and linguistic effort is not made clear by King (1999). Interpreting the messages and symbols offered by a device does involve cognition. However, his choice to separate the two does highlight the importance of considering both the procedures and the messages of the system. This insight is similar to and in line with the principles of semiotic engineering (Souza, 2005).
- 3 Despite my earlier criticism of A. Kintsch and DePaula’s framework, Dawe’s use of that framework was both justified and appropriate given her focus on moderate to severe cognitive disabilities. Her disabled participants were for the most part incapable of procuring assistive devices on their own. Most with their parents or in assisted-living facilities. Compares to individuals with reading disabilities, the expected level of independence of Dawe’s participants was far lower. It was also expected that either a family member or teacher would be heavily involved in the usage and maintenance of any assistive device.
- 4 The PATTC framework is admittedly similar to Scherer’s MPT model (2005), with the exceptions of separating out Task and Ability as well as the emphasis on the interactions. Despite the similarities, I began formulating PATTC before I had read much of Scherer’s work. Although I was aware of her work and had her book on my shelf, it was a happy coincidence when I first thoroughly studied her framework. It is not surprising that the similarities exist as we are working in the same problem space. The differences I include are likely due to my perspective as a designer of technologies. When designing a technology, specific awareness of the targetted task is always necessary. Moreover, technologies are rarely designed for a single individual, so the generalities provided by Ability are helpful for understanding the user population.
- 5 The association of glasses with the clergy and scholars likely influenced the common association of glasses with being smart or well-learned as well as the similar association with nerdiness, though less directly. Engaging in scholarly activities have been viewed by some as a trait of those physically unable to perform real labor. The wearing of glasses for reading would also signify physical weakness. Glasses thus could be seen as a marker of being weak and better suited for non-physical tasks.

CHAPTER 5

METHODOLOGY DECISIONS

It's not high tech. It's not low tech. It's the right tech.

— Dr. Dudley S. Childress on designing prosthetic technologies (Stadtmitter, 2005, p. 8)

The previous chapters have provided background on the nature of reading disabilities, assistive technologies for reading disabilities, and the process of assistive technology adoption. This chapter synthesizes the insights from those literature reviews and establishes a direction for research. The first section details the multiple challenges inherent in this research topic. The following section discusses the limitations of several research approaches. Value Sensitive Design is then presented, and arguments are presented for its applicability. The research agenda for the remainder of the dissertation is then described.

1 Research Challenges

The previous chapters focused primarily on presenting background knowledge necessary for understanding the factors that influence the adoption and usage of ATs by people with RDs. At times, issues and topics that posed challenges for research were mentioned. Here, these issues are reiterated and expanded upon.

1.1 Reading Disability Diversity

A clear message of Chapter 2 is the complexity and diversity inherent to reading disabilities. An RD can affect multiple levels of the reading process. An RD may also affect other cognitive tasks, and there are implications socially and psychologically for persons with RDs as well. Moreover, the severity of each RD trait may differ greatly across individuals. While one reading-disabled person may have significant memory and attentional issues but little difficulty with phonetics, another individual's experience may primarily consist of a severe phonological processing deficit.

The research implication is quite simply that a one-solution-fixes-all approach is unlikely to be successful. Different interventions will be needed for different individuals, meaning more technologies must be available. Diversity of ability and large numbers of available ATs mean that the selection and personalization processes

involved in AT adoption must be conducted with great care. The chances of selecting a tool with poor relative advantage will be high, further increasing the chances of rejection or eventual abandonment.

Diffusion will also be affected by this diversity. Assuming that technologies are actually used in public view (discussed below), the diversity of tools may make it more difficult for awareness to diffuse among the potential user population. It all depends on how the technology is understood or presented. If the tool is framed as phonological processing support, then it will likely only catch the interest of those with a phonological processing deficit. If the tool is instead presented as a reading disability support device, then it may garner the interest of a wider range of potential users.

1.2 Limitations of Current Assistive Technology Options

As already noted, though, the current AT options available are quite limited. Not only do said technologies only address a narrow range of RD-related difficulties, the few tools targetted towards reading tend to focus only on early reading skills and acquisition. This lack of tool diversity has likely fostered a poor environment for AT adoption among adults with RDs. The small number of reading support technologies means that many consumers are unlikely to find a device that offers enough relative advantage or a good measure of compatibility to merit adoption into regular usage. Consumer demand as well may be stunted due to the homogeneity in the options. The available ATs are overwhelming TTS-based, and a reading-disabled consumer may become quickly disillusioned with the possibility of other types of tools being available. Further shopping efforts are then abandoned. Another possibility, though, is that the consumer may seek out and repurpose other technologies as a means of receiving assistance with the reading process. Regardless of the consumer's actions, the implication of this lack of AT diversity is that participant pools will be small. Furthermore, extreme care needs to be taken when deciding what technologies to study.

1.3 Invisibility and Diffusion

A final challenge to conducting research on AT adoption among adults with RDs is the invisible nature of this disability type. As noted in Chapter 2, Section 4.2.7, the social implications of having an RD leads many individuals to conceal their disability from others. As RDs really only become noticeable during reading-related tasks, a sensible hiding strategy is the avoidance of reading in situations around others. The degree to which this hiding may take varies, and some individuals will choose careers involving minimal to no reading whatsoever. Such individuals are unlikely to have any interest in ATs for reading and would probably be poor study participants.

However, some people with RDs will engage in reading activities for purposes such as school, work, civic engagement or pleasure. If these individuals use ATs to support their reading, where and when they do so will influence diffusion of those technologies. If the usage is hidden, such as in an isolated room or office, then observability will be diminished. Because of such actions, talking about the technology will also be avoided.

Public awareness of the technologies will be extremely limited, thus hindering the communication channels that drive the diffusion. Research efforts should address either the hidden nature of RDs or these barriers to innovation diffusion.

2 Potential Approaches

With these research challenges in mind, a methodological direction can be selected. The challenges need to be satisfactorily addressed while also answering two key questions of this dissertation: (1) what factors influence AT adoption among adults with RDs and (2) how can one best utilize these factors to support the adoption and ongoing usage of these technologies? This section turns to previous AT studies for suggestions of methodological approaches.

2.1 New Technology Development

One obvious direction would be to attend to the dearth of available ATs. The reviews of the literature in earlier chapters suggest several new directions. A new tool could be devised to address an RD trait not currently supported. The SeeWord project (Dickinson et al., 2002; Gregor et al., 2003) did exactly this. Through their own review of RD traits, they identified visual factors of typography as a direction to explore.

Unfortunately, the development and evaluation of a new reading technology would not address the broader questions asked in this dissertation. Although developing more assistive tools for reading is important and likely critical for supporting adoption and usage, there is no guarantee that the technology would be used outside of the research study. Even if a commercial version became available, it is still not known if the factors that prevent adoption and usage are solely issues of the technology. If social and environmental factors are involved, a development and evaluation study would not identify them.

2.2 Participatory Design

Incorporating users into the technology design process may be a means to learn of such social and environmental factors. In recent years, several other assistive technology research efforts have engaged in understanding the interactions between users with disabilities and assistive technologies through the use of participatory design (McGrenere et al., 2003; Moffatt, McGrenere, Purves, & Klawe, 2004; Wu et al., 2005; Massimi, Baecker, & Wu, 2007). Participatory design (PD) is a form of user-centered design that emphasizes involving the users throughout the design process (Floyd, Mehl, Reisin, Schmidt, & Wolf, 1989; Schuler & Namioka, 1993). Working together, technologists and users develop technology decisions through an iterative process of exploration and knowledge sharing. These decisions can take many forms, both intangible and tangible: brainstorming new technologies, formulating plans to address current difficulties, improving existing technologies, and completing the development and implementation of a technology. As PD advocates respect

and mutual understanding for all parties involved, it is particularly appropriate for working with marginalized or disadvantaged groups like people with disabilities (Wu et al., 2005).

Unfortunately, this research approach is perhaps a poor choice for AT development for reading disabilities at this time. One weakness of PD is the difficulty in addressing diversity among the users. Any subset of users with reading disabilities is likely to display a wide and potentially conflicting range of difficulties and needs. Identifying priorities and forming compromises is likely to be difficult and/or lead to ineffective designs (Newell & Gregor, 2000). Previous participatory design efforts for AT development have been stymied in this way (Moffatt et al., 2004; Massimi et al., 2007).

Another challenge is that the type of technology to develop is unclear. In Wu et al.'s work (2005) with amnesia patients, the PDA-based orientation technology they developed was informed by previous effective accommodation approaches. Having a specific task to design a technology towards helps focus the participatory design process. For reading disabilities, however, the existing assistive devices are exceedingly limited. Users in a PD effort may have little to any concept of what an assistive reading tool may be like. Without this foundation, suggesting improvements or new tools is likely to be difficult. To address this, one could engage in a brainstorming-focused participatory design practice like futures workshops (Kensing & Madsen, 1991) to help identify a particular tool to design. However, the diversity of the population again hinders the PD design process.

2.3 Survey of Assistive Technology Usage

At the heart of the difficulties with a participatory design approach is the lack of knowledge about what the technology needs of adults with RDs actually are. What reading tasks do they engage in? What areas of reading are most affected? Have they used any assistive technologies? Why or why not? Are they still using them? What other technologies have they maybe repurposed for supporting their reading efforts?

A large-scale survey would be one means of answering these questions. A survey would provide a perspective on technology usage potentially across a range of demographics, occupations, and RD diversity. Moreover, AT usage surveys do have a rich history in AT adoption research. While surveys by Phillips and Zhao (1993) and others covered a wide range of disabilities types, Wehmeyer (1995, 1998) is one of the few to have focused on a single disability—mental retardation.

Given the prevalence of RDs, conducting such a survey of adults with RDs would appear to be straightforward. However, recruiting survey participants is a key issue. In other surveys, the researchers recruited respondents through disability organizations. For example, Phillips and Zhao contacted disability interest groups and distributed surveys at regional and national conferences. Wehmeyer worked primarily through a large organization concerned with mental retardation to recruit individuals who had a family member with the condition. Similar organizations exist for RDs, such as the British Dyslexia Association and the

International Dyslexia Association. However, these organizations cater mostly to teachers and parents of children with RDs. The actual proportion of reading-disabled adults in these groups is unclear. Moreover, consider again the known tendency for adults with RDs to attempt to leave their condition behind as they move into adulthood. Membership in an RD organization is in tension with this trend. Finding participants may thus be difficult, similar to the difficulties experienced by Johnson as mentioned in Chapter 4, Section 3 (see Table 4.2).

Furthermore, consider what the survey data would provide. Essentially, a survey only provides information asked by its questions. A survey would definitely reveal what ATs are and are not used. However, this binary view of technologies being used or not used neglects the complex process that underlies adoption and could perhaps overlook technologies that have been re-invented as assistive devices (Dawe, 2006). Additional questions would be needed to discover repurposed technologies, such as with the survey by Riemer-Reiss and Wacker (2000). Moreover, a survey may find it difficult to capture the myriad influences that context and task have on technology usage unless it asks questions covering the various possibilities. Such a survey would likely be lengthy and unwieldy. Moreover, asking open-ended or exploratory questions would require the respondents to write out their responses, a potentially difficult task for people with RDs.

2.4 Technology Biography

While surveys offer a broad, generalizable perspective, they lack finer details. A smaller qualitative study can better explore the nuances of AT usage across different tasks, contexts, and devices. For example, a study by Shinohara and Tenenberg (2007) provides a vivid picture of a young blind woman's technology choices and usages. To gain such insight, they use the technology biography approach in which the user presents and talks about the technologies in his or her life and answers additional questions posed by the interviewer (Blythe, Monk, & Park, 2002). One of the key aspects of the technology biography approach is that the interviewee determines the topics and technologies to discuss, thus highlighting their importance to the user.

For studying technology usage by reading-disabled adults, the technology biography seems advantageous. The approach would not only reveal what technologies are important to the user but also what reading tasks the user regularly engages in. However, such insights are not readily generalizable. A more critical concern is that a technology biography would require a participant with RD who uses at least some ATs. As mentioned earlier, K. Johnson experienced great difficulty in attempting to find just such a participant for a pilot study on AT usage among college students with RDs (personal communication, October 2009; see Table 4.2).

3 A Different Approach: Value Sensitive Design

Of course, any research approach has its limitations. The criticism of potential approaches presented above highlights the complexity and difficulty of exploring this dissertation topic. The research questions are not

simply about what features should a reading-support device have but push deeper and explore the very nature of technology usage among adults with RDs. This suggests a need to go deeper and explore fundamental aspects of technology and culture. At the same time, any research approach should utilize, when possible, the methodologies used in other AT research. Such a framework needs to permit the synthesis of multiple approaches from different disciplines. One such research framework is Value Sensitive Design.

Value Sensitive Design (VSD) (Friedman, Kahn, & Borning, 2006) is an established design methodology crafted to explicitly include and account for human values throughout the technology design process. To accomplish this, VSD views people and technology as mutually influential. Social systems shape the development and usage of technology, and technology influences the lives and decisions of people. The VSD framework also brings in concepts, knowledge, and methodologies from multiple disciplines such as philosophy, law, social sciences, and engineering.

3.1 Values

A key component of VSD is the concept of values. Throughout history, *value* has been defined in many ways (Friedman, Kahn, & Borning, 2006). For the purposes of VSD, a useful definition is what a person or group of people judge to be important in life. In this sense, a value is not the economic worth or monetary equivalent of an item. Instead, values capture the various standards, philosophies, and principles viewed as key to living life beyond mere subsistence.

Values include both the tangible and the intangible. Easily measured notions such as freedom from physical harm and the right to own property are examples of values. Abstract and moral concepts such as trust, privacy, autonomy, and identity are also considered as values. Differentiating between what is and is not a value is not necessarily straightforward, but one rule of thumb is that a value contains elements of moral or ethical import.

3.2 Stakeholders

Another key component of VSD is its attention to *stakeholders*. The term ‘stakeholder’ was deliberately chosen instead of the more common term ‘user.’ First, stakeholder may apply to either a single person or a group or organization. Additionally, VSD takes an interactional viewpoint that argues that society and technology influence each other. Therefore, designers should be concerned with more types of people than just the intended user population. VSD thus specifically distinguishes itself from other user-centered design methodologies (Nesset & Large, 2004; Friedman, Kahn, & Borning, 2006).

In practice, VSD recognizes two types of stakeholders. The first, *direct stakeholders*, are the target users of the technology being designed. The second type of stakeholder are *indirect stakeholders*. These are individuals who are affected by the technology despite never directly interacting with the technology. To understand the difference between the two, consider the patient database software at a hospital. The direct stakeholders are the doctors, nurses, and staff who enter and retrieve information from the database. Patients are indirect

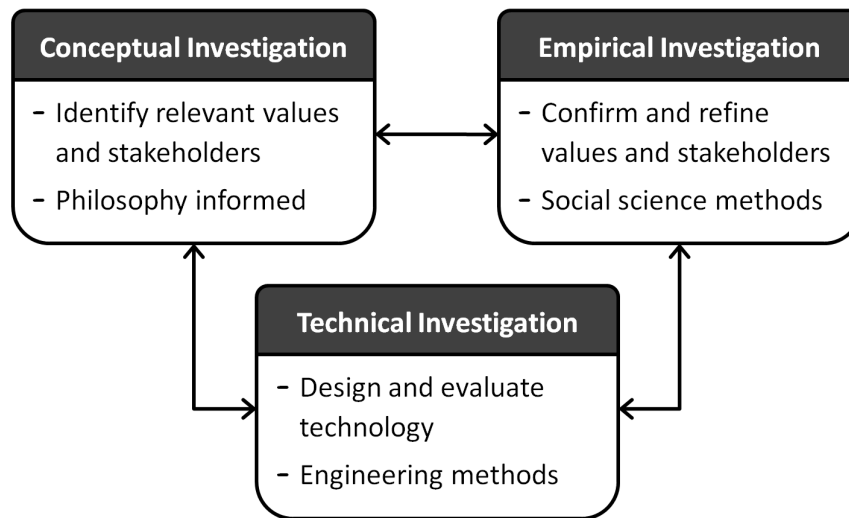


Figure 5.1: Value Sensitive Design's tripartite methodology.

stakeholders in that their care is influenced by the performance of the database.

3.3 Tripartite Methodology

An implementation of VSD is thus about identifying the relevant values and stakeholders and understanding how the technology of interest both influences and is influenced by them. This is scaffolded through a tripartite methodology (see Figure 5.1) consisting of three investigations: conceptual, empirical, and technical. Conceptual investigations involve discovering and understanding the values relevant to the matter under study and are informed through studies of ethics, law, and philosophy. Empirical investigations refine the understanding of values and stakeholders through both quantitative and qualitative studies of the surrounding social context and the users' interactions with the technology. Technical investigations concern the design, performance, and properties of the technology under study and can range from evaluations of preexisting technologies to the development of a new technology.

Although the above description of the three investigations may suggest a linear progression from conceptual to empirical to technical, VSD does not mandate any specified order for the investigations. VSD is an iterative and integrative process. The different investigations may be repeated as is necessary and may occur in any order. Investigations may also overlap in time. For example, an "in the wild" technology deployment may include both an evaluation of the product performance (technical) while also observing the effects it has on the various stakeholders (empirical).

During investigations, techniques specific to VSD may be applied. One common technique is to identify *value tensions* (Friedman, Kahn, & Borning, 2006). A tension occurs when supporting one value impinges and hinders supporting another and may involve different stakeholder groups. Another VSD technique is to recognize *explicitly supported values* which are values important to the goals of the designer but may not be

as critical to the stakeholders (Borning et al., 2005). *Value dams and flows* are another technique that aims to identify values that can either greatly promote or hinder the usage of a technology (Miller et al., 2007). A flow is a value that if handled properly will significantly improve the chances of adoption and usage, while a dam is a value that if handled poorly will greatly impede adoption and usage. Together, these VSD methods (and other methods) refine understanding of the dynamics between technology, society, values and stakeholders.

4 Applicability of Value Sensitive Design

As a research framework, Value Sensitive Design has been previously applied to a wide range of technologies and topics: browser security and privacy (Millett et al., 2001); urban planning and simulation (Borning et al., 2005), and groupware in the software industry (Miller et al., 2007). To the best of my knowledge, Value Sensitive Design has yet to be applied to either assistive technologies or AT adoption. However, multiple reasons motivate its use in this dissertation.

4.1 Interdisciplinarity

One of the clear strengths of VSD relative to this dissertation is that VSD intrinsically embraces working from multiple disciplinary perspectives. Knowledge from any one field is not privileged over another. The tripartite approach integrates multiple research techniques from different fields in a principled manner. Moreover, the focus on values and stakeholders forms an infrastructure to connect and manage the multiple knowledge bases, insights, and methodologies.

The benefit of such an interdisciplinary approach has already been demonstrated in this dissertation. The three preceding chapters showed that a broad array of disciplines were necessary for understanding AT adoption issues surrounding RDs. Education, the science of reading, and disability studies shape the understanding of the disability. Discussions of assistive technologies tapped into these fields and argued as well that there are rich problems for computer science, engineering, and usability studies to tackle. Understanding technology adoption tapped into communication studies and the social sciences. This dissertation has thus already had to integrate background knowledge across multiple disciplines. The usage of VSD techniques will thus further help scaffold such efforts.

4.2 Interactional Viewpoint

Another important strength of VSD is its interactional viewpoint regarding humans and technology. As noted by Friedman and Kahn (2003), different opinions have been expressed as to how humanity and technology influence each other (Latour, 1992; Orlikowski, 2000). The *embodied position* argues that designers imbue technologies with specific intents and that human behavior is then directly determined by the technologies' designs. The opposing view, the *exogenous position*, is that society shapes and forces how a technology will

be used. The *interactional position*, the one taken by VSD, is that while the design of a technology directs and refines how it should be used, the goals and motives of a user can and may transcend the designer's intended usage scope. Integrating the insights from both the embodied and exogenous positions, the interactional approach emphasizes understanding the intents and goals of designers as well as the sociocultural and political contexts where the technology is used.

This interactional viewpoint has been embraced already in this dissertation. My PATTC framework looks at the many interactions between technology, people, and contexts. No direction of influence is privileged in this framework. Put simply, social context's influence on technology usage is just as important as the opposite.

4.3 Technology Diffusion

Similarly, Rogers's diffusion of innovations (Rogers, 2003) is itself an interactional approach. The relative advantage and compatibility features put into a technology by its designers are critical influences in the adoption process. At the same time, communication and social networks drive diffusion. Technology diffusion is both about what technology can do and the sociocultural factors that shape if and when technology is used. The VSD interactional perspective is well-suited to understanding and supporting the adoption of a technology.

Moreover, some precedent has been set for using VSD to study why technology is used. Miller et al. (2007) used VSD to design and deploy a groupware system for knowledge sharing at a software company. Their intent was to identify the factors that would support or hinder adoption of the system among the company's organizational levels and groups. Value and stakeholder analyses were used to identify key features needed in the groupware software, and analyses additionally identified how company policies influenced usage decisions. Although their study concerned a single technology in a very specific context, Miller et al. demonstrated VSD's ability to explore technology diffusion.

4.4 Integration with Disability Models

The interactional approach of VSD is also well-suited to working within disability theory. Two of the dominant models of disability are the medical and social models (Lane, 1997; Clough & Corbett, 2000; N. Matthews, 2009). The medical model frames disability as an aspect of a person—a flaw, imperfection, or problem that requires fixing. On the other hand, the social model posits that disability is just an aspect of human diversity and that most problems experienced by a person with a disability are due to lack of accessibility in the environment or society. Extreme stances have been made by scholars. Some advocate that disability is only a social construction (McDermott, 1993; McDermott & Varenne, 1995; Lane, 1997), while others focus only on the medical aspects of disability (Mobahi & Karahalios, 2005).

It is my experience and philosophy that both viewpoints offer useful insights into disability, an opinion echoed by N. Matthews (2009). In the PATTC framework, knowing about the conditions typical to a disability is useful to a designer, yet a person's own experience and the context help shape how the disability impacts

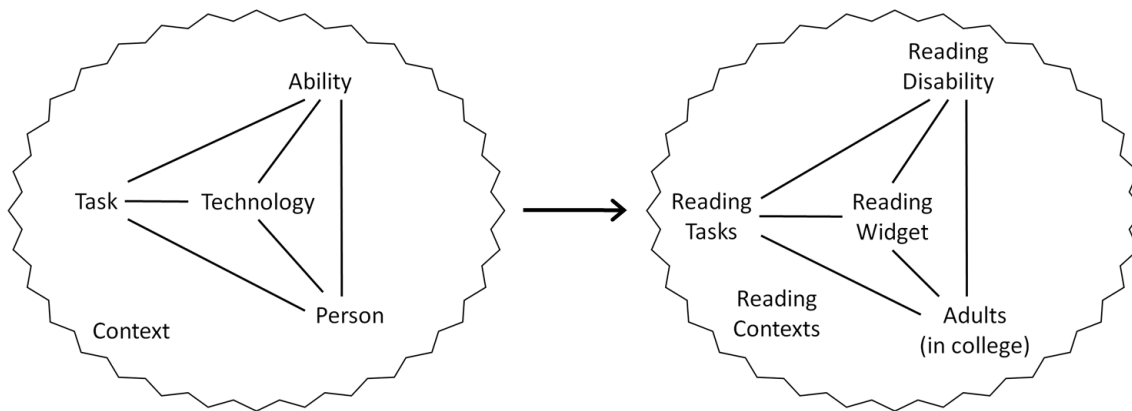


Figure 5.2: Instantiation of PATTC used in this dissertation.

a person's life. Working in disability then is about recognizing both the medical (embodied) and the social (exogenous) aspects. Thus, VSD's interactional approach towards technology transfers to disability as well.

5 Research Agenda

Given the aforementioned applicability, Value Sensitive Design is the primary research methodology for this dissertation. Specific research approaches and decisions can be made towards answering the two key research questions. What factors influence the adoption of assistive technologies by adults with reading disabilities? Additionally, how can one support and promote the adoption and usage of said technologies?

5.1 Frameworks

By choosing Value Sensitive Design as the overarching research framework, the nature of the research is focused on human values and how they influence and are influenced by technology. A wide view of stakeholders is also taken, thereby considering effects beyond those experienced by just end users. Specific studies and inquiries are framed in relation to the tripartite methodology. The research agenda is further refined through the use of two other frameworks: PATTC and Rogers's diffusion of innovations.

5.1.1 PATTC

The PATTC framework provides further support and insight due to its origins in studies of AT adoption—an aspect not shared by VSD. PATTC is primarily used to constrain the scope of the research by specifying some of the components while keeping others open. This instantiation is shown in Figure 5.2.

Given the focus on ATs for people with RDs, Person and Ability are obviously constrained to people with reading disabilities. However, Person is further refined to focus on adults with RDs, with a particular emphasis on people enrolled in higher education. The focus on adults is in response to the previously noted lack of ATs for that age group. The additional emphasis on postsecondary education is motivated by several reasons. First, students with RDs are estimated to comprise nearly 50% of university students with disabilities (L. Lewis et

al., 1999), indicating a large population of potential AT users. Being enrolled in educational programs also helps ensure that these individuals frequently engage in reading. This is a concern given that research suggests people who struggle with reading when young tend to read less as adults (Cunningham & Stanovich, 1997; Edwards, 1994). Additionally, the age of this population tends towards being young. These individuals will have more experience with using digital technologies. Moreover, many of these university students are at a transitional stage of maturity—becoming more and more responsible for personal decisions. For students in K-12 in the United States, the Individuals with Disabilities Education Act (IDEA) (1997) holds schools responsible for providing disability services to students with disabilities. Upon graduation, the student falls under the auspices of the Americans with Disabilities Act (1990; 2008) and is now personally responsible for requesting accommodations. Thus, this age group is at a critical time of development during which AT benefits and hindrances are likely to be evident (Scott, McGuire, & Shaw, 2003; Cory, 2005; Burgstahler & Cory, 2008).

Further constraint is found with the Task concept of the PATTC framework. Only tasks involving reading are considered, but this is still a broad category. What reading activities are engaged in by adults with RDs is open for exploration. For this reason, both informal (e.g., reading the newspaper, surfing the web, enjoying a novel) and formal (e.g., class assignments, work, legal) are of research interest. Coupled to this are the constraints placed on Context. Only contexts in which reading may occur are considered. What these contexts are, however, is uncertain and thereby also open for study.

Finally, the Technology concept is kept open and is abstracted to the notion of a *reading widget*: a digital device designed to support the process of reading. The only assumption is that a user with an RD chooses to use the device. The widget's actual features, function, and form factor are intentionally ignored. Abstracting away the details of the device avoids getting bogged down in the specific features of a device, thereby emphasizing the relationships between the device, the user, and the relevant social contexts. This abstraction also readily allows for the consideration of both existing and future ATs.

5.1.2 Diffusion of Innovations

Rogers's diffusion of innovations is another important component of this research. Particular interest will be placed on known influences on adoption. One of these is the notion of compatibility. Understanding the tasks and goals of the user are key for designing reading widgets that mesh well with the users' lives. However, VSD's emphasis on indirect stakeholders suggests other aspects of compatibility to explore. For example, depending on the usage context, the reading widget may need to meet the values and practices of others in that context. This could include policies at school or a place of work.

Observability and communication channels are two other important aspects from Rogers's model of concern in this research. Understanding the values that influence public usage of reading widgets is necessary

for understanding diffusion. The nuances of when, where, and why adults with RDs choose to disclose or hide their RDs must also be investigated. The communities that reading-disabled adults participate in are also important. Not only are these communities important for facilitating diffusion, they also contain the various stakeholders and value systems that shape and are shaped by technology usage.

5.2 Studies and Analyses

With the frameworks settled upon, the remainder of this dissertation discusses various studies and analyses I performed. In line with the VSD approach, the methodologies are presented in terms of the tripartite methodology. Although the following descriptions are presented in a linear fashion, considerable overlap existed among the investigations.

5.2.1 Conceptual Investigations

VSD studies begin with the initial identification of relevant values and stakeholders. Previous studies have typically begun this identification with a conceptual investigation, although nothing would preclude using an alternative investigation. This effort follows previous practice, though, and engages in such a practice in the next chapter. Stakeholders and values are identified using a thematic literature analysis. Value tensions, dams and flows, and explicitly supported values are also initially explored.

5.2.2 Empirical Investigations

Two empirical investigations are then presented that support and refine the initial value analysis. Online discussions about reading disabilities and technologies gathered from discussion boards and newsgroups are analyzed in Chapter 7. Case studies of adults with reading disabilities and the technologies in their lives are presented in Chapter 8.

5.2.3 Technical Investigations

Three technical investigations follow and conclude the research conducted for this dissertation. The value and stakeholder analyses are used to evaluate existing ATs in Chapter 9. General design guidelines are imparted in Chapter 10. Chapter 11 then provides a detailed blueprint for a reading widget that I hypothesize would help address the various value concerns and design guidelines from the previous investigations/chapters.

6 Chapter Summary

Research methodologies for the remainder of the dissertation were discussed in this chapter. After specific research challenges were elucidated, previous methodologies in AT research were found to be not sufficient. Value Sensitive Design was introduced and established as a strong approach for studying AT adoption among adults with RDs. A specific research agenda was then established using VSD, PATTC, and diffusion of innovations as frameworks.

CHAPTER 6

CONCEPTUAL INVESTIGATION: IDENTIFYING VALUES AND STAKEHOLDERS

I know better than to say that out loud. Everything in my life that I value has been gained at the cost of not saying what I really think and saying what they want me to say.

— Lou Arrendale, a high-functioning autistic, *Speed of Dark*, (Moon, 2003, p. 1)

VSD studies typically begin with the identification of relevant stakeholders and values. This chapter presents a conceptual and empirical investigation that does just that. Different stakeholder types are enumerated. A thematic literature approach is then described and used for value identification. Specific values are discussed in detail. Value and stakeholder dynamics are then discussed in further detail.

1 Stakeholders

As discussed in the previous chapter, VSD's notion of a stakeholder is inherently broader than just the user of a technology (Friedman, Kahn, & Borning, 2006). The term reflects the role that a person plays in the interaction between the usage of technology and the surrounding social context. Thus, two types of stakeholders are considered in VSD: the people who interact with the technology (direct) and those whose lives are affected by the technology (indirect). Moreover, an individual may belong to multiple stakeholder groups.

1.1 Identification Process

To develop an initial set of stakeholders, I conducted an active, free-form brainstorm to list any and all persons involved in the lives of adults with RDs or related assistive technologies. I then further extended this list by reviewing research articles and books that I had previously read. Paying particular attention to texts containing any personal accounts of people with RDs or policies about disability accommodations, I scoured these texts for additional stakeholder types. For example, Cory's dissertation (2005) lists numerous stakeholder types including disability services personnel, faculty, friends, roommates, and family members. Multiple passes further refined and collapsed the list, as did discussions with colleagues.¹ Table 6.1 contains the resulting list

of direct and indirect stakeholders for this study.

An unusual feature of Table 6.1 is that the indirect stakeholders have been separated into three groups: Affected, Affecter, and Both. During the process of identifying indirect stakeholders, I found the traditional VSD approach of considering only those indirectly *affected* by the technology to be insufficient. Consider again the social and psychological aspects of reading disabilities discussed in Chapter 2, Section 4.2.7. Stigmas associated with reading disabilities as well as ridicule from others are likely to shape the public usage of any reading widget, particularly if the widget makes others aware of the user as being reading-disabled. The people behind this stigmatization are not obviously affected by the use of the reading widget, yet their actions affect the user's decision about when, where, and if the AT is used. More generally, many technology use situations are shaped by the actions and decisions of others. The computers and softwares available at a school are decided upon by the school board. Both Orlikowski (2000) and Miller et al. (2007) showed the role of management in the encouragement and discouragement of using new software in a company.

Based on these observations, I decided to encompass this important group of people by expanding the VSD notion of indirect stakeholders. I expanded the category to include both those *affected* by a technology (traditional VSD indirect stakeholders) and the *affecters* who influence technology usage.² Furthermore, since VSD acknowledges that a person or organization may belong to multiple stakeholder groups (both direct and indirect), a third category is also added to describe indirect stakeholders who both affect and are affected by the technology. And as is true with indirect stakeholders, none of the three groups actually use the technology; they just experience or influence the effects of its usage.

1.2 Direct Stakeholders

The primary group of direct stakeholders, those using a reading widget, were defined previously in Chapter 5, Section 5.1.1: adults with reading disabilities with a particular focus on those enrolled in higher education. These individuals use AT to support the reading process for multiple types of tasks for the purpose of education, employment, or pleasure. This usage can also occur in a variety of contexts such as in a classroom, at a worksite, while alone, and with others present, perhaps in a collaborative activity.

Depending on the context and policies surrounding the use of the widget additional direct stakeholders may also be considered (see Table 6.1). In universities, disability services personnel or AT specialists can be involved in the ongoing support of assistive technologies. This can include training the user about the technology, configuring the software to meet the user's needs, and performing maintenance or repairs. Providing digital versions of text for the student is another common duty. The student's instructors may also have to interact with the widget in some way, such as providing assignments and texts in compatible formats for the widget. Such involvement would likely only occur, however, if the student registers with disability services.³ Thus, disability service personnel, AT specialists, and instructors are only provisionally a direct

Table 6.1: Direct and indirect stakeholders. Gray text indicates membership in the stakeholder group is conditional based on external factors.

STAKEHOLDERS			
Direct	Indirect (Affected)	Indirect (Affecter)	Indirect (Both)
Adults with RDs	Classmates	Disability advocates	Instructors
Disability services	Coworkers	Aware allies	Disability services
AT specialists	Study partners	Unaware allies	AT disabilities
Human resources	Activity partners	Stigmatizers	Human resources
Instructors			AT developers
Coworkers			RD/LD community
Study partners			
Activity partners			

stakeholder group. Similarly, an employee only receives accommodations at work if he requests them. Offices of human resources are also provisionally direct stakeholders in this regard.

Another provisional direct stakeholder group are people who collaborate with a user with RD as a coworker or as part of a study group, for example. When working together, group members without RD might access relevant documents using the reading widget. While the provided reading assistance might be unnecessary for such a user, this direct interaction is worth considering. The reading widget should be usable by even those without RDs in order to not stymie any collaboration. Moreover, such a person might not be aware of the widget owner's disability. Care should thus be taken to not accidentally violate the widget owner's privacy.

1.3 Indirect Stakeholders (Affected)

The first group of indirect stakeholders are those affected by the technology despite not using the technology directly. Several stakeholder types were identified as belonging to this *affected* group. The first are students in the same class as the user with RD. Usage of the reading widget is meant to support the reading process, meaning that it should positively impact the user's scholastic performance. While this can include engagement with and contributions to the class, there is also the possibility of the widget providing an unfair advantage. W. M. Williams and Ceci (1999) and Zirkel (2000) are instructors who have raised such concerns.

A similar concern could be made regarding coworkers. Using the widget may lead to better work output and recognition for the reading-disabled user, but perhaps it is the widget itself producing that effect. Other workers may also perform better with the widget regardless of disability status.

The other affected groups were mentioned earlier with direct stakeholders—people who collaborate with the person with an RD. Their collaboration may be affected by usage of the widget in several ways. A possible

benefit would be that the widget user can now perform reading tasks as smoothly and as efficiently as the other group members. However, the group may also experience slowdowns due to having to meet the needs of the widget, such as providing text in the proper input format.

1.4 Indirect Stakeholders (Affecters)

The *affecter* group are those who influence how and if a technology is used despite not directly using the technology. The general disability community is one such source of influence. Their advocacy efforts over the years have influenced accommodation policies and laws as well as public awareness of the issues facing people with disabilities (P. Williams & Shoultz, 1982; Charlton, 1998).

Other influencers can be thought of more generally. Aware allies and unaware allies are people within the user's support network who offer encouragement, comfort, and advice. The terms "aware" and "unaware" reflect whether the ally knows about the user's disability. Studies of patterns of success for students and adults with RDs/LDs have highlighted the importance of mentors, friends, family, and other support networks (Adelman & Vogel, 1990; Gerber et al., 1992; Spekman et al., 1992; Cory, 2005; Kaehne & Beyer, 2009). In many cases, these supporters know of the person's disability, but this is not necessarily the case. Allies and their support can come through people being nice and supportive of each other or through universal design approaches that proactively address disability concerns (Mooney & Cole, 2000; Strange, 2000; Scott et al., 2003; Burgstahler & Cory, 2008; N. Matthews, 2009).

However, interactions are not always positive. Stigmatizers are those that make the user feel negatively about having an RD through direct or subtle comments and actions (Goffman, 1962). The impact of ridicule or poor expectations may be felt regardless of the intention of the source (McDermott, 1993). Just as with the allies, stigmatizers can include anyone in the user's life: family, friends, instructors, fellow students, or even complete strangers encountered in public (McDermott, 1993; Edwards, 1994; Tanner, 2009).

1.5 Indirect Stakeholders (Both Affected and Affecters)

The final group of indirect stakeholders are people who both affect technology usage and are affected by that usage. Instructors can object to or openly support technology usage in their courses and may have to take on extra work to provide those accommodations (W. M. Williams & Ceci, 1999; Zirkel, 2000). A company's human resources department can influence what constitutes a reasonable accommodation. AT developers shape the types of interactions and benefits associated with a technology, and user feedback then shapes future design efforts (A. Kintsch & DePaula, 2002). Disability service personnel, AT specialists, and the RD/LD community help recommend technologies to users and provide ongoing support and advice on its usage.

However, the user's level of disclosure directly shapes his or her interaction with these stakeholder groups. If a reading widget supports hiding and invisibility, this community interaction is stymied. Public usage and discussion of the technology will be unlikely, thereby hindering diffusion. Instructors and human resources

departments may become even less aware of reading-disabled people in their classes or companies. Disability services may also not know of the student's reading disability if the widget removes the need to register for accommodations. In all cases, widgets that promote invisibility can prevent these indirect stakeholder groups from knowing about the people they want to help.

2 Values

Although brainstorming proved to be successful for generating an initial set of stakeholders, identifying a set of values relevant to AT adoption and adults with RDs was more challenging. Friedman, Kahn, and Borning (2006) suggest that a starting point for identifying values is to look at potential harms and benefits that a technology may have for each stakeholder group and then map these harms and benefits to values. Unfortunately, this approach proved difficult even when considering a single stakeholder group such as the main focus on adult students with RDs. Do we consider the harms and benefits regarding the social and psychological aspects of having an RD in today's society? What about the laws and policies that shape how accommodations are provided for education or employment? Furthermore, what problems and challenges arise related to the process of technology diffusion and adoption? The breadth from just one of the stakeholder groups was overwhelming.

2.1 Theme-Value Literature Analysis

The challenge inherent here is due to the wide scope of inquiry. Multiple aspects of technology usage and disability are being explored across multiple contexts. Although previous VSD applications have looked at broad topics such as public deliberation (Borning et al., 2005), the questions studied in this dissertation are less constrained and more general. No specific technology was chosen for study, and even the activities associated with the reading widget are relatively unconstrained. The consequence of such choices requires a different angle of attack for identifying values. Such an approach needs to bring in insights from multiple topics as mentioned while providing proper scaffolding and manageability.

To address these concerns and to capture the various values inherent to the multiple topics from the literature, I shifted the focus from the stakeholders to the complexity itself—the breadth of the literature. Relevant values would be found by reviewing the background literature I had previously surveyed and identifying instances in which human values were ascribed to some aspect under discussion. While this would provide a list of relevant values, it would not address the complexity of managing the broadness inherent in the literature under review. To provide further scaffolding, common themes would also be identified among the papers. Each time a value instance was found in a paper, both a value and a theme would be assigned to that instance. The end result would be a collection of theme-value code labels providing a manageable, concise picture of the literature.

2.1.1 Paper Selection

For this literature review, 57 papers were ultimately chosen and are listed in the annotated bibliography in Appendix D. The literature chosen came from a broad range of fields and topics, including but not limited to assistive technologies, technology adoption, HCI, education, reading science, and disability studies. Although the overwhelming majority of papers are research articles or texts, some popular press publications (e.g., newspaper articles) were also included. In both cases, publications chosen included or addressed social aspects. Those containing words or thoughts from various stakeholder groups were especially targeted. These choices helped ensure that instances of human values could be found in the readings. Reviewed papers found not to include or address human values were omitted from the review.

Because these papers were chosen from the bibliography I assembled in my studies, the selection does not by any means provide a statistically valid representative of all of the publications potentially available. Representativeness was not the goal, however. The purpose of this review was to provide an initial overview of the human values involved in understanding AT adoption among adults with reading disabilities. Findings from this analysis are meant to suggest directions for further inquiry and exploration. The Value Sensitive Design process begins, not ends, with this thematic literature review.

2.1.2 Coding Process

For both the theme and value codings, an open coding approach was used (Taylor & Bogdan, 1998). Instead of starting with a predefined set of themes or values, the theme and value categorization systems were developed during the review process. To help support identification, starting sets for both codes were used, however. The initial set of themes were based on the broad disciplines and types of papers represented in the literature, and included topics such as Assistive Technology Adoption, Disability Issues, and Personal Experiences. Values addressed in previous VSD studies formed a similar list to work from (Borning et al., 2005; J. L. N. Davis, 2006; Friedman, Kahn, & Borning, 2006).

The coding process was conducted in multiple phases. A selection of papers were coded and sometimes suggested additional papers to consider in the review. With each phase, more papers were added to the review and coded. Throughout this effort, previously coded papers were referred to and their codings re-evaluated. During these multiple passes through the set of papers, the value and theme categories were expanded, split, merged, or abandoned as appropriate, although an attempt was made to limit the total number of themes and values to maintain manageability.

2.1.3 Individual Coding Results

The coding process identified 21 themes among the 57 texts as shown in Table 6.2. Despite the breadth in themes, several common emphases were found among the papers, and this relationship is suggested by the ordering of the themes in the table. Several of the papers looked at issues of assistive technologies and

Table 6.2: Descriptions of themes found in the literature review. The number of papers per theme (out of 57) is also shown.

THEME	DESCRIPTION	#
Assistive Technologies	Discusses the functionality, benefits, and/or design of ATs.	25
AT Adoption/Usage	Discusses the adoption of ATs or how people use ATs.	12
Diffusion/Adoption	Discusses technology adoption/innovation diffusion in general (no specific mention of assistive technologies).	7
Human Factors	Discusses supportive features, affordances, and other HCI concepts in relation to assistive technologies.	5
Defining Disability	Discusses how disability can be defined and may includes personal, legal, or social definitions of disability.	15
Medical Model	Discusses and/or uses the medical model of disability (emphasis on bodily difference and correction thereof).	10
Social Model	Discusses and/or uses the social model of disability (emphasis on society's role in disability and accessibility issues)	18
Diagnosis	Discusses diagnosis of a disability and the reactions people may have to being diagnosed.	9
Quality of Life	Concerns the quality of life of people with disabilities, including access to education, employment, healthcare, and relationships with others.	38
Education	Discusses access to education, educational policies, and/or concerns people involved in education (e.g., students and instructors).	31
Laws	Discusses legal aspects of disability: legislation, policies, and advocacy work.	16
Accommodations/ Treatments	Discusses providing accommodations or treatments to people with disabilities and may include issues in accessing treatment, emphasizes on fixes or cures, and the disabled person's desires for accommodations.	25
Pride/Acceptance	Concerns people acknowledging and/or celebrating having a disability.	24
Self-Advocacy	Concerns disabled people taking responsibility for their care, treatment, and livelihoods.	19
Embarrassment/ Self-Loathing	Provides examples of teasing and negative statements from others regarding reading and other types of disabilities. Includes negative opinions expressed by disabled persons as well.	29
Invisibility/Disclosure	Discusses the act of choosing to hide or tell others about having a disability.	17
Stigma	Describes negative emotions and poor social opinions regarding disabilities.	22
General Support Networks	Describes how friends, family, colleagues, etc. who (usually) provide positive support in the lives of a person with a disability.	25
Faculty Support	Mentions specific teachers and instructors as part of a support network. May also discuss lack of support from faculty.	15
Family Support	Describes the role of family members in a support network. May also discuss lack of support from family members.	13
Support Failure	Includes instances of when a support system fails or discusses the implications of such a failure.	19

Table 6.3: Definitions of values found in the literature review. The number of papers per value (out of 57) is also shown.

VALUE	DEFINITION	#
Access	The ability of a person to use a system or service without experiencing barriers or difficulties.	40
Accountability	The state of being responsible for performing certain actions. The ensurance that actions taken can be traced uniquely back to the orginator.	22
Choice	The freedom and opportunity for a person to select among several options, including the option to choose none of them.	34
Community	The sense of belonging to a group of people due to sharing a set of attributes (e.g., locality, ethnicity, ability). The ability of a group to act as a single entity for its own betterment.	36
Empowerment	A person's ability to freely plan, decide, and act as she deems best.	31
Fairness	All individuals should be treated favorably and without bias, dishonesty, or injustice. The belief that reasonable steps should be made to ensure that everyone has an opportunity to succeed in life.	20
Human Welfare	A person's physical, material, and psychological well-being.	22
Identity	A person's understanding of who he is and how he has changed and will change over time. The sense of worth or pride a person has in being who she is.	31
Literacy	The ability to consume and produce information in a prescribed way (reading and writing). The expectation that a member of society has received an education and can read and write.	22
Normalcy	The degree to which a person conforms to the ideals of a society and the accompanying acceptance, rejection, and psychological impact received due to the degree of conformity. An individual's conception of what the qualities and abilities (physical, mental, emotional, etc.) of other members of society are and how it compares to the individual's own qualities and abilities.	31
Privacy	The rights to be left alone and to control how information about oneself is disseminated.	12
Respect	The treating of people with politeness, courtesy, dignity, and consideration.	31
Trust	An individual's expectations or feelings of vulnerability regarding whether people will extend goodwill or betrayal.	23

technology adoption (*Assistive Technologies* through *Human Factors*). General disability issues ranging from scholarly definitions to practical issues of addressing disability in daily life were also prevalent (*Defining Disability* through *Accommodations/Treatments*). Some papers addressed the personal aspects of living with a disability (*Pride/Acceptance* through *Stigma*), while others emphasized the importance of the people who support those with disabilities (*General Support Networks* through *Support Failure*).

Similarly, a diverse range of human values arose in relation to these themes. The 13 values shown in Table 6.3 address many aspects of life and society. Many of these values, such as *Trust*, *Privacy*, and *Human Welfare*, have been previously recognized as commonly implicated in the design of technologies (Friedman, Kahn, & Borning, 2006). *Literacy* and *Normalcy*, though, are to the best of my knowledge, new to VSD.

Table 6.4: Frequencies of the mapping between the themes and values from the literature review. Each table cell represents how many papers were labelled with the (Theme, Value) code-pair.

VALUES THEMES	Access	Accountability	Choice	Community	Empowerment	Fairness	Human Welfare	Identity	Literacy	Normalcy	Privacy	Respect	Trust
Assistive Technologies	17	4	8	3	10	8	2	3	7	1	1	4	4
AT Adoption/Usage	3	2	10	2	4	0	5	1	1	2	1	2	1
Diffusion/Adoption	1	0	4	4	0	0	0	1	2	1	1	1	0
Human Factors	4	0	4	0	0	0	0	0	0	1	0	1	1
Defining Disability	1	0	3	8	4	3	2	7	0	8	0	1	0
Medical Model	3	1	2	1	0	1	1	2	0	1	0	3	0
Social Model	3	3	1	5	1	0	2	3	1	3	0	4	0
Diagnosis	3	3	0	2	0	4	0	6	1	2	2	2	2
Quality of Life	16	3	5	12	7	2	12	9	5	3	1	3	0
Education	20	9	1	10	6	9	5	6	9	5	2	4	2
Laws	11	9	1	3	0	6	0	0	0	0	1	3	2
Accommodations/Treatments	12	8	7	5	4	9	3	3	1	5	4	4	3
Pride/Acceptance	2	2	5	4	4	0	4	12	1	6	1	4	0
Self-Advocacy	2	7	8	1	12	0	4	6	0	4	3	2	3
Embarrassment/Self-Loathing	0	0	3	5	0	0	5	10	13	19	2	9	1
Invisibility/Disclosure	0	3	9	5	3	1	0	10	2	10	7	4	4
Stigma	1	0	1	5	1	0	2	13	5	16	2	7	1
General Support Networks	7	8	3	10	6	0	2	4	2	1	2	6	9
Faculty Support	3	2	2	5	0	3	2	3	2	1	3	8	4
Family Support	0	1	0	5	1	0	2	5	2	2	1	2	3
Support Failure	6	6	0	4	3	1	3	1	6	2	1	3	5

2.2 Mapping Between Themes and Values

The real insights from the literature review and coding come not from looking at the individual coding results, however. Table 6.4 shows the paper counts for the 273 individual (Theme, Value) code-pairs. Certain pairs were particularly prevalent among the texts. For example, (Assistive Technology, Access) occurred in 17 of the 57 papers reviewed, although this is not surprising as the fundamental nature of ATs is about overcoming

difficulties and providing access.

To better facilitate interpretation and analysis of the raw numbers in Table 6.4, the density mapping shown in Figure 6.1 was generated. The purpose of the mapping is to show the relative importance of different values

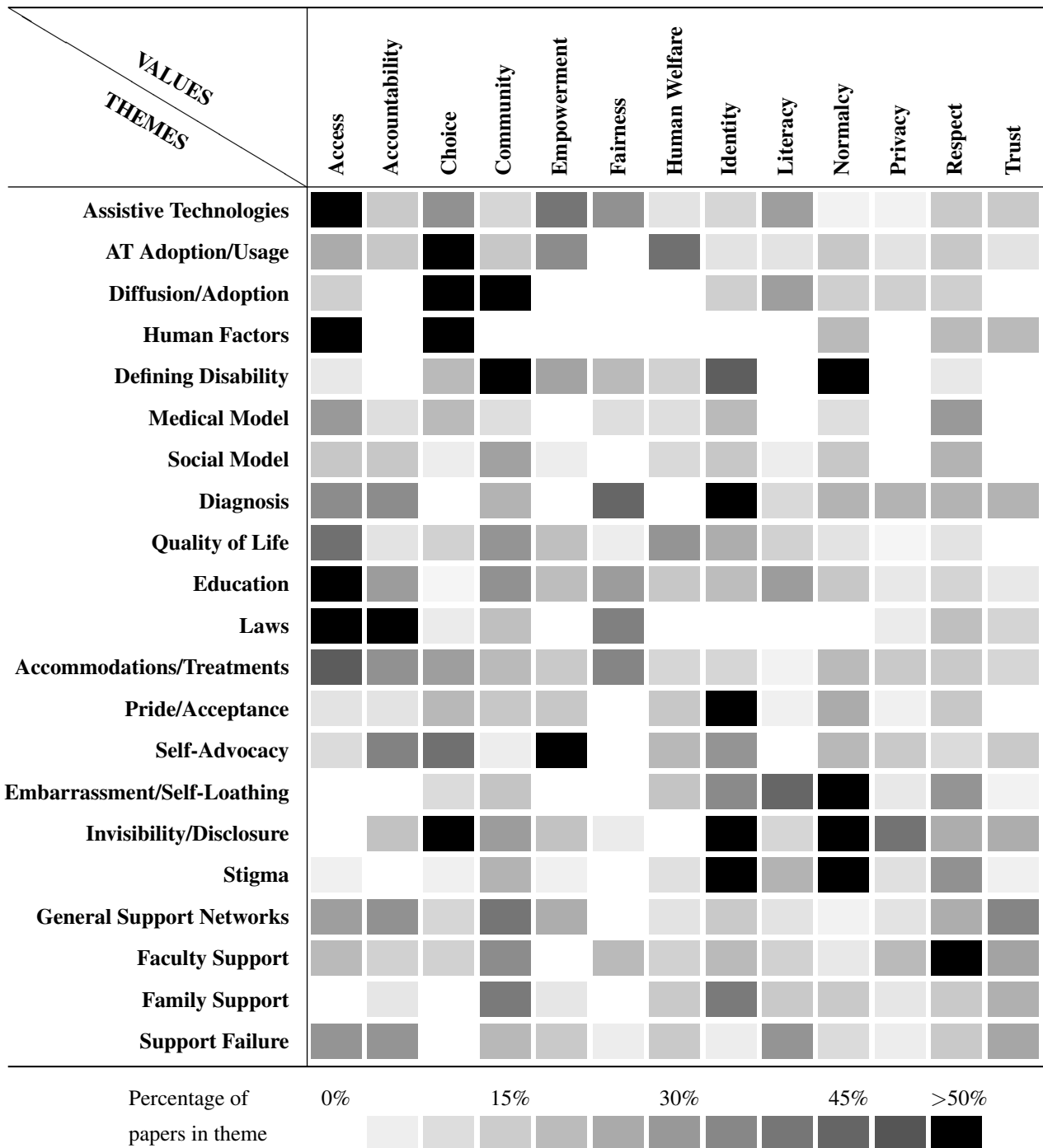


Figure 6.1: Density mapping showing the prevalence of values within each theme. A cell’s darkness reflects the percentage of papers labelled with the theme-value pair (as in Table 6.4) in relation to the the number of papers in the theme (as in Table 6.2).

in each of the themes. Thus, the shading of each cell is determined by the number of papers with that (Theme, Value) label divided by the number of papers overall in the theme. For example, the theme *Pride/Acceptance* occurred in 24 papers overall (see Table 6.2). According to Table 6.4 12 of these 24 papers were labeled with the theme-value pair (Pride/Acceptance, Identity) for a density of 50%. The cell was then shaded accordingly.

Two reasons motivated calculating the densities relative to the number of papers per theme. The first reason is that the themes are not equally represented among the papers. Consider an approach that calculates the densities relative to the number of papers (57). While this would highlight highly-represented theme-value pairs, it would also underemphasize others. Themes with only a few papers, such as *Diffusion/Adoption* with only 7 articles, would automatically show low densities despite their fundamental relevance to this work. Computing relative to the number of papers per theme addresses this issue.

The same argument could be made to motivate calculating the densities relative to the number of papers per value. Calculating relative to the number of papers per value gives a mapping indicating what themes invoked each value the most. However, this runs afoul of the purpose of the theme-value coding. The coding was meant to address the broadness of the research topic and provide value insights into that breadth. Calculating relative to the number of papers per theme does exactly that.

3 Value Highlights

The density mapping (Figure 6.1) them motivates further value investigation. One approach is to look at a single theme and observe the relative emphases on the different values. For example, *Self-Advocacy* primarily involves the value of *Empowerment* but *Accountability*, *Choice*, and *Identity* are also important. Another use of the mapping is look at a value's column and identify what themes for which that value bears any significance. *Respect*, for instance, is involved in every theme but shows particular prominence in regards to *Faculty Support*. Such insights inspire further examinations of the identified values as described in this section. Papers from the review are explored more deeply, and new articles are brought in to further pursue understanding and refinement of the values and themes.⁴ This section discusses some of these insights.

3.1 Access

The ability of a person to use a system or service without experiencing barriers or difficulties

As noted earlier, the value of *Access* appears frequently in the literature review as the concept is the primary motivation for disability rights legislation (*Laws and Accommodations/Treatments* and assistive technology design (*Assistive Technologies and Human Factors*)). In the case of the former, many aspects of daily life have historically been difficult to participate in for people with disabilities. For example, many western societies recognize receiving an education as a fundamental right. Historically, though, individuals with disabilities,

compared to those without disabilities, have faced greater difficulties in accessing learning opportunities at both the K-12 and university levels (Cory, 2005; Ladner, 2008; Lane, 1997; Mooney, 2007; Scott et al., 2003). Importantly, education greatly influences a person's quality of life in terms of finding and performing activities for both leisure and employment (Gerber et al., 1992; Kuusisto, 1998; Scherer, 2005; Vance, 2009). Driven by these concerns, civil rights efforts, policy changes, and disability legislation were made to address disparities in access to education, employment, and life in general.

Providing such access is generally accomplished through accommodations, some of which may involve technologies. The value of access arises in many forms here. Because disability policies require proof of disability, one critical but often important access issue is being able to receive a diagnostic evaluation. In a letter to the editor, Kriscenski-Perry and McColm, notes that teachers are often the first to become aware of a learning-related disability, but overwork, large classrooms, and lack of training may prevent such recognition (Krisenski-Perry & McColm, 2001). Another barrier to diagnosis may be the expense of the diagnosis testing itself (Gross, 2002; Vickers, 2010).

The ability to receive accommodations is another access issue, and as before, expense may be one of the issues. Mooney (2007, p. 53–54) provides an example with the highly respected but expensive and time-consuming Orton Gillingham reading therapy approach. In their software review, Laga et al. (2006) comment on how high cost limits the practicality of the Kurzweil 3000[®] TTS system. Receiving accommodations can be further complicated by what is involved in providing the accommodation. The level of difficulty in digitizing texts was a major factor that influenced long term usage of the software in the study by Elkind et al. (1996). Alan, a reading-disabled college student, chose to switch from his preferred accommodation of books-on-tape to a TTS application because of access issues. The time delays required for a human to produce a books-on-tape led to Alan falling behind in his classes, but because digital text was already available, TTS worked with no delay. Timeliness overrode his preference for the more natural-sounding audiobooks (Deibel, 2008; personal communication with “Alan,” October, 2007).

Perhaps the strongest occurrence of access occurs in the goals and designs of assistive technologies. King (1999), Scherer (2005), and many other discussions of assistive technologies frame ATs as providing opportunities and interactions that did not and could not occur previously. Frequently used metaphors are about conquering or overcoming barriers, chasms, and separations. For example, the digital divide describes the demographic-based disparities regarding who uses computer technologies, and studies have shown that people with disabilities are increasingly less likely to use computers or go on the Internet (Kim, 2005). A screen reader bridges this divide by making it possible for a blind person to use a computer. More generally, an augmented communication device gives a person with cerebral palsy the ability to converse with friends and family, and a wheelchair lets a paralyzed person move about the world.



Figure 6.2: Three images of a wheelchair user provide visual metaphors of disability barriers and access issues: (a) Stairs are an absolute barrier to access. (b) A ramp with an ADA-compliant grade (to scale) provides access. (c) A ramp with a larger grade allows access, but with difficulty.

3.1.1 Rethinking Access

Seeing this viewpoint emphasized in the literature review made me cognizant of an important aspect of reading disabilities in regards to issues of access. This perspective of assistive technologies and access paints disability as an all-or-none issue—without the technology, some activity cannot be done. This is true for some disabilities, but not for all. To convey this distinction, consider the visual metaphors shown in Figure 6.2. A wheelchair user facing a flight of stairs as in Figure 6.2(a) is a common and clear example of a barrier to access. One solution is a ramp as shown in Figures 6.2(b) and 6.2(c). Although both provide a means of overcoming the barrier of the stairs, the two ramps are not equivalent. The steep ramp shown in Figure 6.2(c) may be almost difficult to use as the stairs, while Figure 6.2(b) is both accessible and useable without the need to exert considerable effort on the wheelchair user's part.

As a metaphor for access issues for people with reading disabilities, the steep ramp is more apt. No barrier exists that prevents a person with an RD from accessing a text or book. Such a person is not illiterate and can and does read, albeit with difficulty. A reading widget for RDs is thus not about making access possible but making access easier. The value is still important but manifests differently than with other disabilities.⁵

3.2 Choice

The freedom and opportunity for a person to select among several options, including the option of not selecting any of the options

Another value prevalent in the literature analysis is *Choice*. There are three components to the idea of choice. Choice is first about the freedom to make a selection among several options without undue coercion or force. Secondly, choice is also about having multiple options available to choose among. Finally, choice includes the right to reject all of the available options.

3.2.1 Choosing to Use a Technology

Choice's importance is particularly evident among the themes associated with technology adoption and usage. Diffusion of innovations (Rogers, 2003) describes the process by which adoption decisions are made, and much of King's studies (1999) on AT adoption and human factors has been about understanding this decision

process among people with disabilities. The decision to use a technology is a choice, and the issues of abandonment and rejection directly stem from the freedom of choice.

However, not all adoption decisions are made by the ultimate end user of the technology. Organizations such as businesses or schools make policy decisions about technologies (Orlikowski, 2000; Rogers, 2003). Dawe (2006) identified this as a complicating factor for long-term AT usage among young adults with moderate to severe cognitive disabilities. For reasons of budget, available technologies, and expert opinion, schools would choose one form of a technology (e.g., touchscreen device) to be used at school. The same technology might not be available at home, though, or a different interface might be present (e.g., a trackball). In her interviews, Dawe found that both teachers and parents expressed concerns about this inconsistency.

The question of who makes the choices regarding the treatment of disabled people (including ATs) helped start the disability rights movement. As related by P. Williams and Shoultz (1982) and Charlton (1998), one of the driving concerns that initiated political movements related to disability rights was the exclusion of disabled people's voices in deciding the course of their lives. This movement argued (and still argues) that disabled people need to advocate for themselves and that this self-advocacy needs to be recognized and respected by society. This advocacy extends beyond just care and treatment and includes education, employment, housing, and many other aspects influencing one's quality of life.

3.2.2 Deciding to Disclose or Hide

Choice also becomes particularly relevant in regards to hidden disabilities and the issue of disclosure (*Invisibility/Disclosure*). As mentioned previously, because reading disabilities are not readily apparent to others, individuals with RDs can deliberately control who knows about their reading difficulties. In her study of college students with LDs and other invisible disabilities, Cory (2005) found that many students avoided informing friends and instructors about their disability unless a crisis or incident necessitated disclosure. N. Matthews (2009) additionally explores this issue and highlights how the university environment shapes these students' choices. Choosing not to disclose does have consequences, however, and may lead to poor academic performance and less overall success in life (Gerber et al., 1992; Cory, 2005). Other values are also related to the choice to disclose or hide, such as *Privacy* (March & Fleuriot, 2006) and *Normalcy* (Mooney, 2007). Similarly, the themes of *Stigma* (Kuusisto, 1998; Goffman, 1962) and *Embarrassment/Self-Loathing* (Cory, 2005; Mooney, 2007; Stampoltzis & Polychronopoulou, 2009) also involve the decision to disclose or hide, although these do not necessarily invoke the value of choice but reflect the motivations and repercussions of being able to make such a choice.

3.3 Fairness

All individuals should be treated favorably and without bias, dishonesty, or injustice

The belief that reasonable steps should be made to ensure that everyone has an opportunity to succeed in life

The values found in Table 6.3 are not strictly independent and readily interact with each other. For example, the values of access and choice are deeply intertwined with the value of *Fairness*. Fairness is about having the opportunity to succeed in life, but the individual ultimately decides what to make of those opportunities. But what does it mean to ensure opportunities to succeed in life and not privilege or bias certain groups over others?

This question applies to many elements of life and society, but in the context of disability, fairness has primarily concerned the opportunities to participate in major life activities (ADA, 1990; Sears & Young, 2003). For example, receiving an education, particularly in childhood, has been recognized by our society as crucial to one's future quality of life (Bransford et al., 2000). Legislators passed the IDEA (1997) to mandate providing accommodations for disabled K-12 students. Similarly the ADA/ADAAA (1990; 2008) set access policies so that disabled people can earn a living, use public transit, and engage in commerce and business.

3.3.1 Fairness of Accommodations in General

Ensuring access and providing accommodations raises many issues of fairness, however. One element of concern is the burden placed on those required to provide access and accommodations. Included in the ADA/ADAAA is the concept of *undue hardship* by which an employer or organization may become exempt from providing an accommodation due to reasons of cost, impact, and practicality. For example, small businesses with less than 15 employees are listed as exempt, and the retrofitting of buildings can be delayed if alternative solutions are provided. Several university educators have expressed concern about the burden placed on them when faced with providing accommodations to students with disabilities (Cory, 2005; N. Matthews, 2009). W. M. Williams and Ceci (1999) and Zirkel (2000) expressed concern about the added workload placed upon professors in meeting accommodation needs as well as a lack of training and expertise with respect to disabilities and accommodations.

Another fairness issue with accommodations is whether providing one would give someone an unfair advantage (Edyburn, 2006). This concern can be seen in the limitations insurance policies place on AT purchases. For example, when a woman with ALS (amyotrophic lateral sclerosis) used her insurance to purchase a computer to act as a communication device, her insurers insisted that the machine could only be used for TTS purposes (Vance, 2009). Despite it being a regular Windows machine, features not related to speech such as e-mail, Internet, and productivity tools had to be disabled. Otherwise, insurance would be paying for more than a medical device, which would be unfair to the other policyholders who only receive financial support for their medical needs. Consequently, insurance companies tend to promote the usage of dedicated assistive hardware devices which tend to be more expensive than general-purpose technologies due to the economics of smaller consumer markets (Bigham, Prince, & Ladner, 2008; Vance, 2009).

3.3.2 Fairness of Accommodations Regarding University Students with Reading Disabilities

Debate about the fairness of accommodating university students with RD/LDs is common source of controversy. At the center of the controversy is the suggestion that some students and their parents cheat the accommodation system by purchasing a false RD/LD diagnosis. Receiving such a diagnosis would allow a student to take advantage of common accommodations such as extra time on tests, including major entrance examinations like the SAT and GRE. Two articles in the *Chronicle of Higher Education*, a popular publication for university educators (W. M. Williams & Ceci, 1999; Zirkel, 2000), and a New York Times article (Gross, 2002) raised the spectre of this possibility. However, none of these articles present evidence of a successful attempt. Gross does include comments, though, from psychologists and school officials who have been solicited by parents asking for their children to be screened after a poor SAT performance. Furthermore, disability specialists argue that if diagnosis fraud does occur, the numbers are small and insignificant relative to the scope of other issues involving RDs/LDs and accommodations (Gross, 2002; Vickers, 2010).⁶

Concern about disability fraud does invoke the value of fairness in relation to those without RDs/LDs, but it also leads to unfairness in how some treat those with RDs/LDs. Multiple case studies have recorded instances where a reading-disabled person is accused of being lazy, faking, or being deliberately difficult. Claims of RDs and LDs not really existing are also reported (Edwards, 1994; Cory, 2005; Mooney, 2007; Armstrong & Humphrey, 2009; Tanner, 2009). Such claims become falsely bolstered by the idea of disability fraud. Despite no evidence that such fraud is rampant, the mere possibility suggests one should be concerned about the legitimacy of RDs. This concern then gets coupled with other areas of contention. For example, Zirkel (2000) and Vickers (2010) both note that demographically, a disproportionate number of students diagnosed with dyslexia are white and from economically well-off families. This is presented as support for disability fraud as money is needed to purchase a false diagnosis. The alternative hypothesis that the demographic disparity may reflect access to better funded schools and teachers with the time and training to identify at-risk students (Kriszenski-Perry & McColm, 2001) is not suggested in these papers.⁷ Despite weak or nonexistent evidence, enough concerns and worries are eventually compiled to rationalize and justify expressing severe doubts and distrust about claims involving reading disabilities, such as those made by Zirkel (2000), Leef (2010), and Vickers (2010). Students with RDs are thus unfairly viewed with suspicion, making it less surprising that many choose to not tell others about their disability (Cory, 2005; N. Matthews, 2009).

3.4 Community

The sense of belonging to a group of people due to sharing a set of attributes

The ability of a group to act as a single entity for its own betterment

Of course, the choice to disclose requires other people to be available, which leads to another value seen

throughout the literature review—*Community*. With few exceptions and for better or for worse, humans live and interact with other humans. As a species, we have recognized that mutual effort allows for greater success and ongoing survival and innovation. Hence, many of our decisions are in some way related to defining and building community. Because of this, community came across as a relevant value in nearly every theme as seen in Figure 6.1, but several merit particular discussion.

3.4.1 Technology Adoption

First, community plays a key role in the themes related to the process of technology adoption (*Diffusion of Innovations* and *AT Adoption/Usage*). The important role of communication (Rogers, 2003) and knowledge sharing (A. Kintsch & DePaula, 2002) in the diffusion of a new technology has been previously discussed at length in this dissertation (Chapter 4). What has not been discussed in much detail, however, is the role of shared commonality in promoting adoption and diffusion. Rogers (2003) found that if a potential adopter shared many traits (homophily) with an observed user of a technology, adoption was far more likely to occur. Someone considered as an outsider (heterophily) would be less influential than a solid member of the community. One early adopter in a study of water-boiling adoption in a Peruvian village also demonstrates this effect (Wellin, 1955). Because she had recently moved from a different village and had strong opinions regarding her new neighbors, her usage of boiling water had little and a likely negative influence on the adoption decision by others.

3.4.2 Defining Disability

The defining of community by shared traits has also historically influenced the definition of disability (L. J. Davis, 1995; Lane, 1997; Mooney, 2007). The medical model of disability (Clough & Corbett, 2000) has in general framed disability as an individual being different than what is typically seen among other people in society. However, not all differences may be viewed as a disability. Due to a population bottleneck several generations ago, 10% of the population of the small Pacific atoll of Pingelap now have achromatic vision (complete color blindness). The incidence of achromatopsia is estimated to be only 0.003% elsewhere. Although these individuals are greatly sensitive to sunlight and must avoid day time activities, the achromats on Pingelap are respected and revered as excellent night fishermen due to their greater visual aptitude when performing low-light tasks (Sacks, 1997).

Communities also establish rules and practices regarding disabilities. For example, the ADA (1990) established explicit standards for what constitutes a disability in the United States. Although court cases, lobbying efforts, and new legislation have reshaped these standards from the original (ADAAA, 2008), the original implication is that the community has defined what a disability is and who may be treated as disabled. To receive accommodations, a person must meet the prescribed standards and work within the system built around the notion of disability (Charlton, 1998; Kriscenski-Perry & McColm, 2001; Cory, 2005).

3.4.3 Existence of Disability Communities

So far, this discussion of community has focused primarily on people connected by living close to each other or within a shared political body. Community can also be defined by other traits, such as religion, ethnicity, or field of employment. A natural question to ask is if the nature of having a disability leads to a sense of community among people with disabilities? The success of the disability rights movement in achieving policy changes and legislation like the ADA have occurred in part due to different disability groups uniting for a shared cause (P. Williams & Shoultz, 1982; Charlton, 1998). Thus, a general disability community does exist in the large-scale, but at the individual level this is not necessarily the case. In interview studies with people with disabilities, both Whitney (2006) and myself (Deibel, 2008) found examples of people with recognized disabilities who did not readily consider themselves as disabled or a member of the disability community. For example, Whitney (2006) notes that recognizing oneself as disabled was relatively new to her participants with anxiety and depression (p. 44). Mooney, despite being an avid disability rights advocate, expresses concern about meeting Ashley, an eight year-old deaf-blind girl (Mooney, 2007, ch. 7). As most of his experience and work had involved people with learning disabilities like dyslexia and ADD/HD, Mooney admits that he could not help thinking of Ashley as abnormal and truly hurt by the physical aspects of her disability. Although he eventually found these earlier ideas foolish after meeting her, his experience demonstrates that merely having a disability does not necessarily lead to sense of sharing similar qualities.

On the other hand, a sense of community certainly exists for people with some types of disabilities. Both Lane (1997) and L. J. Davis (1995) have written in detail about the nature and desires of the Deaf community, and the successful development and diffusion of TTY systems to make the phone system accessible occurred in due part to the community advocating for the technology (Lang, 2000). Advocacy and community efforts have developed among other disability types, such as blindness (Kuusisto, 1998) and mobility impairments (Weinberg & Williams, 1978). As for people with reading disabilities, it is less clear if an RD community exists. Some organizations, such as DO-IT (2010) and Project Eye-to-Eye (2010), have formed in recent years to foster connections among people with LDs and RDs. However, there do not appear to be equivalents to advocacy organizations like the World Federation of the Deaf (WFD) (2010) and National Federation of the Blind (NFB) (2010). A key aspect of these organizations is that people with those disabilities are active members. When one looks at RD advocacy organizations such as the International Dyslexia Association and the British Dyslexia Association (discussed earlier in Table 3.1 on page 49 in Chapter 3, Section 2.1), the emphasis is placed primarily on teachers and parents of children with dyslexia. Only a small portion, if any, of the organizations' materials will address issues of being an adult with dyslexia in terms of higher education or employment. The emphasis on parents and teachers does make some sense as RDs have a significant impact on school and one's future, and the ability to advocate for one's self comes with maturity. Unfortunately, this same

emphasis reduces the voices and presence of people with RDs within these organizations and communities. While people with RDs may be involved, their presence is less visible.

Further confounding the existence of an RD community is the hidden nature of the disability. Many people with invisible disabilities choose not to disclose to others (Cory, 2005; N. Matthews, 2009). Because of this, perception and awareness of the disability will not be readily apparent to both those with and without the disability. One participant in a study by Tanner (2009) was amazed when she first entered the room of a continuing education course for adults with dyslexia. She noted that she had “. . . never met another dyslexic person until I walked in the door (p. 795)!” Because interaction with each other is not widespread, the RD community cannot readily achieve cohesion and act en masse.

3.5 Literacy

The ability to consume and produce information in a prescribed manner (reading and writing)

The expectation that a member of society has received an education and can read and write

Another implication of communities is the expectations that the whole places on its members. One such expectation is that of *Literacy*. A consequence of our society moving from an agrarian focus to both an industrial and information society, education has received more and more recognition and importance and influenced the building of schools at both the elementary, secondary, and postsecondary levels (Bransford et al., 2000). In particular, the emphasis on communication skills such as reading and writing has become so ingrained that literacy is arguable an inherent value in our modern culture.

The idea of literacy as a value may be difficult to conceptualize as we typically define literacy as a specific state of being—the ability to read and write. This is a valid definition of literacy, although it is important to understand that as our society changed, what it meant to be able to read and write itself transformed. Prior to World War I, the common expectation of literacy was the ability to “. . . reel off memorized portions of basic American texts such as the opening paragraph of the Declaration of Independence” (Bransford et al., 2000, p. 133). Because of the growing mechanization in warfare, soldiers needed to be able to read and comprehend any written instructions. Literacy thus evolved from being able to read aloud to comprehending the text being read. This definition has been further refined, and many literacy researchers now work with the notion of multiliteracies instead of a single, monolithic notion of literacy. Such a view recognizes that comprehending and conveying information in different genres and different media types all involve different skills and practices (New London Group, 1996; Kist, 2004). Writing analytical essays in history is its own literacy, as is casual chatting online via instant messaging. Any one individual thus holds differing levels of competence in different literacy practices.

Although these various definitions of literacy as a state of being capture what it means to be literate, the

notion of literacy also goes beyond the individual. Literacy has become an integral aspect of today's society as evidenced by the emphasis on schooling and the proliferation of information communication technologies that do not use the human voice. This idea that literacy is essential for society is not new, however. In a brief overview of the history of the teaching of reading, M. J. Adams (1990) demonstrates how ongoing efforts and debates have been waged in making sure that people acquire strong reading skills. One notable example is the classic text *Why Johnny Can't Read* by Flesch (1955). Objecting to the then current usage of the whole word method in reading education, Flesch argued for a more phonics-based approach. Although he referred to scientific studies of that time, he also positioned his arguments as pro-democracy and anti-communism. The whole word method, he argued, limits readers to only the words they have been taught. Phonics, though, give readers the freedom and ability to face and identify new words:

There is a connection between phonics and democracy—a fundamental connection. Equal opportunity for all is one of the inalienable rights, and the word method interferes with that right.

(Flesch, 1955, p. 130)

Flesch's book fomented public response, and the debates about the teaching of reading were no longer just the domain of teachers and cognitive scientists (M. J. Adams, 1990).

Considering literacy as a concern of society results in expectations and judgments being placed on people's reading and writing abilities, particularly for those who continually struggle due to a reading disability. In a study of the instant messaging practices of teenage girls, March and Fleuriot (2006) found that one participant chose not to use instant messaging because of her dyslexia. One participant with an LD in Cory's interview study of college students with invisible disabilities (2005) mentions how she had been teased the night before when a visitor to her house openly mocked and ridiculed a spelling mistake she had made (pp. 58–59). In his memoir, Mooney (2007) recounts multiple instances of embarrassment and dread when faced with reading aloud in front of others. The same experiences of ridicule and shame are repeated in other case studies of the lives of people with RDs (McDermott, 1993; Edwards, 1994; Pollak, 2005; Stampoltzis & Polychronopoulou, 2009; Tanner, 2009). In an example not involving people with RDs/LDs, Gomez, Stone, and Hobbel (2004) studied an 8th grade remedial reading class and found that the students deliberately engaged in tactics to prevent the teacher and the school from labeling them as struggling readers.

3.6 Identity

A person's understanding of who he is and how he has changed and will change over time

The sense of worth or pride a person has in being who she is

Although literacy was inherently involved in their study, Gomez et al. (2004) focused their efforts on another value—*Identity*. One's sense of self and pride in who one is changes with experience and time. Identity is

about recognizing the individuality that each member of society possesses. Elements that help define identity include one's abilities, schooling, jobs, family, and communities to which they belong, and sense of success in life (Cory, 2005; Pollak, 2005; Whitney, 2006).

Within the scope of this research, a key question is how having a disability fits into one's identity. There is a difference between recognizing that one has a disability versus becoming that disability. For example, Mooney (2007) talks about his friend Kevin who has severe ADD/HD (p. 75–77). Kevin is a very dynamic, spontaneous individual who flits between different tasks and interests. In many ways, he is the poster child for hyperactivity, and one may begin to question where Kevin's personality ends and the ADD/HD begins. Moreover, does being labeled as having a disability end up defining how a person acts? McDermott (1993) found that when people around him knew about a boy's LD, the boy tended to live up to their expectations and experienced difficulty.⁸

Dealing with this conflict may lead some individuals with disabilities to try to deliberately separate themselves from their disabilities. Kuusisto (1998), despite being essentially blind from birth, deliberately did not use a white cane or a guide dog until his mid-30s. Despite the risks and difficulties, he did not want people to first see him as blind (*Invisibility/Disclosure*). Another example is provided in Sacks (1985) profile on Wicky-Ticky Ray, a man with Tourette's syndrome. In many ways, he enjoyed how his random tics and spontaneity benefitted him in his social life and his hobby of jazz drumming. However, he also knew that the same attributes hindered his ability to succeed in his business career and role as a father. This motivated him to go on medication. While his life improved significantly in the areas he desired, he missed the spontaneity and fun, especially in his hobbies. He eventually found a compromise. During the work week, Ray takes his medication and is a successful businessman and father. On the weekends, he lets his Tourette's come forth and enjoys the dynamic edge it gives to his social life and drumming. His disability plays both a positive and negative role in his sense of self.

For people with RDs, the role of the disability in defining their identity takes many forms. Having struggled with reading, some report finding some strength and reassurance when they receive from the official diagnosis (Pollak, 2005; Brown, 2009; Stampoltzis & Polychronopoulou, 2009). The problem is no longer due to personal failure and lack of effort. However, *Embarrassment/Self-Loathing* arises from the combination of ongoing difficulties and mockery from others and may then lead to the aforementioned desire to separate the disability from who they are. Taking advantage of RD's invisibility, they carefully decide to whom, if anyone, they disclose to about their disability (Edwards, 1994; Riddick, 2000; Cory, 2005; Pollak, 2005; Stampoltzis & Polychronopoulou, 2009). This comes at a cost, however, as studies of successful adults with RDs/LDs have found that acceptance of one's disability is a significant factor in both academic and career achievements (Adelman & Vogel, 1990; Gerber et al., 1992; Spekman et al., 1992; Alexander-Passe, 2006).

3.7 Privacy

The rights to be left alone and to control how information about oneself is disseminated

This notion of controlling disclosure and hiding one's disability invokes the value of *Privacy*. Although not originally recognized as a fundamental right, the growth of information communication technologies such as photography and telegraphy inspired the need to better protect individuals from the increasing penetration and observational abilities of the media and society (Warren & Brandeis, 1890). Included under the umbrella of privacy is the right to control knowledge about one's health, of which disability is a part (P. Williams & Shultz, 1982; Cory, 2005; N. Matthews, 2009).

In particular, respecting student privacy is a critical aspect of how accommodations are provided at universities (Cory, 2005; N. Matthews, 2009; Vickers, 2010). Disability services offices act as a knowledge mediator. Students must submit documentation demonstrating their disability to the office where it is evaluated. If approved, accommodations are provided by careful communication with instructors. An instructor is presented with specific accommodation instructions. While these might include a general description of the student's disability (e.g., a learning disability), no specific details are given. How the disability manifests in the student, its assessed severity, how it was assessed, etc. are all kept private by the disability services office. Furthermore, policy dictates that the instructor cannot discuss the student's disability and accommodations with anyone other than the student and the disability services office. This last part has been the subject of controversy due to questions about the fairness of accommodations (Gross, 2002; Leong, 2005; Vickers, 2010). For example, scores on aptitude tests like the SAT used to indicate if testing accommodations such as extra time had been provided. This practice was eliminated after a lawsuit successfully argued that it violated students' right to privacy about having a disability. Leong (2005) and Vickers (2010) argue that this hinders test validity and score interpretation as time-based performance is a factor in determining potential aptitude.

Privacy of one's disability also arises in regards to the usage of assistive technologies. When used in public, a technology may convey knowledge about a user's disability or draw undesired attention to the user. Sara, a blind college student, mentions privacy when describing two watches that she possesses (Shinohara & Tenenberg, 2007). One watch speaks the time aloud when a button is pressed, while the other has raised numerals and hands that she can feel. Sara prefers the latter as she can check the time without disrupting those around her. However, Sara's example was the only instance in the literature review of privacy being discussed in regards to the themes of *Assistive Technologies* and *AT Adoption/Usage*. Given the many times that control of disclosure, hiding, and invisible disabilities have been discussed, one would expect that privacy would be a more common concern, especially given that privacy has been a focus in many other technology studies (Millett et al., 2001; Toney, Mulley, Thomas, & Piekarski, 2003; Friedman, Howe, & Felten, 2002; Friedman,

Kahn, Hagman, Severson, & Gill, 2006; Friedman, Smith, Kahn, Consolvo, & Selawski, 2006; Miller et al., 2007).

3.8 Normalcy

The degree to which a person conforms to the ideals of a society and the accompanying acceptance, rejection, and psychological impact received due to the degree of conformity

An individual's conception of what the qualities and abilities (physical, mental, emotional, etc.) of other members of society are and how it compares to the individual's own qualities and abilities

Given the oft repeated mentions and discussions of hiding and controlling disability disclosure, one begins to question what is driving this desire to hide having a reading disability. The previously mentioned values of community, literacy, identity, and privacy have all influenced such actions. At the core of the motivation to hide, however, is the perhaps surprising value of *Normalcy*. I use the term surprising as the idea of normalcy does not readily conform with the idea of a human value. Conjuring notions of conformity, sameness, boredom, and the typical, why would people or society judge normalcy to be important in life?

3.8.1 Defining Normalcy

To understand why normalcy can be considered as a human value, one needs to first understand the history of the word and concept. Etymologically, the usage of the word 'normal' to describe a person or a behavior is fairly recent to the English language. As researched by L. J. Davis (1995), normal was primarily a mathematical term used in discussions of statistics and geometry. When talking about people and behaviors, the word "ideal" was used. The concept of the ideal is based in classical philosophy such as Plato's works, and the idea of the ideal was for people to strive to achieve this perfect state of being. Emphasis on the ideal faded as science and industry provided society with the tools to understand and control the world. Statistics, averages, behavioral assessments, and scientific data collection all provided tools to say what was average, typical, and normal for human beings. One could now put a number on how well a person conformed to identified norms and then use that information to control, shape, and presumably better the human race (L. J. Davis, 1995; Mooney, 2007).

In practice, working definitions of normalcy are a blend of both the notion of the ideal and the scientific average. For example, it is normal/ideal for every person to have two arms, but the average number of arms is actually slightly less than two due to amputations and congenital deformities. A less contrived example is the ideal view of the typical American family: one or more children living with both mom and dad in a house with pets. Divorce, single-parenting, economics, allergies, and many other factors have been reshaping what defines the average family. With these examples in mind, clearly articulating what is normal is difficult. On one level, normal is defined according to ideals created by society that reflect but also push against what

is actually typical. Moreover, this gestalt notion of normalcy gets filtered and interpreted by the individual. Asking and deciding if a person is normal can thus have multiple answers depending on who is asking. Most importantly, the subject of this question may be the asker herself.

3.8.2 Normalcy as a Value

Before discussing normalcy and reading disabilities, however, the issue of normalcy as a human value should be addressed. As stated previously in Chapter 5, Section 3.1, a value is something that a person or culture views as important. Given the connection to notions of conformity and sameness, the reader may object to the idea of normalcy being viewed as important and worthy of protecting. The very idea of promoting normalcy may conjure images of dystopias where individuality and creativity are verboten. One such example is science fiction short story *Harrison Bergeron* by Kurt Vonnegut (1961/1988). Why would a designer using VSD want to promote a concept with such dangerous implications?

There are multiple problems with this argument. First, the potential of a value to have negative implications does not make it ineligible for consideration in Value Sensitive Design. Many of the values suggested as starting points by Friedman, Kahn, and Borning (2006, p. 17–18) have potential bad consequences. Autonomy allows for people to make their own decisions, even bad ones. Privacy protects one's freedom to conduct part of one's life in secret, but it also limits the detection and prosecution of criminals and terrorists. Moreover, privacy works against the values of transparency (openness to review) and accountability (J. L. N. Davis, 2006). Such tensions are recognized and embraced by VSD as important for consideration in the design of technology (Friedman & Kahn, 2003; Friedman, Kahn, & Borning, 2006).

The VSD methodology also does not preclude any value from consideration even if the researchers disagree with it. For example, the UrbanSim system (Borning et al., 2005; J. L. N. Davis, 2006) is a VSD-designed computer-simulation tool for projecting urban development scenarios. Environmental sustainability is often arises as an important issue and value to some stakeholder groups. Personal conversations with with Dr. Alan Borning and Dr. Janet Davis show that they share the same opinion. However, both acknowledge that environmental sustainability cannot be an intrinsic value in UrbanSim as it is meant to facilitate public discussion and deliberation of urban planning decisions. Some of the involved stakeholders may not value sustainability and instead favor other values interests (e.g., economic gain or individual property rights). Despite the difference of opinions, the UrbanSim developers recognize those stakeholder viewpoints as worthy of respect, recognition, and support within the simulation system.

Still, is normalcy a value in the sense that society recognizes it as important? Recognizing the role of normalcy in our lives is particularly difficult as we take much of it for granted. Both medicine and ergonomics engineering are governed by the idea that humans more often than not fit into particular ranges of sizes, chemistries, shapes, and measurements. In western society, we also typically assume that our neighbors and

even complete strangers generally will not attack, rob, or kill us. A sense of normalcy is at the center of what makes life run smoothly. Issues that disrupt this flow, such as crime and sickness, violate normalcy.

3.8.3 Stigma and the Consequences of Normalcy

By far, the greatest motivation for including normalcy as a value is that the literature review found that issues of normalcy were highly important to many people with RDs and other disabilities. Disability clearly conflicts with the notion and value of normalcy. Physically or mentally, a disability distinguishes a person as being different and not normal (Goffman, 1962; L. J. Davis, 1995; Cory, 2005; Scherer, 2005). This distinction has even been enacted into law (ADA, 1990; ADA, 2008). Labeling a person as not normal has wide repercussions as society is constantly on the watch for deviations from the norm. Foucault (1977/1995) likens society to a prison, in that people are constantly on guard and monitoring others for what is considered acceptable behavior. When such differences are identified, they are addressed. L. J. Davis (1995) demonstrates this through an analysis of how people with disabilities have been treated throughout history, including the pro-oralism/anti-sign language movement in education of the deaf and eugenics-based forced sterilization programs of people deemed mentally deficient.

The actions taken by society need not be as deliberate as the examples provided by L. J. Davis. The mere knowledge that society will react to difference is what drives the idea of stigma (Goffman, 1962; Cory, 2005). Stigma is the belief that society will act with disapproval of a deviance from the norm. Like normalcy, stigma is a gestalt phenomenon created from society but instantiated by the individual, meaning that it is up to the individual to conceptualize and define what the stigma is and if it applies. This individual process can be informed from actual experience and evidence of stigmatization, but perceptions without substantiation from others may also influence this process.

The effects of stigmatization are particularly strong for people with RDs/LDs. As already mentioned, society values literacy and difficult with those skills is often viewed negatively. Thus, a reading-disabled person may directly experience internalized embarrassment, ridicule from others, and lowered performance expectations (McDermott, 1993; Edwards, 1994; Cory, 2005; Mooney, 2007; Tanner, 2009). Indirect actions can also contribute to the stigma. For example, making dyslexia the subject of a joke can help promote the conclusion that having an RD is undesirable. Amazingly, such jokes can even be found in research publications on topics unrelated to RDs (Klare, 2000; Swisher, Hyden, Jacobson, & Schruben, 2000).

While the indirect, untargeted acts of stigmatization cannot be avoided, Goffman (1962) does note that direct stigmatization can be avoided by passing as normal. This is clearly only possible when the deviance is not readily apparent. While wheelchair users cannot hide their mobility impairments, people with reading disabilities can and do choose to hide and may even deny their disability. When he was in sixth grade, (Mooney, 2007) decided he would and could only be a great soccer player.⁹ Due to the trials and scars of

growing up with dyslexia, many of the participants in Edwards's interview study (1994) opted for careers where reading expectations would be minimal and nonexistent. Several even refused to pursue higher education despite being qualified and encouraged by teachers and family. Even people with RDs who go to college may engage in hiding, in part due to the desire to avoid the repercussions of bearing the disability label (Cory, 2005). The desire to avoid the embarrassment and shame associated with reading difficulties may even infiltrate into one's personal and social life. In the study by Tanner (2009), a woman described the extreme actions she takes to hide her dyslexia from others (p. 793). She always insists on the same restaurant when going out to eat with others because she knows what she can order there. At any other restaurant, she will struggle with reading the unfamiliar menu.

3.9 Other Values

The eight values discussed above emerged as particularly prominent in understanding the complexity of AT adoption and adults with RDs. This by no means implies that the other five values in Table 6.3 are insignificant. *Accountability* is a key concern built into disability legislation and the policies governing the providing of accommodations (ADA, 1990; W. M. Williams & Ceci, 1999; Zirkel, 2000; ADA, 2008; Kaehne & Beyer, 2009; N. Matthews, 2009). Similarly, *Empowerment* is integral in the motivation for disability rights, access legislation, and self-advocacy (P. Williams & Shoultz, 1982; Charlton, 1998; Ladner, 2008). *Trust* is intricately connected to the value of fairness and was particularly threatened in the discussions about if it is right or fair to provide accommodations to college students with RDs/LDs (W. M. Williams & Ceci, 1999; Zirkel, 2000; Gross, 2002; Leef, 2010; Vickers, 2010).

Some of these values are also perhaps best viewed more as fundamental values in that they appear across nearly all of the themes. In Figure 6.1, the columns for *Human Welfare*, *Respect*, and *Trust* are all nearly uniform shades of gray. Clearly, a person's well-being (human welfare) is important and should be invoked nearly always. The same can be said for respect and trust. It should be noted that respect and trust do show a higher concentration among the themes involving support, but again this makes sense as these values are intrinsic to interaction with others. The high concentration of papers tagged with (Faculty Support, Respect) reflects how issues involving reading disabilities manifest quite frequently in educational settings. Many of the papers in the literature review concerned school experiences, hence the high prevalence of the role of teachers, both positive and negative, in supporting people with RDs.

3.10 Seeing the Connections

Together, these values form a complex web of interactions, but the two sets of connections shown in Figure 6.3 merit additional attention. Figure 6.3(a) concerns the identity politics at play in the lives of adults with RDs. In defining what is normal, the community draws upon literacy skills. Because of this, people with RDs must decide how to externally represent their identities to others, and many choose to keep their disabilities private.

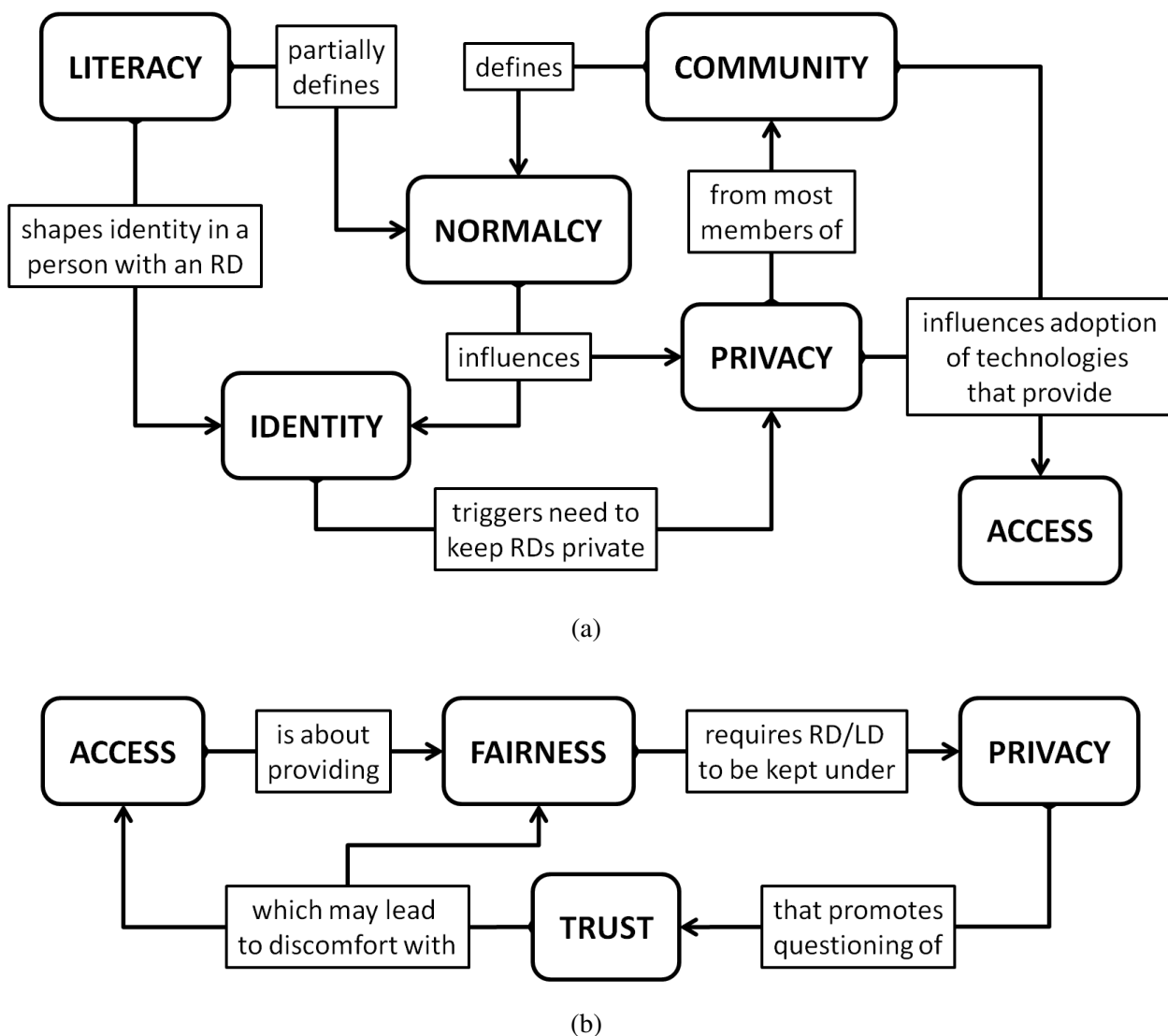


Figure 6.3: Interactions and connections among the identified values. (a) The intertwined roles of Normalcy, Literacy, Identity, and Community. (b) The cyclic interactions of Access, Privacy, and Fairness.

However, this privacy influences how well the subcommunity of people with RDs can promote and diffuse any reading technologies that improve access to the information society.

Some adults with RDs decide not to hide their disability from everyone, such as in the case of university students who request accommodations. As found in the literature review, further value interactions occur as shown in Figure 6.3(b). Accommodations are about promoting and improving access so that students who are intellectually capable can participate in education. However, laws, human rights, and policies also recognize that knowledge of a person’s medical condition is protected under the mantle of privacy. Thus, it is only fair that disabilities also receive the same protection, meaning that those asked to provide accommodations receive only minimal information about the receiver’s disability. For some, such information restrictions

raises suspicions, leading them to question the actual need for accommodations (W. M. Williams & Ceci, 1999; Zirkel, 2000; Leef, 2010; Vickers, 2010). This feeds into a larger debate about whether providing accommodations gives unfair advantages to disabled people over their nondisabled peers.

4 Discussion

Thus far in the chapter, stakeholders and values have been identified and described. Further insights can be gained through the use of the tools and techniques found within the VSD methodology. These include recognizing which values are explicitly supported, identifying tensions that arise due to the interaction of the different values and stakeholders, and identifying central value issues that will either block or promote technology usage. Together, these suggest directions for further investigations (conceptual, empirical, and technical) and highlight limitations in the what has been currently identified.

4.1 Explicitly Supported Values

The notion of *explicitly supported values* was first proposed by Borning et al. (2005). In their work on an urban development simulation system for promoting public engagement and discussion, Borning et al. found it worthwhile to distinguish between values important to some of the stakeholders and values inherently important to the goals of the designer. These latter, explicitly supported values are not simply the wishes of the designers but are supported by findings from the principled value analysis. To varying degrees, several of the identified values are explicitly supported in this work: access, literacy, and particular issues involving respect and choice.

That access is an explicitly supported value is obvious and naturally given: access is inherent in AT design (King, 1999; Newell et al., 2003). The definition of access in Table 6.3 is the ideal of minimizing barriers that hinder a person from using a system or information. For any reading task, be it for education, work, or pleasure, this dissertation's primary aim is to reduce or eliminate any obstacles experienced by adults with RDs in today's information society.

Similarly, literacy is inherent to the goals of this work and is thus explicitly supported. This research is driven by the consistent belief that reading is a critical skill expected to be possessed by all members of society (Kist, 2004; New London Group, 1996). A reading widget is meant to promote and support users' literacy efforts. However, it is ultimately the user's choice to engage in literacy acts. As previously mentioned, Edwards found that a fair portion of the recently graduated high school students with dyslexia that she interviewed chose to not continue their education despite sufficient academic skills and promise (Edwards, 1994). Some participants even chose careers where reading would be minimal or nonexistent. Given the explicit support of literacy, the reading widget is not targeted towards such persons. However, if they change their minds, the widget will still be available to support their endeavors.

Finally, respecting the choices made by people with reading disabilities to disclose or hide must be explicitly supported. To the reader, this may seem like an obvious design criterion as it is not my purview to tell others what to do. By explicitly stating this need, though, I recognize a personal conflict I have in regards to hiding one's disability. I am a disability advocate: I participate in programs like DO-IT (2010) and promote inclusive teaching methods (Deibel, 2008). I am also disabled. In both my personal life and advocacy work, I recognize, embrace, and talk about my disability in much the same way as other advocates such as Mooney and Cole (2000). Developing supportive technologies for adults with RDs may lead to tools that promote hiding and protecting the user's privacy. Although this may go against my preferences as an advocate, I must also respect such choices and desires. This is one of the primary motivations for the explicitly supported values methodology. Although respecting the desire to hide and keep one's disability private goes against my values as a designer, it is important that I do not privilege my values over those of the stakeholders. Thus, I make the critical decision to explicitly support their values over my own.

4.2 Value Tensions

Another common practice in VSD is to identify tensions between different values (Friedman, Kahn, & Borning, 2006). A value tension occurs when supporting one value impinges on and hinders supporting another value. Value tensions help identify aspects of the design that require careful attention and further investigation. Tensions may also occur when different stakeholder groups disagree about the relative importance of various values.

Multiple value tensions have arisen in the discussion of values in this chapter. For example, a tension between access and fairness arises in regards to what assistive technologies insurance companies are willing to finance. In the case of Kara Lynn, her insurance would pay for a laptop computer as a means of speech support only if the computer's functionality was stripped to permit only speech functions (Vance, 2009). Another such tension experienced by people with disabilities is between identity and normalcy. Having a disability is part of one's experience and life but may also place additional burdens and difficulties that are not faced by most other people. This leads to internal conflict between accepting one's disability and the desire to live an easier life. Kuusisto (1998) and Wiccy Tickey Ray (Sacks, 1985) are two examples of how such a struggle can unfold.

Many value tensions center around the value of privacy. For example, one tension already touched upon involves privacy and community. The better the support of the privacy of individuals with RD to control who knows about their disability, the more difficult it becomes for the RD community to identify its members. Even without this tension with privacy, membership identification for the RD community is complicated due to the disability's invisibility. Community also greatly influences technology diffusion and AT adoption (Dawe, 2006; Riemer-Reiss & Wacker, 2000; Rogers, 2003). This tension suggests the need to find ways to support community among people with RD while still respecting their privacy.

Privacy is also in tension with the value of identity. In studies of successful persons with RDs, acceptance of the disability is a crucial element for achieving success in life (Adelman & Vogel, 1990; Gerber et al., 1992). Acceptance should also include a willingness at times to seek help from others. However, in the act of keeping an RD invisible, acceptance and seeking out help can be compromised. Cory and Edwards found some students do not ask for help to avoid treating their disabilities as an excuse. Some of the students even went so far as to deceive themselves and deny having an RD to avoid managing it (Cory, 2005; Edwards, 1994). Such behaviors have the potential of hurting future success. This tension suggests that accepting having a reading disability (identity) needs to be carefully balanced with controlling the level of disclosure to others (privacy).

As shown in Figure 6.3(b), privacy also comes into tension with fairness, access, and trust due to how accommodations are provided. Because disability is covered under privacy rights, knowledge of the use of accommodations in schools and on evaluative entrance exams (e.g., SAT) can only be disclosed if the disabled person chooses to do so (Gross, 2002; Leong, 2005; Vickers, 2010). Privacy policies also restrict the amount of information presented to instructors who are requested to provide accommodations to a student. Depending on the level of disclosure chosen by the student, the instructor may be simply told that the student has requested and met the requirements for receiving accommodation X. Even the student's actual disability may not be identified (Leong, 2005; Vickers, 2010). Although the student's request has been vetted by the disability services office, this black box of information can frustrate some and lead to concerns about the reliability and trustworthiness of the system (W. M. Williams & Ceci, 1999; Zirkel, 2000; Leef, 2010; Vickers, 2010).

4.3 Value Dams and Flows

Value dams and flows are another VSD method for analyzing stakeholders and values. Developed by Miller et al. (2007) during the design of a groupware system for a software company, dams and flows are a means to identify critical design aspects that could make a technology deployment a success or an utter failure. A value dam is a feature that, for value reasons, is strongly opposed by some (possibly only a few) stakeholders. If the opposition is strong enough, implementing the feature could incite this small group to actively undermine usage of the technology—an outcome worth avoiding. Alternatively, a value flow is a feature heavily supported and desired by a significant number of stakeholders for value reasons. Recognizing a value flow is one way to encourage adoption.

The method used by Miller et al. to identify dams and flows were opinion surveys which positively or negatively rated system features and then certain response thresholds were selected as indications of either. Although the method they presented for identifying dams and flows was specific to empirical investigations, I argue that dams and flows can be initially recognized in any of the tripartite investigations. During a technical investigation, an engineering choice may be particularly controversial for a value-related reason (a dam). A third-party database system may raise concerns over privacy, for example. Similarly, building off of an existing

interface the users are already familiar with promotes the value of access and ease of use and thereby encourage usage (a flow). Value dams and flows are also identifiable during a conceptual investigation. During the philosophically informed inquiries into the values and stakeholders at play, certain values may stand out in how they influence or are influenced by the technology under study. Whether they are recognized during technical or conceptual investigations, these value concerns can should be reasoned as possible dams and flows. During the ongoing VSD process, they should be explored further and ideally verified in an ensuing empirical investigation.

During the conceptual investigation presented in this chapter, the value of access stood out as a potential dam. In the history of ATs for supporting reading, one of the major barriers to usage is the need to digitize texts (Elkind et al., 1996; Laga et al., 2006; Bookshare, 2010a). If the process of digitization is too time-consuming, users will readily give up on the technology, hence poor support of access to texts will hinder the adoption process.

Identifying the connections among the various values as in Figure 6.3 helps in the detection of dams and flows. In Figure 6.3(a), normalcy and privacy play a central role in the overall system. Privacy, in the sense of helping maintain an appearance of normalcy, is a value flow. As mentioned multiple times, people with RDs have a strong culture of controlling the degree of disclosure about their disabilities. If the reading widget contains features that allow and support the management of one's privacy, the technology will integrate with preexisting cultural practices and thereby more likely to be adopted. A widget that broadcasts to others about the user's reading disability, however, will be less appreciated and likely rejected.

Meanwhile, Figure 6.3(b) also suggests a value dam in fairness. The reason is a familiar one. When a student requests accommodations for a reading disability, the accommodations are meant to allow the student to perform as well as she would if the disability was not present. Importantly, accommodations should not provide an unfair advantage. Any AT must be considered in terms of fairness before an instructor will allow its usage by a student with RD. Even a small claim of unfairness is likely to have major impact within an academic institution. Some instructors are already vocal about students with learning and reading disabilities having unfair advantages (W. M. Williams & Ceci, 1999; Zirkel, 2000; Vickers, 2010). For students with RDs, if a reading widget is forbidden or discouraged by an instructor, usage of the widget in other situations may also diminish to the lack of portability and universality. Because of this value dam, a reading widget should include feature and policies that support discussion and management of fairness among the various stakeholder groups.

4.4 Missing Stakeholders and Values

Finally, having performed this initial identification of values and stakeholders, it is natural to ask if any of either group has been overlooked? To address this concern, Value Sensitive Design does not stop after the

initial identifications. VSD's tripartite methodology is iterative and integrative. The additional investigations presented in the following chapters are not only about applying the findings from this chapter but are also for seeking out evidence that supports and challenges them. If a value or stakeholder group is found to be missing, this spurs further investigations and integration of any new insights.

Another means by which gaps can be found is by communicating this research to others. For example, during this dissertation's defense, one audience member inquired as to why the value of diversity was not included. Diversity—the encouragement and desire for people in a group to come from a variety of backgrounds, cultures, education, or other demographics—is viewed as important by many. Promoting a diverse student body is particularly common at the university level, especially in engineering fields and computer science (Maruyama & Moreno, 2000; Lazowska, 2002; Blum & Frieze, 2005). Naturally, disability is a form of diversity, so it was surprising that diversity had not been explicitly called out in the literature I reviewed. In some ways, the value of normalcy includes diversity in the sense that the two are opposites and naturally in tension with each other. Because of this audience member's insight, exploring diversity as a value has become a goal for future work, and planned efforts to do so are discussed in Chapter 12, Section 2. As a start, a reanalysis looking for mentions of diversity was conducted and integrated into the writeup of the empirical investigation presented in the next chapter.

5 Chapter Summary

This chapter presented a conceptual investigation that defined relevant stakeholders and values for this research. In identifying stakeholders, a new type of stakeholder, those who affect technology usage, was developed. A thematic literature analysis was also used to investigate the many roles of values in the complexity of understanding AT usage and adoption among adults with RDs. The identified values were discussed in detail. Explicitly supported values, value tensions, and value dams and flows were described. Together, this initial stakeholder and value identification and analysis forms the basis for the VSD investigations in the following chapters.

NOTES TO CHAPTER 6

- 1** The value and stakeholder identification presented in this chapter began primarily during my enrollment in the Value Sensitive Design course taught in Spring 2008 by Drs. Batya Friedman and Alan Borning. The discussions with the instructors and my classmates at that time were quite valuable and influenced the VSD portion of this dissertation.
- 2** One difficulty with this decision is that the term stakeholder loses some of its appropriateness here. In the case of a company executive who insists that the employees use a specific software package, the productivity of the company and her paycheck are at stake. However, what stake does a person who ridicules another have? Social psychology has explored questions like these to understand activities such as bullying and teasing. Some theorize that bullying and teasing is a means of establishing dominance or feelings of superiority over others with the motivation being driven by either arrogance or the need to cover feelings of shame or low self-esteem (Simmons, 2002). In this sense, a stigmatizers' senses of self-worth and identity are at stake. Acknowledging this, though, does not mandate that we support this action. Value-sensitive design creates awareness of values important to the various stakeholders, but VSD does not mandate that the designer must respect and support those values.
- 3** An instructor may choose to provide accommodations to a student without going through official channels such as the disability services office. Such an instructor would be entering an ethical and legal quagmire, though, as this would be deemed as preferential treatment to a student and is thus unfair to the instructor's other students. Although accommodations may be viewed by some as preferential treatment, disability services provide a legal and sanctioned justification for them. Otherwise, the professor cannot treat one student differently than another. This means that an instructor can offer accommodations only as long as they are made available to all students if the students so desire. This is one of the central tenets of inclusive teaching (Clough & Corbett, 2000; Deibel, 2007b; N. Matthews, 2009).
- 4** Any of these newly identified articles, papers, or books could (and should) undergo the theme-value coding process and thereby be added to the literature review and its visualizations. Both the open coding approach and the paper selection process used in theme-value literature analysis is an ongoing process potentially without end. Presented in this dissertation is a point in the review process in which the number and breadth of papers selected was found to be sufficient to prompt insights into the broader research goals. Additional coding and refinement of the themes and values can occur, and efforts to do that are described in the future work discussions in Chapter 12.
- 5** Other disabilities besides reading disabilities also fall under this notion of "steep ramp" access. Another

example involves people with low vision issues such as glaucoma or effects related to albinism. In many situations, these individuals can see and perform visual tasks but may experience difficulties. Technologies that help people who are blind will also help people with low vision by providing an alternative to visual input. However, other tools such as magnifiers work by augmenting the sight of the user, essentially decreasing the steepness of the ramp. The insight here is that assistive technologies are both about building ramps and improving existing ramps.

- 6 Dr. Rebecca Cory, the Manager of Disability Services at North Seattle Community College in Washington State, has an excellent metaphor regarding disability and accommodation fraud—“the Wal-Mart shoplifting policy.” Large retail stores like Wal-Mart are concerned with shoplifting and therefore put in place safeguards to limit and prevent it. Of course, some shoplifting still occurs. The stores could increase their security, impose stricter controls on the customers, and pursue further efforts to eliminate any and all shoplifting, but eventually the time, cost, and repercussions of such anti-theft policies would end up costing the company more than what they lose from the occasional theft. The primary goal of the retail store is to sell merchandise; shoplifting prevention is secondary.

Disability services works in a similar way. The goal is to provide appropriate accommodations for people with disabilities. Policies exist for determining who qualifies, and safeguards such as licensing and vetting of diagnostic clinicians are in place to prevent fraud. Some deceit and fraud can occur, but the risk is kept small enough so that accommodations can still be delivered in a timely manner without undue effort on the part of the applicant (Personal communication with Cory, February 2010).

- 7 Note that this disparity in access to well-funded schools invokes the value of fairness as well.
- 8 In discussing McDermott’s study (1993) with colleagues, several have commented about similarities to the the concept of *stereotype threat* (Steele, 1997). This phenomenon describes how a member of a group associated with a negative stereotype may subconsciously conform to the negative stereotype if it is suggested. For example, commenting that girls perform worse at math than boys right before an algebra test may lead to female students scoring lower than they would normally. One explanation is that the stereotype threat adds additional pressure by suggesting that one’s performance is representative of the entire group.
- 9 Eventually, Mooney did change his view of what he could become, eventually graduating with honors from Brown University with a degree in English of all fields. His memoir/travel essay (Mooney, 2007) about disability, normalcy, his life, and the lives of others is one of the best reads I experienced during my work on this dissertation. I highly recommend the book.

CHAPTER 7

EMPIRICAL INVESTIGATION: ONLINE DISCUSSIONS OF READING DISABILITIES AND TECHNOLOGIES

The judges of normality are present everywhere. We are in the society of the teacher-judge, the doctor-judge, the educator-judge, the social worker-judge; it is on them that the universal reign of the normative is based; and each individual, wherever he may find himself, subjects to it his body, his gestures, his behavior, his aptitudes, his achievements.

— Michel Foucault, *Discipline and Punish: The Birth of the Prison* (Foucault, 1977/1995, p. 304)

Having identified relevant values and stakeholders, the next step in Value Sensitive Design is to conduct empirical investigations that explore, challenge, and refine them. To conduct such research on elements of human culture like values, at least two approaches can be considered. The first is to talk to the relevant parties directly (interview study), while the other is to independently observe public conversations involving the relevant parties (observation study) (Taylor & Bogdan, 1998). Each approach has its own strengths and weaknesses. Interviews guarantee that the topic of interest will be addressed, but the role of the interviewer may influence the participant's responses. Observational studies can reduce or eliminate such influence and allow for the participant to discuss topic more naturally and unprompted. One major challenge with observation studies, though, is successfully finding conversations and situations to observe that are relevant to the purpose of the research. Moreover, as the researcher is ideally an outside observer, a participants cannot be asked to clarify his thoughts and opinions as could be done in an interview session.

Fortunately, the advantages of both methodologies can be gained by conducting multiple studies using the different approaches and triangulating the findings (Taylor & Bogdan, 1998). As such, both an observational study and an interview study were conducted. This chapter presents the first—a study of online discussions about RDs and technologies from message boards and newsgroups. In the first section, the study is described in terms of its motivation and methodology. Three online asynchronous discussions are then separately analyzed using the value and stakeholder frameworks. The findings are then summarized.

1 Study Description

In a public observation study, the researcher does not interact directly with the participants of interest. Instead, the researcher observes from afar, takes notes, observes, and potentially eavesdrops on conversations (Taylor & Bogdan, 1998). Several aspects of reading disabilities, however, pose challenges for conducting such a study if the participants of interest are people with RDs. Although RDs are not exceedingly rare, the prevalence rate of 7–15% does make finding such individuals potentially difficult (Sands & Buchholz, 1997). Furthermore, without any visual indicators of the disability, identifying whether a person has an RD without directly asking them can only occur if the person publicly discloses it. Given the issues of stigma discussed in the previous chapter, though, such disclosure and openness are also unlikely (Cory, 2005; Tanner, 2009).

1.1 Message Boards and Online Observations

With the advent of Internet-based communications, new opportunities for conversations have developed (Hine, 2000; Black, 2005). One such venue is the message board, alternatively known as a web forum, discussion board, newsgroup, bulletin board, etc. This online facility allows for a group of physically-separate people to communicate, albeit not in real-time. Any member can issue new messages or reply to existing messages. The forum itself is a repository for these messages. A conversation, or thread, on a forum consists of an initial posted message followed by replying posts. Depending on the board's configuration, messages may be listed in chronological order or threaded (each post is positioned relative to the post that it is a reply to). The underlying digital communication technology can take many forms. Most message boards are web-based and accessed solely through an Internet browser. Newsgroups, however, are accessed primarily through a news reader or e-mail, although web archives are also often available as well.

Message boards and similar venues have also created new opportunities for observational research. Ethnographic techniques have been repurposed for conducting studies of online communities and conversations (Hine, 2000; Black, 2005). Importantly, this provides a means to address the challenges of conducting such a study of people with RDs. Message boards typically form around a shared topic of discussion such as hobbies, medical issues, and fandoms. Forums concerning RDs/LDs will not only more likely provide a higher percentage of users with RDs, but such a forums focus on support and community also leads to more people disclosing about their disabilities in their posts. Additionally, not all board members will necessarily have a reading disability. These forums are also used by parents, teachers, and researchers who work with people with RDs. The views and opinions of both direct and indirect stakeholders can be collected and studied.

1.2 Methodology

Thus, an observational study of conversations concerning reading disabilities and technology on online message boards was conducted. Particular focus was placed on understanding the roles of and issues associated

with technology in the daily lives of people with RDs. Discussion threads were analyzed in relation to the previously identified value-stakeholder framework to verify, challenge, and refine that model.

1.2.1 Identifying Discussion Threads for Analysis

To find discussion threads for analysis, multiple message boards were consulted. These boards were found through several means. Some forums selected were associated with the websites of major RD/LD organizations such as those listed in Table 3.1 in Chapter 3 (page 49). Other discussion groups were identified by conducting an online search. The words used for the search included terminology related to RDs, technology, and message boards, such as “reading disability message board” or “dyslexia computers discussion forum.” In general, most of the message boards consulted focused on reading or learning disabilities. However, the search efforts also found forums about related topics such as teaching and disability rights. The conversation discussed in Section 2.2 of this chapter, for example, came from a website concerning the teaching of writing composition at the university level.

Once a message board was found, a search was conducted for individual threads to be analyzed. Topics and subjects lines were skimmed for any threads potentially related to the study’s focus. Search features were also utilized to find threads mentioning computers or technology. If the forum was not specifically about RDs, searches were also conducted for terms such as “dyslexia” and “reading disability.”

Beyond being about a topic relevant to the study, several characteristics were also desired for threads. A thread would consist of multiple posts involving the exchange of multiple ideas and opinions. Such a thread should also involve actual conversation among the posters. An unacceptable thread would involve the asking of a question, an answer, and a reply to say thanks. Ideally, a thread would also involve several contributors as this would potentially bring in a broader range of perspectives and stakeholder groups.

1.2.2 Analysis

Once selected for study, each thread was analyzed to produce illustrative case studies. This form of case study involves studying a few instances of a phenomenon in depth with the intent of illustrating what is occurring (General Accounting Office (GAO), 1990). The goal is not to make generalizable claims but to provide rich, descriptive data in relation to a framework or topic under study.

To produce the case study, several types of data were collected about the thread. First, the text of the entire thread was gathered, including indications of who authored the individual posts. If a poster identified as having a disability, that was noted. Such claims were trusted, and, in the same vein of traditional observation studies, no additional efforts were made to verify those claims (Taylor & Bogdan, 1998; Hine, 2000). Logistical information such as the time and date of the posts will also be collected. A characterization of the originating message board or newsgroup was also developed. Finally, the discussion content was analyzed using a qualitative approach, with particular attention to word choices and any discussions of human values,

technology usage, and disability issues. Short quotes regarding such topics were also noted for later use when reporting about the case.

1.3 Human Subjects Concerns

Conducting online observation studies does raise several ethical issues regarding human subjects research, and these concerns have been noted by previous researchers (Hine, 2000; Black, 2005). Because of the nature of the Internet and how message board postings work, it is not possible to confirm the ages or legal competence of the posters on these forums. Issues of confidentiality and anonymity are also complicated. Unlike a spoken conversation, the text of a message board discussion continues to exist even after the conversation has finished. Even if the message board discards older messages after time has passed, web archives and caches make it possible to retrieve them. Search engines like Google make it possible for a person to find the source data using a small quote or screen name.

Posters to a message board do have a modicum of control over their privacy, however. By using screen names and not their real names, a layer of anonymity is put in place. However, any information that a person posts to the message board or keeps in a public profile is in the open for others to see and use. For this reason, most boards make profiles private and accessible only to members of the discussion board community.

Because of these concerns, I worked with the University of Washington's Institutional Review Board (<http://www.washington.edu/research/hsd/>) to identify how to best conduct this study and still respect the rights of the posters on the message board. Recognizing that complete confidentiality and anonymity could not be guaranteed, we established several guidelines for how the data would be treated and presented in order to make it more difficult to trace the findings back to the original sources:

- Names of the message boards and their URLs are never reported. Instead, a message board is only referred to through a brief descriptions such as “the discussion forum for a leading organization for providing information on learning disabilities to professionals and parents.” Pseudonyms for a forum may also be used.
- All screen names are replaced with pseudonyms.
- The only information presented about posters is what they make publicly available. Private profile data available only to forum members is not collected.
- Posting dates are only reported in a general sense such as “winter of 2006.” The timing between posts in a thread may be reported in a relative sense: the original post will be at time zero; a following post could be at 1 day, 2 hours; another post at 1 day, 2 hours, 10 minutes; etc.
- Any direct quotes are limited to short statements in order to reduce their searchability.

With these policies agreed upon, the study was approved.

Table 7.1: Descriptions of the three threads included in the illustrative case study.

ONLINE DISCUSSION THREADS	
1. A Call For Help	
<i>Source:</i>	Public message board for discussing dyslexia-related issues. Unaffiliated with any organization.
<i>Description:</i>	Multiple posters with reading disabilities respond when a man with dyslexia and dyscalculia desperately pleads for help in achieving his desire to finish college.
<i>Posts:</i>	17 messages by 8 posters
<i>Time:</i>	Across 3 months in Autumn 2006 70% of posts in first three weeks
2. Composition, Computers, and Disability	
<i>Source:</i>	Discussion forum for an online conference for college instructors interested in using computers for teaching English composition.
<i>Description:</i>	Several conversations by college English composition teachers about supporting disabled students in relation to the growing interest in digital media literacy practices.
<i>Posts:</i>	23 messages by 7 posters
<i>Time:</i>	1 week in Winter 2009
3. Macs, Dyslexia, and a Documentary	
<i>Source:</i>	Cross-posting on three newsgroups: a UK-based discussion of Apple computer products, an international support forum for people with dyslexia, and a group for amateur radio operators.
<i>Description:</i>	An initial thread about usefulness of Macs for dyslexics evolves into discussion of the recent documentary <i>The Dyslexia Myth</i> (D. Mills, 2005) and if RDs actually exist.
<i>Posts:</i>	215+ messages* by 37 posters
<i>Time:</i>	1.5 years starting in Autumn 2005 95% of replies within first month
	* Some posters' messages were not archived but are evidenced by partial quotes by other posters.

2 Three Conversations

A total of three discussion threads were selected and developed into illustrative case studies and are listed in Table 7.1. The first is a classic example of a person with an RD/LD reaching a breaking point and realizing that he needs help in managing school and his disability. The responses by others with RDs in the forum community touch on accommodation policies, self-advocacy, and helpful technologies. Next is a discussion by college English composition instructors about using computers to support students with disabilities. These indirect stakeholders talk about multiple disability types and a small debate erupts over what is and is not a disability. The third discussion begins with a discussion about Macintosh computers and users with dyslexia,

Table 7.2: Descriptions of the key participants in the “A Call for Help” thread.

Participant	Description
Todd	The creator of the thread. He is attempting to earn his bachelors degree in international relations but his learning disability is causing immense difficulties.
Maya	An architect who has faced difficulties in her profession due to her dyslexia and can relate to Todd.
Kilgore	A teacher who works with math students with learning disabilities.
Will	A British man with dyslexia who comments about spellcheckers.
Marybeth	A woman with dyslexia and dyscalculia who also has a daughter with the same conditions.
Advertiser	A marketer from a company selling a “treatment” for dyslexia.

but the recent airing of a British documentary on dyslexia triggers multiple conversations about what it means to have an RD and whether RDs actually exist. Together, these threads address many of the themes and values identified in the previous chapter.

2.1 Discussion 1: A Call for Help

The first thread came from a public message board for dyslexia support. This board had an open posting policy, meaning that anyone could post to it without having to officially register.¹ The policy created a community of posters that included regular contributors as well as visitors asking questions or seeking support. This thread was of the latter type—a poster new to the boards beseeching for help.

2.1.1 Opening Post

In Autumn 2006, Todd,² who had never posted to the board before, posted what is best described as a desperate plea for help. He described how he had gone to college but kept failing a course on statistics. A professor recommended that he be tested for learning disabilities, and it was determined that Todd had dyslexia and dyscalculia (an LD involving working with numbers and mathematics). Despite the diagnoses, he still struggled with math classes as well as a foreign language requirement. After six years of trying, he gave up and left with an associates degree which he described as “Pathetic. I still feel [sic³] like a failure.” After ten years, he still wants to earn his bachelors and maybe a masters in international relations but is convinced that he will “. . . NEVER pass because of the math. It is not possible. PERIOD.” Todd describes how he has been scouring the Internet for information on how a person with an RD/LD can survive college but is still lost. He ends his post with the simple request, “Please help.”

2.1.2 Descriptions of Responses

Todd’s post is reminiscent of the phenomenon described by Cory (2005) in which a university student with an invisible disability decides to not register with disability services but a crisis eventually leads her to seek out help. Todd’s case is different as he left college and now seeks to return ten years later, but there are parallels. In

particular, like many students entering college, he does not know how to navigate the policies and bureaucracy associated with requesting and receiving accommodations (Cory, 2005; Burgstahler & Cory, 2008). In Todd's case, he was not diagnosed until he was already in college, leaving him with even less experience managing his disability in an academic setting.

Overall, Todd's post resulted in 16 replies, three of which were from Todd replying to the comments and questions from the others. Table 7.2 lists the key participants. Many of the other members clearly recognized and related to his situation. One poster, Maya, articulated her own experiences:

Boy do I feel for you. . . I am a server dyslexic myself. I have my college degree. . . a Master Degree in Architecture from Virginia Tech . . . I have struggled for twenty years to get these degrees

She then talked about some more recent struggles regarding a licensing exam for her job in which she was denied accommodations. Maya expressed that access is a fundamental right under the ADA and that she was fighting that decision. She then told Todd that he needs to do the for himself as well—be his own advocate. Other posters also informed Todd of how to advocate for his rights to educational access: who he should contact, what documentation he will need, what his accommodation needs may be, etc. Even when Todd expressed concern that he might not get accommodations or might not even be able to get back into college due to needing to pass entrance exams, the other posters reassured Todd and reminded him that accommodations are a legal right. Like all people with disabilities, he deserves a fair shot at a college education.

Although this relating of shared experiences and giving of advice might suggest the board's sense of community was in complete agreement, some members constructively criticized some of Todd's statements. For example, many of Todd's concerns were over the need to successfully fulfill a math requirement. His frustration is based not only in his litany of previous bad performances, but he argues that he would never use any knowledge of mathematics in his field of international relations. Kilgore, who teaches math to dyslexic students, challenged Todd on this last point and argues that people in business and politics should understand some math such as statistics but not necessarily geometry. This criticism was part of Kilgore's larger effort to make clear to Todd that he needed to clarify and specify what he will need to get through college while still being realistic. Todd will need to take a math course, but it should be one relevant to his needs and accommodations should be in place for him.

2.1.3 Discussions of Technology

Within this thread, some discussion of the helpfulness of technology also occurred. Todd mentioned in his opening post that when it comes to writing, most of his problems were with spelling, but spellchecking software readily addresses this issue. However, several of Todd's posts contained misspellings. As quoted earlier, Todd misspelled the word "feel." It is unclear if he used a spellchecker before submitting his messages, but given the emotions seen in his posts, spelling was probably a low concern for Todd. Furthermore, the

interface he used to post may not have included a built-in spellchecking feature.

Will, a dyslexic from Britain, laments that he has not shared the same level of success with spellcheckers, however. As he puts it, “i haven’t found spell checkers to be that good i find they only correct, the easy and balk on the hard.” Notably, many of the posters who disclosed having an RD made spelling errors that would not be caught by spellchecking software. Such examples included writing “server” for “severe” or “secede” for “succeed.” Each word was correctly spelled but wrong for the context. This is the lexicality effect previously identified by Bourassa and Treiman (2003) in their studies of spelling errors made by writers with RDs.

In addition to the discussion of spellcheckers, two other tools were recommended. However, the responses from the posters were quite different. Marybeth, who has dyslexia and dyscalculia like Todd, recommended a math tutorial software⁴ that was found to help her daughter who has the same RDs/LDs as her mom. Maya herself expressed interest in the software for herself and thanked Marybeth for the suggestion.

The other, less appreciated recommendation came from a poster outside of the board community. In an advertisement personalized to Todd, a marketing representative promoted her company’s supposed special educational approach that can “fix” dyslexia. She pointed Todd to the company website, noting that they “guarantee results!!” Both Kilgore and Maya attacked and denied her company’s claims. Kilgore called on his expertise as a teacher of students with RDs/LDs and criticized the company’s description of dyslexia symptoms. He also politely inquired about some design elements on the website that make the text unfriendly to people with dyslexia. Maya, on the other hand, attacked the very idea that dyslexia is something that can simply be cured:

You can not fix dyslexia. . . it is a life long disability. . . you can learn clues to help assist you but you can not be “fixed.”

Essentially, these forum members reacted strongly to questionable claims made by an outsider. By responding as they did, Kilgore and Maya worked to ensure that the support offered by their community can be trusted.

2.1.4 Thread Summary

This thread shows how a message board’s community can form together to offer advice and support to both new and long-term members. Stakeholders present in this conversation included people with RDs, teachers, and parents. Although raised as a concern in Chapter 6, Section 3.4.3, this forum is one example where people with RDs are active members of a reading disability community. Additionally, the conversation touched primarily on the values of access and fairness and the themes of accommodations and self-advocacy. Issues of trust in advice and treatments also arose.

2.2 Discussion 2: College Writing Instructors Discuss Disability

The second thread included in this illustrative case study did not come from a site focused on reading disabilities. In fact, this thread was the only discussion involving disabilities on the entire board. The board in

Table 7.3: Descriptions of the key participants in the “College Writing Instructors Discuss Disability” thread.

Participant	Description
Amber	The creator of the thread. A graduate student interested in supporting students in college writing courses that make extensive use of digital technologies.
Lily	An author and poet with a mobility disability who tries to stay aware of accessibility issues.
Clark	A writing instructor who is a fan of classroom of technologies who usually tries to check for any accessibility issues before using them.
Virginia	A writing instructor who has worked with multiple students with RDs/LDs.
Amos	Identifies as Deaf, he is a graduate student with strong opinions about what is and is not a disability.

question was a discussion forum set up for an asynchronous, online conference about the use of computers in teaching English composition at the college level. Thus, participants in the thread (key ones listed in Table 7.3) were primarily instructors, educators, or researchers interested in topics related to the conference.

2.2.1 Opening Post

This thread involved the intersection of teaching digital composition skills and inclusive education. Amber, a graduate student (field not specified), states that she has two research interests regarding university students with disabilities. First, she wants to know about the digital literacies in which these students regularly participate. Second, she wants to identify what access barriers, if any, they experience. Towards answering these interests, Amber asks forum participants who are composition instructors to discuss their experiences with students with disabilities as well as any opinions involving disability issues and computer-based reading and writing.

2.2.2 Discussions of Digital Literacies and Disabilities

Amber’s post triggered several discussions. Some posters gave examples of how digital literacies provide new opportunities for some disability groups. One composition instructor discussed the impact of online video services on people who communicate with sign language. For many individuals who are deaf and particularly for those born deaf, sign language is their primary language and English is secondary. Video allows some individuals to create blogs and even “write” novels using sign language.

Discussion of access issues with digital practices was also a concern for some of the instructors. Lily, an author and writing instructor, creates interactive poetry on-line through the use of hypermedia and dynamic HTML. Because she has a mobility disability, Lily tries to remain cognizant of all forms of access barriers and has adjusted her web poems to use accessible web formats.

2.2.3 Teaching Students with Disabilities

Access issues were a particular concern when students with disabilities came into play. For example, Clark has been a long time fan of using web technologies in his teaching and does his best to ensure that tools like

screen readers work successfully with his web pages. Amber's thread made him unfortunately realize that he had failed to continue that practice when he adopted a new tool into his teaching practice:

I'm a big fan of our CMS [content management system]... However, I just realized that I'm not entirely sure if text readers and magnification work... a disheartening thing to realize.

Another instructor participating in the discussion used the thread as an opportunity to find help for one of her students. Virginia stated that one of her students in her freshman English course has dyslexia. The university provided him with a reading pen, but the student rejected the device because it "...was too slow, clunky, and he hated the sound of the computer voice." She asked if anyone participating in the thread knew of other TTS approaches that the student might like. Amber replied that she had seen some students use the Kurzweil 3000[®] software (Kurzweil Educational Systems, 2006) as well as free alternatives like ReadPlease (2005), although she had not necessarily heard great things about them.

However, when it came to truly supporting students with disabilities, the instructors identified respecting student wishes as more important than technology. Virginia related an experience she had years ago with a student who had several LDs. With previous students with RDs/LDs, she had taken care to spend extra time and offer more support to them, but she had not been able to do so with this student. Worried that she was neglecting him, she asked the student if there was more she could do to help him. His reply surprised her:

He said that he appreciated the fact that I didn't hover over him in class and that I only came to help when called me because in high school his teachers hovered, which made him feel different and too dependent.

This made Virginia more aware that students, disabled or not, have unique preferences for how they should interact with the instructor. Some are more independent; others want more explicit support.

More generally, this triggered a greater discussion of the importance being aware that some students have disabilities. Several posters discussed how the thread helped to remind them about disability and access issues. This inspired Amber to thank the other posters for providing her with an insight:

...we have yet to hit a critical threshold [of number of students with disabilities] that makes awareness of disabilities an important issue for faculty. I commend all of you for having the awareness now.

Others echoed this value of maintaining awareness and connected it to inclusive education notions of proactively addressing access issues before they arise (Burgstahler & Cory, 2008; Deibel, 2008).

2.2.4 Defining Who is Disabled

Some dissension did occur in the thread, however. After the post about video blogging and deaf individuals, one poster objected to associating being deaf with having a disability. Stating that he lost his hearing at some point in his life and attended Gallaudet University, Amos argued that the culturally Deaf are not disabled but are

instead a distinct linguistic group. The basis of his argument was that in a community where everyone knows American Sign Language, a Deaf person would not experience any difficulties as they place no importance on hearing in their daily lives. This argument has been made previously by other Deaf scholars (L. J. Davis, 1995; Lane, 1997).

For the purposes of this study, the legitimacy of Amos's argument is not important. What is relevant is the impact that his multiple postings on the topic had on the thread. After Amos's first post on this topic, Amber acknowledged his perspective and tried to redirect the discussion back to the thread's original topic. Amos continued discussing this issue, though, and made multiple posts pointing to scholarly articles and quoting large sections of text from those articles (one of which was the article by Lane (1997) from the theme-value literature review). In terms of content alone, Amos's post accounted for more than half of the text in the overall thread, dominating and essentially drowning out the other discussions.

Moreover, certain elements of how Amos characterized disability are worth noting given their connections to normalcy, stigma, and perceptions of disability. When discussing disability, Amos used terminology associated with the medical model of disability such as "defect" or "loss." He objected to using these terms to describe a Deaf person, but applied them to other disability types. At one point, Amos compared denying the teaching of sign language to a child born deaf as "...equivalent of taking a beautiful bird that can fly and chaining it into a tiny wheelchair." This statement led Amber to post due to his continuous assertions of disability being a flaw or a state that no one would want to experience had become insulting to those reading the thread. Amos replied that such statements were valid and not insulting because:

... everyone who uses a wheelchair would gladly give it up if there was a way to have an operation to have the use of their legs restored.

The only support for this claim provided by Amos was an unsourced opinion essay by a Deaf scholar named Finklestein. Notably, his claim is demonstrably false. In a (1978) survey of wheelchair users, Weinberg and Williams found that half of the people they surveyed saw advantages in their physical disabilities and would not wish to be no longer disabled. Still, Amos argued that no one wants to be in the state of having to use a wheelchair, and therefore it was perfectly acceptable to equate being in a wheelchair to a state of confinement. However, since Deaf people do not find fault with their inability to hear, one should respect their identity and choice to not be treated or accommodated as having a disability.

In its entirety, Amos's arguments about what is and is not a disability invoked many value issues. He admitted to having a condition that is legally and commonly recognized by American society as a disability. As one of the cultural norms of this society is to communicate verbally, he likely often faced barriers in accessing aspects of daily life. However, he embraced a viewpoint in which people like him are not disabled because it is part of their identity and thereby not a fault. To him, disability is to him about faults, defects, and

deviations from what is normal, yet the vast majority of American society would also not include his hearing disability under the notion of normal. He insisted that his view of what is normal was correct and demanded that it be respected even though it disrespected those with other types of disabilities. Amos's negotiations and navigation around what defines a disability highlights the complex interactions of the sense of self and various definitions of normalcy.

2.2.5 Thread Summary

This thread does not involve the primary stakeholders of adults with RDs. Instead, the views and perspectives of college-level instructors who teach English reading and composition courses are presented. One poster's views of what is and is not a disability touches on many of the dynamics discussed in the previous chapter about normalcy, disability, and identity. More illuminating, however, were the conversations of the other posters and their repeated mentioning of the importance of keeping aware of the needs and access issues of students with disabilities. This notion of being aware of events, needs, and aspects of the community one finds oneself in can be thought of as a value, and this value is conspicuously missing in the current value-stakeholder framework. Further investigation of the value of awareness of or connectedness to one's community is warranted, and attention should be given toward its relation to this important group of indirect stakeholders is warranted.

2.3 Discussion 3: Dyslexia, Macs, and a Controversial Documentary

The final thread selected for analysis comes from newsgroup postings. Newsgroups are similar to discussion forums but also share some features with e-mail distribution lists. Each newsgroup is associated with a particular topic of interest, and members can choose to create, receive, and reply to discussion threads posted to a newsgroup. Moreover, it is possible to crosspost a discussion across multiple newsgroups if the focus of the discussion spans several topics.

This conversation comes from a crossposting that eventually involved three distinct newsgroups. The first, *uk-apple-group*, was a discussion and technology advice forum for British users of Apple computer products. Also involved was the *rd-help-group*, an international support forum for people with dyslexia. Finally, an interest group for amateur radio operators, *amateur-radio-group* was involved in a few posts in the thread.⁵

2.3.1 Opening Post

This thread began with Nick (who later disclosed being dyslexic himself) conjecturing about the superior utility of Macintosh computers (Macs) for people with dyslexia. At the basis of his argument is his characterization about people with dyslexia:

Dyslexics are picture thinkers.... They excel at processing non-verbal information. Loads of dyslexics are apparently the creative types -into art. Apparently many are computer experts, architects, graphic designers...

Table 7.4: Descriptions of the key participants in the “Dyslexia, Macs, and a Controversial Documentary” thread. Participants who specifically mention having seen the documentary are noted.

Participant	Description
Nick	The creator of the thread. He is dyslexic and postulates that Macintosh computers are especially dyslexia-friendly.
Neville	A British man with dyslexia who is an active participant on both the uk-apple-group and the rd-help-group. He is very open about educating others about dyslexia and watched the documentary.
Ruth	A member of the uk-apple-group. She is not dyslexic but considers herself more as a visual than a verbal thinker. She watched the documentary.
Dylan	A British man with dyslexia. He does not consider himself to be a picture thinker.
Ross	A member of the uk-apple-group. He takes a neutral stance on several issues. His posts aim contribute information and not opinions.
Lester	A member of the uk-apple-group. He questions the notion of dyslexia and tries to view disability as a weakness compensated by strengths in other areas.
James	With his mild case of dyslexia, he favors Macintosh’s built-in dictionary application.
Mike	A member of the uk-apple-group. He states he has dyslexia. He also admits that lack of effort on his part contributes to his difficulties.
Leroy	A member of the uk-apple-group who challenges Mike about his laziness.
Henry	A member of the uk-apple-group. He denies the existence of dyslexia and argues that it is actually a lie constructed to hinder the lower class. He watched the documentary and agrees completely with its conclusions. His posts were not archived in the newsgroups.
Fred	A British man who has been diagnosed as dyslexic but does not experience enough difficulties to qualify for accommodations.
Timothy	An American man who was diagnosed with dyslexia early in his childhood, he describes the negative implications his disability had on his interactions with others.

Opining that the Mac interface is “so intuitive,” Nick reasoned that “. . . loads of Mac users are dyslexics.” As proof, he noted that Neville, a poster to the uk-apple-group, had disclosed about his dyslexia. Nick then asked the members of the uk-apple-group and the rd-help-group if they knew of any other dyslexic Mac users?

2.3.2 Ensuing Conversations

In cross-posting, Nick brought together two newsgroup communities with different backgrounds and interests. With the exception of Neville (one of the most active participants in the thread) and Nick, most of the posters previously followed only one of the newsgroups. The thread grew quite rapidly and averaging 35 new posts per day in the first three days. Overall, the combined efforts of thirty-seven posters (Table 7.4 lists key discussants) led to a thread that spanned over 1.5 years and 215+ messages.

The exact number of posts in the thread is uncertain. Because of how newsgroups are implemented, the exact number of posts is uncertain. A newsgroup server does not necessarily archive every message, creating gaps in the overall thread. In particular, the messages of one poster, Henry, were not archived. Their presence,

however, is partially provided as other posters would quote sections of Henry's postings in their replies, but an exact recreation of everything he wrote is not possible.

This massive, cross-posted thread resulted in multiple conversations and subtopics of varying relevance to Nick's original post. One off-topic example involved a lengthy discussion (45+ posts) on the merits and reality of anarchy as a political system.⁶ Another conversation concerned different styles of posting to newsgroups, including some historical discussion of how the Usenet community had changed over the years. For the purposes of this study, though, several strands of discussion are particularly relevant to the current study. First, some of the discussion did focus on Nick's original thesis: Macs are dyslexia-friendly. Arguments supporting and challenging this view were given. Second, some of the thread moved on to discussing the accessibility of other technologies for users with dyslexia. Finally, a majority of the thread evolved into a series of debates about the nature and existence of reading disabilities, fueled in part by the then recent airing of a controversial British documentary, *The Dyslexia Myth*.

2.3.3 Macintosh Computers and Dyslexia

Despite being the topic of the opening post, only a few responses addressed Nick's assertion that Macs are a great computer for users with dyslexia. The posts that did concern the post centered on either of the two premises assumed by Nick. First, he argued, dyslexics are visual thinkers. Second, Macs use a visual-friendly interface.

One of the first replies supported the second element of Nick's argument. Ruth stated that although she is not dyslexic, she considered herself to be primarily a "picture thinker" who finds it much easier to work with drawings or pictures than just text and numbers. As an example of this, she compared her first experiences using PowerPoint and Excel. She had quickly picked up the "image driven" PowerPoint interface but stumbled and struggled with the text and grid nature of Excel. Although she did not directly make the connection, her post suggested that a different interface approach could be better for visual thinkers. A few other posters echoed this sentiment as well. James, who claims to have a mild case of dyslexia, espoused this view, but noted that his preference for using a Mac was not the visual features but the integrated dictionary application that he uses all the time.

However, more individuals argued with Nick's opening post by contesting the first premise of his argument. Two posters who disclosed having dyslexia, Neville and Dylan, both challenged the idea that dyslexia is associated with strong visual thinking skills. Dylan used himself as a counterexample:

I'm not. Indeed, I find pictures a pain in the backside in many situations. I would far rather read instructions in Czech than follow a set of pictures to complete a task.

Neville provided a broader perspective as to why people with dyslexia might show greater relative strengths in graphic design and other areas of visual arts. He argued that our society likes to find the positive when faced

with an apparently negative situation. In the case of disabilities, this means that people expect to see a strength substituting for the weakness:

you do find some really very bright dyslexics with very good visual skills. personally i think that the evidence is somewhat circumstantial, and that really it amounts to emotional bargaining, ie you lose something but you gain something else.

its the same reason for some of the interest in steven hawkins, humans have a desire to even it out, to see the silver lining, be it real or not.

Thus, Neville argued that people with dyslexia might gravitate to fields like art not due to superior visual skills but due to a nurtured desire to avoid fields involving more reading and writing. Society's perspective on and definition of disability, however, may lead to the misinterpretation of such decisions as indicative of strengths that do not necessarily exist.

Interestingly, Nick's original post and these responses reflect what is known in the research literature. As part of their SeeWord project, Dickinson et al. (2002) did identify that direct manipulation interfaces with immediate visual feedback were preferred by their dyslexic participants. However, this preference was attributed to memory and sequential processing difficulties and not necessarily exceptional visual skills. The argument that people with RDs may or may not have strong visual skills was also discussed in Chapter 2, Section 4.3. Although some scholars like West (1995, 1997) have argued that dyslexia leads to great feats of visual thinking, studies of visual ability in people with RDs has failed to find evidence of such superior abilities (Winner et al., 2001).

2.3.4 Large Texts and Reading

Despite the lack of direct discussion of Nick's primary questions about Macs and dyslexia, other conversations did venture into the usability of other computer technologies for people with dyslexia. Somewhat ironically, one of these discussions involved Nick's difficulty with following the progress of the newsgroup thread he started. Roughly thirty days after his initial posting, Nick posted a reply to Neville asking how the thread was going and if there were any of "... the posts are worth wading through." Several posters responded negatively to the idea that others should help Nick manage reading his e-mail and newsfeeds. One poster jokingly described a "usenet reading service" in which someone will not only relieve a person from "reading tedious articles written by other people" but would also do all of the "sifting, thinking and understanding" as well. Such negative reactions are not surprising, but Ross noted that Nick might be somewhat justified in his request to Neville:

...for somebody who really has trouble reading- as the OP [original poster] seems to have- it must be absolute hell, and take ages, even to skim through a load of replies. In fact I suspect that somebody with severe dyslexia skimming might simply be impossible.

Ross added that asking a friend to summarize the thread could be quite helpful, but it would have been far more prudent and diplomatic to request that help in a private communication. It is quite possible that Nick meant for this to be a private message to Neville, but everyone in the newsgroups did end up receiving it.

Acknowledging the possibility that reading the thread involved access issues, several individuals replied with strategies for better managing the potential flood of messages from a newsgroup. Some suggested that Nick could configure his newsreader to limit the number of messages received on a daily basis to a manageable amount. Neville confirmed Ross's suspicions that a busy newsgroup thread like the current one could be difficult for a person with dyslexia. Depending on the degree of reading difficulty experienced, Neville noted that text-to-speech is sometimes helpful:

text to speach can be slow and fairly dry, i use it sometimes, mostly if its a massive block of text,
but to be fair my reading is genurally good.

This is the only mention of TTS in the entire thread, and Neville notes that he does not use it that much. Moreover, he laments that “most tecnogical methods of helping one read fall down in some way or other, realiticly.”

2.3.5 Spellcheckers and Spelling

Despite the lack of discussion about technologies that support reading, several issues related to spelling and computers were mentioned. Neville noted that spelling was a major obstacle for when using the search features in any operating system. If he misspelled any of his search terms, nothing would be found. He did offer a solution in that it would be nice if the search functions worked “. . . like google does where it finds what you typed but also asked did you mean this?”

Spellcheckers were suggested as potentially useful, but several issues were noted. Although a spellchecker can identify when a word is spelled wrong, the user must sort through the suggested correct spellings. Neville articulated this point several times:

i can look at word and it looks as wright as the correct spelling. one problem with spellcheckers
is chosing the wright word as they can bring up a number of almost identical looking words
. . . all the options it gives look just the same. which means i have to be very careful not to chose
the wrong one and put a correctly spelt but totaly random word in. . .

This led Lester, a member of the uk-apple-group, to suggest integrating “a spell checker with a thesaurus, that not only gave a list of alternate words, but a few words on the meaning of the word.” This suggestion led to mentions of earlier word processing software that had similar functionality, but these posts noted that Lester's idea had not truly been implemented despite being seemingly easy to do so.

More generally, the challenges of spelling garnered discussion from many posters. Neville, as an active poster in both the rd-help-group and the uk-apple-group, commented about his own struggles with spelling.

Despite an early diagnosis of dyslexia and extensive remediation, he stated that "... though my writing and spelling did improve dramatically they are still very poor." James noted that he experiences similar difficulties, but not nearly as bad as Neville's. Despite the poor spelling, several posters complimented and respected Neville on his ability to make "... points in a very articulate, intelligent way." Another poster noted that since joining the uk-apple-group, Neville's spelling and grammar had either improved significantly or that he had become inured to his writing errors.

An important observation involving the value of literacy came from Ruth when she commented about the difficulty inherent in the English language:

Let's all be a bit kinder to ourselves and the world - the English language is bloody difficult to spell. Ghoti⁷ and all that. :-)

Follow-up posts recognized the idiosyncrasies of spelling in English. Moreover, some of the responders suggested and debated whether other languages might be easier in terms of spelling rules. Some of their suggestions, such as Spanish, Italian, and Russian, have been verified in studies comparing the difficulty of learning to read and write across languages (Seymour et al., 2003). However, a few balked at the suggestion that English is difficult and interpreted such claims as a call to abandon the language for another. Ross noted the similarities of this reaction to past efforts at introducing simplified spelling:

Many simplified spelling systems for English have been suggested, some partially adopted; I believe Webster was a partial adopter ... None of it ever caught on in a big way. Probably a combination of inertia (mostly) and snobbery as in 'any fule kno how to spel that'.

This expectation that everyone possesses literacy competence was shown in other elements of this thread. Mike, who disclosed having an RD, discussed his own struggles with spelling:

I'll freely admit some of it laziness. I don't take time to read my work. But even when I do, carefully, I'll still miss having substituted completely the wrong word.

Leroy quickly identified the crux of Mike's problem: "You just rush things." Even after Mike and Neville articulated that their phonological processing deficits occur even when they focus on the text, Leroy continued to discount their reading and writing problems by asserting that, "Mistakes are only obvious when you see them." Leroy failed to show empathy and understanding about how literacy is experienced differently by people with RDs.

2.3.6 The Dyslexia Myth

The public perception about what is normal in regards to literacy and what is a reading disability constitutes the majority of the thread due in part to the fortuitous timing of Nick's original post. Roughly one month prior to his post, the documentary *The Dyslexia Myth* had aired on Channel 4 in Britain. This controversially-titled one-hour special challenged that popular conceptions of what dyslexia is are wrong (D. Mills, 2005). The

documentary refuted notions that dyslexia is caused by visual problems or reversal of letters and recognized that visual stress is a separate issue. The role of intelligence in reading was similarly debated. The act of letter and word decoding was stated to be a basic neurological skill independent of intelligence. It was therefore argued that the notion of defining dyslexia as struggling with reading despite having normal to high intelligence was unfounded as intelligence was unrelated to reading. Dyslexia, in essence, only exists as an artificial construct. This led to the controversial argument that the public funds used to screen for, identify, and provide accommodations to British students with dyslexia could be better spent improving and implementing the teaching of literacy skills.

As earlier when Amos argued whether deafness is a disability, debating the validity and legitimacy of the documentary⁸ is not important. Instead, many of the uk-apple-group members had watched the documentary, as had some of the British members of the rd-help-group. The recency of their viewing increased their awareness of dyslexia and primed them to ask questions and express doubt. Thus, the stage was set for a debate much larger than the usability of Macs for people with dyslexia. The majority of the thread evolved into heated debates about what dyslexia is, does it exist, and how to best address the needs of people with dyslexia. Elements from and references to the documentary itself were referred to and shared.

The documentary's discussion of the relationship between intelligence and reading ability continued into the thread. Multiple posters referred to a provocative demonstration from the documentary in which a young woman with Down Syndrome read aloud from an advanced text with polysyllabic words. Although her reading was flawless, the tone and intonation she gave to the text as she read made it "... clear as a bell that she didn't understand it." Such an example demonstrates that some aspects of reading do not require even a normal level of intelligence and begets the question as to why a person with normal or better intellect could possibly struggle with reading? This creates a conundrum regarding how to properly evaluate struggling readers within a society that expects and values literacy competence.

While several posters only implied or talked around that question, Lester directly asked the question, "Can you be a poor reader and still [be] intelligent?" In pondering the answer to his own question, Lester postulated about what makes a person with dyslexia different and settled on "... a mild kind of 'brain damage' in specific regions of the brain responsible for processing sensory information." Furthermore, in discussing the possibility of advantages gained from having a disability, he suggested that such "subtle abnormalities" could lead to stronger abilities in other areas. He stated, without references for support, that people with manic depression are strong at word play and rationality and that "... a gifted blind person would have marvelous abilities in 'other' areas." Whether deliberately intentional or not, Lester's thoughts and choice of words clearly defined a notion of normal brain function and ability, separating people with RDs from the general community. He tempered this distinction and abnormality, though, by suggesting that members of this group

may also be better than others by exhibiting superior abilities in other areas. As an unintended consequence of such statements, a person with an RD who lacks such bonus abilities is thereby less valued and in a poorer state of existence. This is the heart of disability-related stigma. In all fairness, though, Lester did attempt to couch his discussion and express its limitations by noting that different cultures value and interpret differences differently, even stating positively about the values of respect, diversity, and awareness:

... as a society we need to understand what makes up a human being, and how we can all support each other with a diversity of neurotypical individuals.

Other posters did not hold such a position of respect. In particular, Henry directly challenged and dismissed the notion of reading disabilities:

Dyslexics are just *poor readers*. If you are from the lowest classes, or none too bright, you'd just be described by more traditional terms like "illiterate" or *crap at reading*. Dyslexia is just a term used to describe people who appear *too intelligent* to be such poor readers.

Henry's arguments are directly in line with the thesis of *The Dyslexia Myth* documentary, but he expanded the debate to include issues of income levels, class privilege, and fairness. In the discussion that followed his initial claims, he further articulated that being labeled "dyslexic" was a privilege afforded to "... middle class people who have parents that can afford the ridiculously expensive diagnosis required to be officially awarded with 'dyslexia.'" Henry's view of RDs is that as today's society values intelligence and literacy, it is unfavorable to perform poorly, therefore those with the means have found a way to avoid the negative association by formulating an excuse that can be purchased. Moreover, since remedial instruction and "good teaching works for most poor readers," Henry argued that spending more time, funding, and attention on dyslexic students denies help to lower-income struggling readers, thereby reinforcing society's class structure. These statements fit with Henry's other posts that he is a proponent of anarchism and believes that "... school is more about control than education."

Responses to Henry took several forms. Many posters challenged individual claims that he had made. For example, several posters asked for Henry to name the test that well-off parents pay for their children to take in order to gain a diagnosis. Henry evaded such inquiries by referring to the documentary's claim that no definitive test exists for distinguishing dyslexic readers from otherwise struggling readers. Despite several posters pointing out the contradiction of him claiming that there is a test but no real test exists, Henry failed to back his accusation of there being a diagnostic available for purchase by those with the financial means.

Others pointed out that Henry's claims of dyslexia diagnoses and class were false given the nature of the British public education system. Dylan stated that the

free state education system...diagnose dyslexia for bright children who struggle to read, for average ability children who struggle to read and, indeed, for those who could be outshone by

a 1W light bulb.

Neville also noted that, “you generally will have to pay for the tests but not the whole amount,” and that the tests are priced at “. . . a level to discourage every one from trying just in case. but still affordable.”

Others did comment that some financial issues were involved in diagnosing and receiving accommodations. Neville, in discussing testing costs, posted that teachers are responsible for identifying students who may be at risk for dyslexia. However, not all teachers are well-trained in this manner, a point also made by Kriscenski-Perry in regards to why RDs/LDs are often diagnosed more often in areas with higher economic levels (Krisenski-Perry & McColm, 2001). Mike did note that he was advantaged in that his school recognized his reading difficulties as more than just being a slow reader. He admitted that “. . . in other educational circumstances I would simply have been ignored as a thickie or labelled a lazy waster.” Fred, who disclosed as being dyslexic, stated that diagnoses and accommodations are not necessarily linked. Although he has passed some tests for RDs/LDs, his reading is only mildly affected and does not qualify for aid.

Further arguments and dissension were raised against another aspect of the claims by Henry and the documentary—that the diagnosis of dyslexia is an award and positive thing. The idea that receiving a diagnosis provides an explanation for poor reading performance and a ticket to free accommodations was directly challenged by several posters recounting their experiences living with dyslexia. Nick related how when he received private tutoring in some classes, he could perform very well. Those who knew he was dyslexic resented his good performance, and several teachers concluded

. . . concluded that I was very intelligent was very lazy (which was not true - it was hurtful. I wasn't lazy - I just didn't understand material in the way it was presented)

The poster Timothy also related his experiences with an early diagnosis of RD/LD. Placed into special education classes in first and second grade, he was regularly called a “retard” by regular school kids and repeatedly got into fights with those kids as he was “. . . was an ultrasensitive and highly intelligent child, and so I was keenly aware of the insults and cruelty.” Like the students interviewed by Edwards (1994), he kept the shame with him throughout his life. When he changed schools and was no longer in the special education classes, he kept his past a secret:

I never forgot where I came from. I always kept the shame and believing that I am stupid because of my special education experiences.

This only changed when he began to read about his disabilities and could form a positive identity around having a disability. As Timothy stated:

I feel the problem is that too many people think special education is for the mentally retarded and not for remediation at all. This is why a lot of people don't understand that people with learning disabilities can get their problems corrected

In replies to Timothy's posts, Neville agreed and recalled his own past with teasing and the emotional scars he carries to this day. Both he and Timothy explicitly reject Henry's and *The Dyslexia Myth's* claim that their diagnoses were completely advantageous. Although tutoring, accommodations, and understanding their struggles were all positive outcomes, the negative social implications of having RDs/LDs were far from insignificant.

2.3.7 Thread Summary

This thread is a rich congruence of discussions of reading disabilities, technologies, and the social aspects of RDs/LDs in today's society. Both people with and without RDs conversed in this thread. Although informative about computer choices and issues relating to reading and spelling, the airing of *The Dyslexia Myth* fostered a powerful debate about the existence of dyslexia and the implications it has in relation to access, fairness, and modern society's valuing of literacy. Awareness of how people differ was brought up and both appreciated and rejected.

3 Discussion

In these three discussion board threads, how people converse relatively unprompted about reading disabilities and technologies was observed. Various technologies were discussed. Notably, most of the ATs concerned spelling and writing and very few that provided mathematics support. The few mentions of text-to-speech were the only tools mentioned that support the reading process. This supports the concerns expressed in Chapter 3 that there is a lack of either awareness of or overall availability of ATs for supporting reading.

Each discussion thread provided insight and support to the value-stakeholder framework proposed in the previous chapter. With multiple examples, the value of literacy in today's society and how it shapes a community's notions of normalcy was emphasized. Issues of access and fairness arose as well. Respect and the lack thereof came into play in many ways. Most importantly, the voices in these threads were not only people with RDs/LDs. Family members, teachers, members of other disability groups, and general members of society all contributed.

Moreover, gaps were found in the value framework. Two values, awareness/connectedness⁹ and diversity, were identified as pertinent and influential in these threads. Todd's unawareness of the type of help and support he could receive, the instructors' appreciation in being reminded of access issues, and a shared viewing of a documentary fostered discussion of dyslexia all show that awareness of various issues shapes discussions and opinions among various stakeholder groups. Recognizing that people differ in important and sometimes meaningful ways also came through several times in these discussions. Sometimes this diversity was embraced; other times it was rejected as not even existing.

Some elements of the value-stakeholder framework account for these notions of awareness and diversity.

The notion of access is inherently about understanding and being aware of potential barriers. How the community defines normalcy is similarly influenced by notions of awareness and what forms of diversity are represented. One's sense of identity is also framed by diversity and awareness of how one fits within a community. Normalcy and diversity clearly exist in a paradoxical tension with each other. While normal suggests sameness, the goal of diversity can be thought of as everyone being different as the typical state.

The literature review in Chapter 6 that formed the basis of the value-stakeholder framework was not meant to be comprehensive or final. While this empirical investigation supported some of its elements, it was found to be incomplete. As is the nature of the integrative and iterative process inherent to Value Sensitive Design, additional investigations to explore awareness and diversity are warranted.

4 Chapter Summary

This chapter presented an empirical investigation of conversations involving reading disabilities and technologies. In order to observe public conversations unprompted by a researcher's inquiry, discussions from online message boards were analyzed. Three threads involving various stakeholder groups were described in relation to the value-stakeholder framework laid out in the previous chapter. The analyzed threads replicated and supported many of the themes and issues found in the initial literature review. Two values, diversity and awareness, were noted as potentially missing from the existing framework, suggesting further research directions.

NOTES TO CHAPTER 7

- 1 Unfortunately, the open posting policy eventually led to the demise of this discussion forum. With increasing frequency, more and more posts were generated by spam bots. Two years after this thread began, at least 90% of all threads were advertisements. Towards the end, there were some posts about how to salvage the community and its efforts at providing support to people with dyslexia, but by that time, most of the posters had already abandoned the board.
- 2 Todd, like all other names in this chapter, is not this poster's actual screen name. Instead of using abstract identifiers such as numbers or letters, real names were chosen to help emphasize that these case studies are about real humans. Pseudonyms were also selected to reflect the apparent gender of the posters.
- 3 As is to be expected, misspellings occur frequently in the posts. Whether this is due to many of the posters having reading disabilities or because it is casual writing on-line is unclear. Regardless, all quotes will replicate the original spelling and grammar errors but will no longer be indicated with a *sic*.
- 4 The software recommended by Marybeth was Maths2XL and was available at <http://www.maths2xl.co.uk/index.html>. As of August 31, 2010, this website no longer appears to be available.
- 5 The involvement of the amateur-radio-group newsgroup was minimal and limited to two posts that involved two posters from that newsgroup. While the first post appeared to connect to a discussion of difficulty with spelling, the reply was basically an insult rejecting the claim. To understand the nature of this debate, I looked into the newsgroup and found that at the time, there was an ongoing debate about people with RDs/LDs participating in amateur radio. Apparently, radio operators were required by federal regulations to use acronyms and codes on the radio, and people with RDs/LDs had extreme difficulty using them to the point that an ADA access complaint was issued. The result was a move away from the requirements, which led to dissension and complaints among the members of the newsgroup that eventually festered into name-calling and slinging of insults.

Thus, in the process of working on my dissertation, I determined that for a time, there was a notable and documentable hatred of people with dyslexia among at least one set of amateur radio operators. Aside from this footnote, though, I have not pursued this finding any further. For completeness, though, it should be noted that amateur radio operators are members of the affected/affecter indirect stakeholder group. They are affected when people with dyslexia participate in ham radio and has difficulty using acronyms and codes. Furthermore, through actions such as those demonstrated on this newsgroup, they exert a stigmatizing influence on the use of ham radio technology by adults with RDs/LDs.

- 6 For the most part, this discussion of anarchy was irrelevant to the focus of the study. Some elements

deserve some appreciation and mention. On one level, the debate provided insights into the political viewpoints of several posters, including Henry Score's. Several of the posters take and report their results from the political compass online assessment (<http://www.politicalcompass.org/>).

More generally, though, is what the conversation tells about the posters and their digital literacy practices. Most of the participants in the anarchy conversation seem to come from the uk-apple-group. They would call upon previous newsgroup conversations in indirect ways. Some would refer to a previous political debate in another thread. The link to the political compass was retrieved when one poster recalled an earlier newsgroup thread involving an online quiz about political beliefs, but it took another poster to find and post that link. Essentially, the conversational history shared by uk-apple-group community augmented and shaped their current dialogues.

7 Ghoti is a pathological example of how complex English phonology can be and is actually pronounced the same as the word 'fish' (Carney, 2001). The 'gh' is pronounced the same as in 'tough,' the 'o' as in 'women,' and the 'ti' as in 'nation.' Together, these produce the same phonology as the more common spelling of 'fish.'

8 Given that this dissertation was written five years after the documentary aired, it should be fairly obvious to the reader that the notions of dyslexia and reading disabilities have not been abandoned by educators, psychologists, etc. Still, *The Dyslexia Myth* did create some uproar when it was first shown. The Dyslexia Institute, the British Dyslexia Association, and the British Psychological Society all issued responses and critical articles after its airing (Cramer, 2005; Nicolson, 2005). These criticisms involved the documentary's narrow view of reading as only word decoding, the ignoring of research demonstrating genetic and neurological underpinnings of RDs, and the sole focus on how dyslexia manifests in young children learning to read.

Additionally, some parents of dyslexic children expressed concern that their child's accommodations and support might be taken away. This concern even worked its way up to Parliament. Lord Andrew Adonis, the education minister at the time, stated before the House of Lords that the documentary caused undue anxiety and dyslexia would continue to be recognized as "... a complex neurological condition and that people with dyslexia do need proper support to develop the reading, writing and comprehension skills essential to succeeding in school, in life and in work" (BBC News, 2005).

9 For the remainder of this dissertation, this potential value of awareness/connectedness will be referred to simply as "awareness." This may change in the future if a more appropriate term is identified.

CHAPTER 8

EMPIRICAL INVESTIGATION: LIFE STORIES OF ADULTS WITH READING DISABILITIES

The year was 2081, and everybody was finally equal. They weren't only equal before God and the law. They were equal every which way. Nobody was smarter than anybody else. Nobody was better looking than anybody else. Nobody was stronger or quicker than anybody else. All this equality was due to the 211th, 212th, and 213th Amendments to the Constitution, and to the unceasing vigilance of agents of the United States Handicapper General.

— *Harrison Bergeron* (Vonnegut, 1961/1988, p. 7)

This chapter presents the second of two empirical investigations conducted for the VSD analysis presented in this dissertation. As a complement to the observational study presented in the previous chapter, this investigation involved interviews with ten adults with reading disabilities about their literacy practices, usage of technologies, and the impact that having an RD has played in their lives. The first section provides some background on similar interview studies previously conducted that motivated this study. The study methodology is then described. Each of the ten interviewees are then briefly introduced. Various highlights of their interviews are analyzed, and the implications of these insights are discussed. A summary of the investigation's findings concludes the chapter.

1 Cases Studies and Semi-Structured Interviews

A major challenge in studying the social aspects of disabilities is the variance in those experiences. The age of diagnosis, the school one attends and its facilities, the response and support from family and friends, and ones interests and abilities all influence the impact that a disability may have on a person's life. With all of these confounding external factors, conducting studies that are readily and reliably generalizable is difficult. One research approach has been to embrace this complexity by using interviews to develop illustrative case studies of people with disabilities.

As mentioned in the previous chapter, an illustrative case study provides an in-depth exploration and description of a complex phenomenon (GAO, 1990). Collecting data for a case study can be performed

observationally as in the previous study on discussion forum threads, but another method is the semi-structured interview (Taylor & Bogdan, 1998). In such an interview, a set of prepared questions acts as a guide for the researcher. While the researcher will work to ensure that certain key questions are asked of every person interviewed, the semi-structured format also allows and encourages the researcher to interject with additional questions as appropriate. Importantly, however, the flow of the interview is meant to be primarily driven by the participant. The participant is asked to talk openly and freely about whatever he or she views as important and is thus encouraged to elaborate and even take the conversation in an unanticipated direction.

Semi-structured interviews have been used previously in several VSD studies (Friedman et al., 2002; Friedman, Kahn, Hagman, et al., 2006; Miller et al., 2007), and Kahn (1999) also provides guidelines for using semi-structured interviews to probe value issues. More importantly, though, is that illustrative case studies and semi-structured interviews have been used successfully in previous disability research. This method was used by Edwards (1994) to study the educational experiences of recent secondary school graduates with dyslexia and by Cory (2005) to study college students with invisible disabilities. These methodologies have also been used to study the influence of disability on various psychological elements, including queer identity and sexuality (Whitney, 2006), identity development and sense of self in people with dyslexia (Pollak, 2005), and reactions to dyslexia diagnosis and labeling (Riddick, 2000). My own study on the experiences of university students with disabilities taking computer science courses (Deibel, 2007b, 2008, in press) used this approach, and its set of interview questions were partially derived from the studies by Edwards (1994), Cory (2005), and Whitney (2006).

2 Study Methodology

Due to these previous successes in using semi-structured interviews to develop illustrative case studies on social aspects of disability, the same approach was used to conduct an empirical investigation on the role of technologies and literacy in the lives of adults with RDs. The goal of these case studies was to provide insights into the life stories of these individuals by asking them to discuss their experiences with school, work, and home life in relation to their reading disability. As suggested by the earlier conceptual investigations, the interviews emphasized the social aspects of managing their disability such as requesting accommodations, emotional reactions, and how, when, and if they decide to disclose their RDs to others. The interviews also inquired about what literacy practices the participants typically engage in as well as their use of both assistive and mainstream information communication technologies in their day-to-day lives.

2.1 Participant Recruitment

The participants for this study belong to the primary direct stakeholder group—adults with RDs. To ensure that the participants regularly engaged in reading tasks, emphasis was placed on recruiting individuals enrolled

in post-secondary education as the demands of attending school would presumably encourage reading. Calls for participation were distributed to local universities and colleges. Disability student services personnel were contacted at these schools and were asked to pass on the call for participation as well as help post provided fliers in public areas on campus. Fliers were also distributed at a local comic and animation convention due to my previous experiences of having met many attendees with RDs/LDs at such events. To encourage participation, a \$20 gift certificate was offered as compensation.

Upon expressing interest in participating in the study, the participant was first screened (via phone or e-mail) in order to meet the following criteria for inclusion in the study:

- The participant was at least 18 years of age. Some preference was given to recruiting younger participants as they would have lived more of their lives with disability legislation such as the ADA (1990) and IDEA (1997) in effect.
- The participant had been diagnosed as having a reading or learning disability sometime in the past. Participants did not have to provide evidence of this diagnosis but had to be capable of talking about how the diagnosis was made. People who self-diagnosed themselves as being dyslexic or having a learning disability were turned down for participation. If the person's learning disability did not impact reading, that person was also excluded from participating. For example, a woman with only dyscalculia (math and number related learning disability) did not qualify.
- The participant did not have a severe visual impairment. Common eye problems like nearsightedness, farsightedness, or astigmatism were allowed. This criteria helped ensure that any difficulties experienced with reading were due to the reading disability and not a vision problem.

Due to the small sample size and the low prevalence of reading disabilities in the population, no attempt was made to control for ethnicity, gender, or age distribution among the participants.

2.2 Data Collection

Once approved for participation, a meeting time and place was arranged for conducting the study. All of the data for this study was collected during these one-on-one meetings. Locations were chosen to be convenient for the participant and typically took place in a private area such as a study room in a library or an office conference room. The duration of these meetings was between 60–90 minutes. I wrote notes during each interview, and audio recordings were also made of the interviews.¹ These recordings were then later transcribed.

Moreover, the nature of this study was to be exploratory. In that sense, some preliminary analysis was conducted after each interview. The purpose of this analysis was to identify themes and topics not listed in the set of questions or value prompts but were brought up in conversation by the participants themselves. If such items were found, new questions and dialogue prompts were added in order to explore these topics with later participants. The interview process was thus in a state of continuous refinement.

Table 8.1: Semi-structured interview questions used for the life stories study of adults with RDs.

CATEGORY	QUESTIONS
Disability & Identity	<ul style="list-style-type: none"> - Describe yourself. How do you want people to see you? - Describe your reading disability. <ul style="list-style-type: none"> - What are its symptoms? - How and when were you diagnosed? - How has your reading disability influenced your life? - Is your disability part of your identity?
Life Experiences	<ul style="list-style-type: none"> - Describe your experiences <ul style="list-style-type: none"> - in K-12. - in college and / or graduate school (if applicable). - with employment (if applicable). - What, if any, positive aspects / experiences have you had regarding your RD? - What, if any, negative aspects/ experiences have you had regarding your RD? <ul style="list-style-type: none"> - Have you ever asked “Why me” in regards to having a disability?
Interactions with Others	<ul style="list-style-type: none"> - Discuss privacy and your disability. <ul style="list-style-type: none"> - Who do you tell? Not tell? - Why? - What has been the role of others in regards to your RD? <ul style="list-style-type: none"> - Family? Friends? Teachers and mentors? - Have you ever been treated with charity or kid gloves due to your RD? - How do you wish people to treat you regarding your reading disability? - How do you wish society / environment would support you in regards to your RD?
Accommodations	<ul style="list-style-type: none"> - Have you ever applied for accommodations? <ul style="list-style-type: none"> - Why or why not? - If yes, describe the application experience. - If yes, what accommodations did you request / receive?
Literacies & Technologies	<ul style="list-style-type: none"> - What reading tasks do you engage in on a daily basis? <ul style="list-style-type: none"> - Do you or have you ever tried to learn a foreign language? - What technologies do you use / have used in your daily life? <ul style="list-style-type: none"> - Texting? Instant Messaging? Message Boards? Chat rooms? Facebook? Blogs? Smartphones? Webcomics? Video games? MMORPGS? Wikis? - How do you wish technology would support you in regards to your RD?

2.2.1 Demographic Data

At the start of the interview, several elements of demographic data were collected from the participant. In addition to the traditional age, gender, and ethnicity, participants were asked to describe their educational history. This included the year they completed high school or its equivalent as well as a summary of any participation in higher education. For each stage of their schooling, the year, location, intended degree, and field of study were collected. Questions were also asked about their current or recent employment status.

2.2.2 Interview Questions

Following these demographic questions, the semi-structured format was described to the participant. As explained, the goal of the session was to have the participant talk freely and openly about their RD/LD and its influence on the participant's life, relationships, education, career, and technology use. It was also explained that to help direct the conversation, I would refer to the interview questions in Table 8.1. Covering all questions was not expected as the emphasis was on discussing the topics of most importance to the participant.

The interview questions in Table 8.1 were derived primarily from the protocol used in my earlier study on the experiences of students with disabilities (Deibel, 2007b, 2008, in press). Those earlier questions were edited in order to specifically focus on reading disabilities. Questions were also added regarding the participant's reading habits and technology usage. Overall, the questions cover the five high-level topic categories as shown in the table.

2.2.3 Value Prompts

After conducting a pilot interview, it was decided that a small validation exercise for the value framework needed to be added at the conclusion of the interview. Using the list of values in Table 8.2, the participant was given one term at a time and asked to perform a free association with the word and provide a definition relevant to his life and experiences. A brief discussion typically followed each response, and sometimes additional questions were asked. For example, for the term "community," the participant was asked to list communities in which he belonged. If neither the disability nor the RD community was mentioned, this omission was broached to the participant.

The list in Table 8.2 is a conglomeration of the various values suggested in the iterations of the open coding used in the theme-value literature analysis. As the online discussions study was being conducted in parallel with this study, the value of "awareness" was included here. The list is in alphabetical order save

Table 8.2: Ordering of the value prompts used in the life stories study of adults with RDs.

ORDERING OF VALUE PROMPTS	
1. Access	9. Identity
2. Accountability	10. Literacy
3. Autonomy / Empowerment	11. Privacy
4. Awareness	12. Pride
5. Charity	13. Respect / Courtesy
6. Choice	14. Trust
7. Community	15. Normalcy / Ideal
8. Fairness	

for “normalcy/ideal.” These terms were saved for last in order to not have these important terms influence responses to the other values. One goal of this activity was to receive feedback from the direct stakeholders about the various value terms that had been considered. Participant definitions would be used to refine the value working definitions as well. Comparing the associated responses with the rest of the interview content was another goal. A participant may show a disconnect between her definition of a term and her actions. For example, she might state that normalcy is unimportant in her life but also describe multiple instances in which she went out of her way to hide her disability from others.

2.3 Analysis

As mentioned previously, some preliminary analyses were conducted between interviews as a means of refining the exploratory nature of the life stories study. After completing the interviews, formal analysis began on the audio recordings and written notes collected during each participant’s session. These were then transcribed and digitized for easier analysis. Per the requirements agreed upon with the University of Washington’s Institutional Review Board for conducting this research, the transcripts and notes were anonymized. All identifying information, such as names, locations, and schools, were edited out and replaced with pseudonyms.

Once this was completed, the original analysis plan was to create detailed participant profiles like those produced by Edwards (1994) and Scherer (2005). Such in-depth case studies would be used to convey the complex social aspects of reading disabilities that shape the disclosure practices, identity management, technology choices, and navigation of normalcy experienced by adults with reading disabilities. Although developing these profiles is planned for future publication, a smaller analysis was instead conducted for the purpose of this dissertation. This analysis focused on insights from the value-stakeholder framework. Emphasis was placed on characterizing the literacy and technology practices of the participants by using the interview questions to identify relevant sections of the transcripts. An open coding approach was also used to identify discussions that involved the values of normalcy, privacy, identity, and community. Instances of other values were noted as well, but these four were chosen due to their direct roles in social interaction.

3 Participant Overview

Table 8.3 lists the nine participants in the order in which they were interviewed for the life stories study. The table itself lists ten participants, however, as one participant’s interview transcript (Alan’s) from my earlier study (Deibel, 2007b, 2008, in press) was included in in this empirical investigation. As the interview protocol from that study directly influenced the questions in Table 8.1, Alan’s session can be viewed as a preliminary interview trial. The questions were later refined for the second pilot interview with Kellie, which led to the addition of the value prompt activity in Table 8.2.

Table 8.3: Overview of participants in the life stories of adults with RDs study. Table contains demographic information, age of diagnosis, high school graduation year, and higher education and employment history. Abbreviations in table: HS (high school); PNW (Pacific Northwest, USA); SE (Southeast, USA); CA (California); UK (United Kingdom).

Name	Age	Gender	Ethnicity	Diagnosed	HS	Higher Education	Employment
Alan ^a	26	M	Caucasian	6	2001	Visual Arts (AA), PNW community college, 2005 Visual Arts / Disability Studies (BA), PNW public research university, 2008 Applied Visual Arts / Graphic Design (BA), PNW public research university, 2012	Graphic designer at universities attended
Kellie ^{bc}	29	F	Caucasian	7–8	1998	Comic book art (BA), SE private art college, 2002	Webcomic artist
Tara	48	F	Caucasian	9–10	1979	PNW community college, 2002 Psychology (BS), PNW public research university (junior 2010) Intention to continue on to graduate work	Full-time student Previous: Horse therapy with abused children
Harold	24	M	Pacific Islander	21–22	2004	Communications (BA), PNW private religious university, 2010	Intern at local TV station
Ashley ^c	31	F	Caucasian	28–29	1997	13 years struggling in college with a major in Nursing Political science (BA), PNW private religious university, 2011	Nanny
Clarissa	18	F	Caucasian	10	2009	Journalism, PNW community college (freshman 2009)	Full-time student
Calvin	35	M	African-American	28	1993	General studies, CA community college, 1993 English / Technical writing (BA), CA state university, 2001 Diversity & contemporary writing (MA), UK public university, 2006 Computer networking certificate, PNW community college, 2010	Currently unemployed Previously a technical writer at a finance company
Darren	31	M	Caucasian	8–9	1996	International relations (BS), NE private research university, 2001 Level 1-2 teaching credentials, State of California, 2008 Computer science (BS), PNW private university (started 2010)	Full-time student Previously a public school teacher for students with LDs
Emily	22	F	Caucasian	7–8	2006	History (BA) / Education (minor), PNW public research university, 2010	Academic coach/mentor for local school district
Nigel	24	M	Caucasian	6–7	2004	Computer game art (BA), UK public university, 2008	Freelance 3D artist

^a Participation from Deibel (2007b, 2008) included in this study.

^b Pilot interviewee. Did not perform value prompt task.

^c Interview not recorded.

3.1 Biographical Sketches

A viewing of Table 8.3 reveals that the participants exhibit a wide diversity of traits. These five men and five women range in age from 18 to 48 (avg. 28.8). They have pursued or hope to pursue different fields of study and different career paths. Their experiences with their disabilities also varies in multiple ways. Although space prevents fully conveying their experiences, the following brief biographies highlight key elements of their lives.

3.1.1 Alan

As mentioned previously, Alan was a participant in my earlier study on the experiences of students with disabilities in computer science courses (Deibel, 2007b, 2008, in press). Born with an LD significantly affecting his short-term memory and reading/writing speeds, he is fortunate to have an exceptionally supportive family that helped him by reading texts aloud and being active advocates of his right to receive an education. Unfortunately, he has also faced challenges to this right. Alan was once denied membership (temporarily) to an academic honor society because he used accommodations in his classes. Several instructors have expressed to him that his disabilities made him incapable of achieving his goals and was even told that he could not fulfill the duties of a graphic designer despite having a resume demonstrating successful internship work. Prevented from earning a degree in graphic design at one university (instead earning one in visual arts), he decided to enroll at another university with a graphics design department that is less close-minded. Facing and overcoming these challenges have galvanized Alan into being an active advocate for people with disabilities. He regularly volunteers in mentoring efforts to help disabled students transition from high school to college.

3.1.2 Kellie

Sharing Alan's interest in art is Kellie. Kellie is a successful webcomic artist and has been producing a popular autobiographical webcomic for over nine years. One of five siblings in her family with learning disabilities, she was raised with a strong work ethic and that her disability was never an excuse. This meant, as she said, many a late night crying at the kitchen table trying to get homework done. Developing alternative strategies and learning to advocate for her learning needs, she persevered and became an avid reader, albeit taking what she perceives to be twice as much time compared to others. She even went to art college to study the art form that got her into reading—comic books. As her RD significantly impacts her spelling, her disability often becomes a visible component of her comic art whether she intends for it to or not.

3.1.3 Tara

Tara, the oldest of the participants, is currently embarking on a major career change by returning to college to earn a degree in psychology with an intent on doing masters level work related to educational psychology and LDs. This desire is a reflection of growing up with a significant RD and ADD/HD. Essentially unable to

read until fourth grade, Tara only picked up literacy skills after a year of dedicated, focused tutoring. Despite making tremendous gains in her reading ability over that year, her academic performance varied through the remainder of her years in school. Due in part to undiagnosed ADD/HD, school failed to offer the direct feedback and ongoing motivation that tutoring had provided. On her own, though, she could at times personally motivate herself. Loving to read historical and fantasy novels, Tara can immerse herself in a book over several weeks. In doing work where she can help others, such as tutoring or animal therapy with children, she taps into a deep desire to help others enjoy learning and persevering through difficulties. This is the driving force behind her enrolling in college at her age. Although she admits that her confidence abandons her at times, Tara's personal mantra that she wants to share with others is "I don't give up."

3.1.4 Harold

Unlike the previous three participants, Harold was not diagnosed with a reading disability until he was in college. Never an avid reader, he stopped reading books on his own in fifth grade, preferring shorter news and magazine articles. At school, he typically showed an inconsistent strong performance on assignments but failing examination scores. Harold never considered these as possible signs of having an RD until one of his professors suggested he talk with the university's disability services. With their help, he underwent psychological evaluation which revealed several impairments that make reading comprehension a slow, error-prone process. While he can usually get the high-level, main ideas of what he reads, he struggles to get the details and notice the intricacies in a text. As it was only in college that such deep-level comprehension was regularly expected of him, his reading disability went unnoticed until then. This new diagnosis led to changes in Harold's life such as developing better skill management and using accommodations such as books-on-tape. Quite happy that the diagnosis has made it possible for him to finish college and go on to a career in television news, Harold does not go out of his way to tell others about his RD. While he is willing to let his successes make him stand out, he does not want his disability to do the same.

3.1.5 Ashley

Like Harold, the next participant was not diagnosed with having an RD until attending college (the same one as Harold). Unlike him, though, Ashley struggled for thirteen years trying to earn a degree in nursing. Always a slow reader, Ashley eventually found the heavy reading loads, poor grades, and repeated failures to be too much and suffered an acute stress attack. Working with a counselor, it was determined that she had an RD and ADD/HD. Moreover, it became obvious that finishing her nursing degree was too challenging and stressful. This hit Ashley hard, as she considers herself a person of strong Christian faith and finds great strength in serving and helping others. Nursing would have allowed her to combine earning a living and serving others. Fortunately, Ashley was able to find an alternative direction. Earning a degree in political science, she has focused on global development and non-government organizations. With the help of accommodations, she has

been able to finish her degree, including several terms doing international studies in Africa. Still, she avoids letting her RD define who she is. She has found that many of the other people she has met who also have ADD/HD or RDs let the disability become the dominant aspect of their identity. Ashley does not want to limit herself to such a “disability box.”

3.1.6 Clarissa

Recently graduated from high school, Clarissa is currently enrolled in a community college and hopes to transfer to a state university’s journalism program after a few years. Excited about being on her own for the first time, she avidly approaches new challenges in life and considers herself to be a fast learner. Expressing and demonstrating her learning, however, is not always easy. Having both dysgraphia and mild dyslexia, her spelling and writing skills are poor. Teachers have ripped up her written homework for being illegible, and friends have mocked her notes and writing. Mistaking letters or flipping word order has also led to some embarrassing misunderstandings when reading. Despite these negative aspects, Clarissa is fairly open about her LDs and willingly tells others about them. She enjoys reading, but finishing a book that becomes boring is often a problem. Another challenge she is facing is in requesting her own accommodations. At the time of the interview, she was currently ineligible for receiving services until she updated her disability documentation. When asked about what accommodations she expects to receive, she included receiving extra time on assignments. When mentioned that this accommodation was uncommon at the college level, Clarissa did not express any concern.

3.1.7 Calvin

Calvin is the third participant in this group whose RD was not diagnosed until adulthood. In his case, he was enrolled in a writing masters program in Britain when instructors noticed that his writing had structural problems they commonly saw in their dyslexic students. Subsequent reading evaluations found evidence of slow reading, comprehension difficulties, and problems with linear tasks such as writing. Calvin exhibited these traits throughout his time in school but were not caught. He suspects that race played a role in his RD not being caught earlier in that the schools he attended were typically 80-90% white students. His struggles academically were stereotypically accepted, even by Calvin himself. Being diagnosed with an RD, however, allowed him to be less critical of himself and to challenge lowered expectations due to his race. Importantly, he does not view the RD as an excuse for failure but rather a clarification of what problems need to be addressed. Not everyone in his life has shared this view, though. Several people have questioned why he went into technical writing despite having a reading disability. When he told a previous boss about the RD, she decided that he did not belong in his job and harassed him continually about it to the point that the human resources department had to intervene. Because of this, he has decided to never again inform employers about his RD.

3.1.8 Darren

Darren, although born in America, spent a portion of his early childhood, including his first two years of school, in Israel. He was taught in Hebrew but also tutored in English. When he moved back to the United States at age 8, he was struggling with reading in English. Although they first ascribed these challenges to his earlier multilingual education, his teachers soon realized that he had a reading disability. When he reads, Darren primarily just scans for the main ideas, skipping over details as a means of compensating for his slower reading speed. He spent two years in a special school for LDs and was then mainstreamed into a regular school where he received an hour of specialized tutoring each day. His time at the special school was not great. Many of the students had severe behavioral problems, and the teachers emphasized general life skills and not future academic success. He appreciated being mainstreamed, although being excused to attend tutoring did make him noticed. Fortunately, he found good friends that accepted him, although several did express confusion as he did not appear to be the stereotypical special ed kid. In high school, the school cut the LD tutoring program, leading to academic struggles, poorer performance, and a feeling of being abandoned by the school system. When he enrolled in college, he used accommodations but graduated with grades too low for what he needed to attend law school. Instead, he opted to go into teaching and focused on students with LDs in an inner city school. Calling on his own experiences in such classes, he deliberately chose to focus only on the kids who showed signs of wanting to be taught, offering only marginal support to the rest. He decided to return to college for a degree in computer science with a long-term plan to develop educational technologies that would help capable but struggling students like he was.

3.1.9 Emily

Also interested in teaching is Emily, a recent graduate with a bachelors degree in history. With her tremendous interest in reading, she has self-admittedly come a long way from the girl who did not learn how to read until fourth grade. First diagnosed with dyslexia in first grade, she spent the next 8 years working with a private tutor. Speaking highly of her time working with Ms. Madison, she shared how the tutoring helped her develop personal strategies for learning. She still deals with poor spelling and found it hard to keep up with reading in her college courses, often only completing two-thirds of what was assigned. Due to her K-12 education in a small, private religious school, Emily found the transition into college challenging at first. She had no previous experience in requesting accommodations and did not even know that disability services were even available. Still, she persevered and completed the courses she needed to eventually become a high school history teacher. In talking with Emily, her dedication to teaching comes through clearly. Every night, she spends at least 30 minutes reading before bed, usually books on education or teaching. She speaks highly of her mentoring and tutoring efforts with a local school district. She tries to pass on the important lesson that it is okay to struggle. Sometimes she will mention her RD, but mainly only to students she knows also have an

RD/LD. Otherwise, she does not go out of her way to tell others. Emily is not ashamed of it but also does not see the need to share that fact openly.

3.1.10 Nigel

The last participant interviewed is Nigel, a freelance 3D computer artist. Originally from Britain, he now lives in the United States with his American wife. When describing himself, he talks about creativity and his passion for games but also mentions his poor short-term memory. This particular symptom of his dyslexia is the only one he mentions openly, for otherwise he remains mum about his dyslexia. This omission is not due to embarrassment about his past as he instead feels quite lucky in many regards as to how his RD has impacted his life. Diagnosed early in school, he was sent to a private school specializing in the education of students with dyslexia.² Nigel greatly values the specialized instruction he received at that school. Due to changes in his family finances, his parents could not afford to send his brother (about eight years younger and also dyslexic) to that private school. Nigel shared how he feels his brother has fared less well due to the lack of specialized instruction. Moreover, Nigel sees himself as better off than many of his peers from that school. Many of his friends also had dyspraxia, and their clumsiness often signified disability to others. Nigel recognizes that it is easier for him to hide his dyslexia from others and just pass as a “normal bloke.” He also chooses not to tell employers or coworkers and will sometimes report less hours at work if he feels he spent too long struggling on a job. To Nigel, dyslexia is not the core of his identity, but he also admits that he has no conception of life without it. Being happy in life is how he defines success, and he is greatly appreciative of the help he has received from others, especially the government services for dyslexic students available in his home country of Britain.

4 Interview Highlights

As is suggested by the above biographies, the interview questions and value prompts produced a bevy of data and insights into the lives of these adults with reading disabilities. For the purposes of this VSD study, the following section presents several relevant highlights from the interviews.

4.1 Literacy Practices

One clear conclusion from the interviews is that these individuals do read. Since most of the participants were currently enrolled in university courses, this is unsurprising. Tara and Darren both mentioned that all they had time for were their course readings and textbooks. Other participants went into detail about the enjoyment they gain from reading for pleasure. When asked to describe himself, the first thing Calvin stated was “I love to read.” Since the purpose of the interview may have primed him to mention reading, he was then asked how he would introduce himself if he was meeting someone casually at a bar or party. His response was still to mention his love of reading and his interest in discussing the politics and history he learns from his reading.

Clarissa and Emily similarly discussed how they frequently read multiple books at a time and love to receive new recommendations from friends. Kellie related the amusing anecdote of the time she started reading a new fantasy novel from one of her favorite authors. She started reading at breakfast and only realized that she had spent the entire day engrossed in the book when her boyfriend returned from work at dinner time.

Not all of the reading occurred with books, however. Ashley, also busy with her classes, only made time for reading the newspaper. Harold similarly preferred to read news articles, often going online for them. Nigel follows several blogs on a daily basis and may occasionally read books from his favorite author.

That these participants engage in and enjoy reading beyond what school and work require is of great significance. Studies of lifelong reading habits have demonstrated what is known as the Matthew effect: the rich get richer and the poor get poorer (Cunningham & Stanovich, 1997). This effect describes how the gap in reading performance between poor and good readers grows over time. People who read frequently when younger will continue to read more as they grow older while those that resist or avoid reading when younger will continue to read little as adults. These findings are strong motivators for employing early interventions when a child struggles with learning to read.

In the case of people with RDs, a reasonable expectation would be that the early, often emotionally frustrating, struggles with learning how to read would result in disinterest with reading in adulthood. In a way, Harold is an example of this outcome. Aside from what school required, he stopped reading fiction in fifth grade. On the other hand, Kellie, Calvin, Cassie, and Emily go against this prediction. All reported pains and delays in their early school years but also readily conversed about the enjoyment they find in books. Although they admit that reading can be a slow process, they still do it on their own volition.³

4.2 [Assistive] Technology Usage

Since the participants engage frequently in reading, this suggests that there may be some interest in technologies that support the act of reading. However, assistive technologies were rarely mentioned in the interviews. Several of the participants were unaware of what ATs were available for RDs and could only suggest online dictionary websites and spellcheckers when pressed for examples. Tara and Calvin volunteered for the study hoping in part to learn about computer tools that might help them.

4.2.1 Text-to-Speech

In regards to text-to-speech, several participants expressed significant problems with using it. Darren flat out stated that he had no patience for TTS systems as they did not mesh well with the skimming practices he had developed as self-accommodations for his RD. Tara had tried using talking books that she got from a recording service for the blind, but she found that her attention and comprehension were worse than with regular text. Nigel admits he never explored the potential of TTS, partly due to his college courses being more technically focused. Emily chose not to look into TTS as she knew she benefited from the visual aspects of text.

The artificiality of computer-generated speech was highlighted as a problem. Harold and Ashley used audiobooks for their course readings that were produced on a weekly basis from their school's disability services office. Both had looked into the TTS option, but, since their school provided audiobooks with such efficiency, they preferred hearing the human reader. Harold did use TTS software for small tasks at his intern job at the news station when necessary. Alan, having been helped by his family reading aloud to him, also preferred audiobooks over TTS as he was accustomed to the nuances of human speech when following along with a text. However, his school's disability office was not always as timely in providing audio versions of his course readings, due in part to delays on the part of his instructors. Constantly falling behind in his classes due to these delays, he opted to use TTS in his last two terms of school so that he could graduate on time.

4.2.2 Color Overlays

Only two participants mentioned using color overlays—Calvin and Nigel. This is not that surprising given that only these two participants ever requested accommodations in Great Britain. As mentioned in Chapters 2 and 3, overlays have a controversial history. Although they are accepted more openly in Britain (Evans, 2001), their usage is not as encouraged in the United States (G. J. Williams et al., 2004).

Calvin and Nigel both mentioned the usefulness of color overlays but at the same time did not rave about them. Nigel remembered using an orange-tinted overlay for a time in his schooling but could not recall when he stopped using it. Calvin also said that using a green overlay did enable him to read for longer stretches of time and reduced the frequency of needing to take breaks from reading. In particular, he found that putting one over the screen of a computer was really helpful, but he kept forgetting to use it. Permanently attaching the overlay was not an option as he shared the computer with his wife and because not every web site or software application worked well with that tinting.

4.2.3 Other Technologies

While they might not have used many assistive technologies, the participants did utilize many types of mainstream digital technologies. For example, all participants had cell phones and used them frequently. Although Darren stated that he abhorred texting, the others all texted on a regular basis with Harold and Clarissa both confessing to texting perhaps too much. Ashley stated that she prefers texting over talking on the phone as it gave her more time to formulate her responses. Some problems were expressed with texting, however. Most avoided using text speak (e.g., “idk” for “I don't know”) as they had enough difficulties with spelling regular English writing correctly, although Ashley attributed her avoidance due to her age. The T9 predictive text technology used for making texting more efficient was also a source of disdain. Emily purchased a phone with a full keyboard in order to avoid using T9. Calvin admitted with pride that he had finally mastered using T9 after two years of struggling with it.

Use of different technologies on the Internet varied in regards to whether it was used for reading or writing.

Several individuals would regularly read short articles on the web from blogs or news sites. Nigel, for instance, follows several blogs, although he rarely contributes any comments. Facebook was also checked frequently, although both Clarissa and Darren admitted that they preferred to read and not post messages. Clarissa attributed this hesitancy in part due to her poor spelling and writing skills, a response similar to a dyslexic respondent in the study by March and Fleuriot (2006).

Instant messaging, chat rooms, and discussion forums were also generally not utilized that often. The speed of real-time chatting imposed the challenging expectation of needing to respond quickly. Tara does sometimes use chat to keep in touch with one of her children who is currently in Europe, but she does prefer to use voice chat when possible. Kellie in particular found the amount of information available online as overwhelming and avoided it as much as possible.

A few participants also commented about their experiences reading from computer screens. Kellie noted the experience is very different and that she needs the tactile experience that comes from a printed book. Calvin admitted to often becoming lost due to the linked document structure on websites. He also recalled trying to use a Kindle (Amazon, 2010) but something about the electronic ink display caused eye strain. To help her read certain websites, Tara will adjust the default fonts her browser uses.

4.3 Value Instances

As part of the analysis of the transcripts, particular focus was placed on discussions concerning values of normalcy, privacy, identity, and community. Between the interview questions and the value prompts, the participants readily and repeatedly discussed these values in relation to their interactions with others. Hiding or telling others about their RDs, navigating how to request accommodations, and defining one's sense of self were all topics of deep discussion.

4.3.1 Normalcy, Privacy, and Identity

As listed in Table 8.2, the last term mentioned as a value prompt was normalcy. Of the eight participants who were asked to define and reflect upon that word, all eight essentially asked the same thing: what is normal? Darren defined it as something defined by television. Nigel felt that normal is unimportant and boring. Emily stated that she would not want to be normal. Calvin distinguished normalcy from the idea of norms. To him, a norm is an impression of what is typical for a population, and norms vary across contexts and points of view. Ashley insisted that society pays too much attention to what is normal.

At first glance, these responses suggest that normalcy is not a value embraced by these individuals. While this is very likely true in terms of their personal value systems, they frequently discussed the negative aspects of their disabilities throughout their interviews. Tara talked about her need to defend her struggles in life, feeling ashamed about her past mistakes. In past moments of frustration, Ashley has expressed a desire to be like everyone else. Clarissa and Emily mentioned times in which their classmates and even their close friends

would openly mock the messy handwriting, error-filled spelling, or difficulty reading aloud due to their RDs.

The participants also discussed making careful actions regarding the privacy of their RDs. Alan usually feels comfortable telling other students and his instructors about his disability. However, he avoided telling the undergraduate teaching assistants in the computer animation course he was taking. The class had a reputation of being difficult, and these teaching assistants were students from previous offerings. Alan was put off by the “bravado... we made it through this class” attitudes they exhibited. Those attitudes, he felt, belittled his own struggles in the course. Alan did not want his disability to provide the TAs with another reason to flaunt their egos at him. In reflecting on normalcy, Nigel similarly commented that he wants others to judge him on his personality, not his disability. Earlier in the interview, he adamantly stated that he would not use a technology at work that would identify him as being dyslexic. When you tell someone you have dyslexia, you end up being treated differently. The other participants expressed similar perspectives. Harold noted that society does not like it when a person is singled out by some means. After his negative experiences with a previous boss, Calvin has decided to never tell an employer ever again about his RD. These deliberations about whether or not to disclose to others reflect a recognition of being different from others and that sharing this difference comes with negative consequences.

A striking example of this attitude is seen with Kellie. The impact of her RD on her spelling is frequently seen in her comics. Readers would often comment on the errors. Some did so nicely, but others would do it in a mocking manner. As her comic gained in popularity, the comments increased to the point that she felt compelled to post an explanation of her frequent spelling mistakes (excerpted below):

yes I fucking know I can't spell. Do you think that it could POSSIBLY have escaped my notice after 12 YEARS of special education...the CONSTANT reminder and LIFE LONG ridicule SURE AS HELL keeps me fucking awair!! And no I'm not FUCKING OVERREACTING!!!

So if anyone wants to tell me that I can't spell and to enlighten me on the wonders of a new and fun invention called a dictionary or spell check then I would be overjoyed to tell them to GO TO FUCKING HELL AND DIE IN A VAT OF PIG SHIT.... No, I'm not bitter. I've just had to put up with this shit for my WHOLE LIFE and I've sat there and taken it...

words of condolence, apology, ridicule or support are unwanted and unneeded

The visceral emotion in this message cannot be overlooked. When asked about this statement, Kellie recalled the tremendous catharsis of writing those words and still believed firmly in what she wrote. She talked about how she did not know which was worse: the mocking e-mails or those saying that they felt sorry for her having dyslexia. The latter brought back memories of the struggles, shame, and embarrassment she has felt due to her disability. Still, she recognized some value in being as visible as she is. At comic conventions, readers will come up and tell her that they are dyslexic too and that they are grateful for success. Kellie comments that she

has become an advocate because she cannot hide so readily.⁴

Similar examples of violating one's privacy and normalcy were echoed by some of the other participants. Nigel mentioned that there are times when he tells others. While such occasions include when he is struggling and needs help, Nigel noted that he will speak up if somebody is talking negatively about people with dyslexia. At that point, he will offer himself up as a person with dyslexia who is doing quite fine in life. As mentioned before, Emily will tell a student of hers about her RD if the student also has an LD. In doing so, she wants to demonstrate that the disability has not held her down in working towards her goals in life. Similarly, Tara empathizes with others who face struggles in school and this has motivated her to help kids learn to believe in themselves. As part of his ongoing disability advocacy efforts, Alan also readily speaks up when he comes across an instance where a person with a disability is being treated unfairly.

Overall, there is a disconnect between the participants' views on normalcy and their actions that beget privacy and hidden disability identities. Unfortunately, this disconnect was not recognized until after the interviews were completed, and thus the reasons for it were not adequately explored. One possibility is that because of the suffering they receive from society's treatment of people who are different, these individuals willingly or forcibly break with their personal value systems. Another explanation for this disconnect is that the participants may have not been reporting their personal views of normalcy and were instead reflecting how society at large views and defines normalcy. Our society has become increasingly more aware and embracing of diversity, going as far to say that we are all the same in that we all different.⁵ The participants may have been reflecting this recognition of social diversity in their responses. Paradoxically, though, saying being different is common technically defines normalcy as a lack of sameness despite the more common connotation of normalcy as sharing sameness.

4.3.2 Community and Awareness

Given its role in the diffusion and promotion of AT usage, the value of community in the lives of participants was an important focus during the analysis process. When asked to define community, the eight participants generally responded with similar meanings, essentially viewing community as a group of people who share a common element such as a place, purpose, history, or knowledge. Harold and Calvin emphasized having aspects in common such as heritage or neighborhood. Clarissa and Nigel emphasized how people in a community help and support each other, and Ashley further emphasized this helping aspect by stating that community is "... people who surround you during trials [in life]."

These definitions were also reflected in the communities in which they considered themselves members. Emily, Ashley, and Calvin talked about their churches. Those currently enrolled in school mentioned their classmates as forming a community, although Ashley felt isolated a bit due to being ten years older than most of the other students. None of the participants, however, mentioned the disability or RD community as one

to which they belong. When this was pointed out, the participants explained their omission. Nigel stated rather fondly that he was a member of such a community when he attended the private school for dyslexics. Nowadays, though, he knows the RD community exists but chooses not to be involved. Calvin echoed a similar view and compared it to his affiliation but lack of involvement in the African-American community. Emily stated that she only knows three other students with dyslexia at her university and that they are at best passing acquaintances. Two participants spoke negatively of disability communities. When he thinks of the idea of an RD/LD community, Darren thinks of the “bums in high school” that were always getting in trouble, and he views it as a good thing that he moved away from his hometown. Ashley mentioned again her interactions with an ADD/HD support group in which she found that the members had let their disabilities become the dominant factor in their lives. She would probably say the same about Alan due to the prominent role that disability advocacy plays in his life. By focusing so much on disability, Ashley feels that these individuals “box” and remove themselves from larger aspects of society.

The reason behind Ashley’s distaste for such isolating behavior can be seen in her responses to the prompt for awareness. She considers awareness to be about reaching outside one’s self in order to learn about what is around and available. She emphasized how particularly important awareness is for people with disabilities so that they can learn how to address their disabilities. Other participants connected as well the notion of awareness to community. Tara’s first response to the prompt of community was to comment, “Really really important. . . [I] wish they knew how important at times.” Minutes earlier, she had discussed the importance of empathy and being aware of other people’s experiences, needs, and feelings. Emily herself mentioned in regards to awareness that disabilities are not spoken of enough by general society.

These comments about community and awareness reveal an observable tension between what was said earlier about normalcy, privacy, and hiding. Emily flat out states that disabilities should be spoken of more regularly but also admits to not telling others unless there is an opportunity to connect to someone else who also has an RD/LD. Seeking out help in the form of accommodations requires a person to stop hiding and expose themselves to the opinions and views of the community. Importantly, there are implications of a community that readily offers help to its members. In a community that says, “We help people who need help,” the person being helped is, in some ways, removed from belonging to the community (the helpers). The normal action of this community is to provide, not receive, help, thereby separating such individuals and marking them as distinctly different. Moreover, wanting to help others is a desirable and positive trait, thereby making being normal a worthwhile goal, ergo encouraging people to be on the giving end of help.

Awareness among members of a community can provide a means of addressing this tension, however. Using Ashley’s and Tara’s point of awareness being about empathy and reaching outside one’s self, one can see that every person requires help at times. A community can shift what is considered normal by embracing

this and saying, “Every one of us at times needs help, and we as a community will provide that help.” With such a social perspective, asking for help would likely incur less risks and threats to the requester’s sense of identity and belonging.⁶

4.3.3 Accommodations and Fairness

Some help does come from the use of accommodations, however. All ten of the participants used some form of academic accommodations in their college courses. As previously mentioned, there was some limited use of audiobooks and overlays. Otherwise, most of the accommodations did not rely on advanced technologies: extra time on tests, notetakers, and private rooms for test taking. Some of the participants were also allowed to use a laptop instead of writing out answers by hand, and in Nigel’s case, he received a personal laptop through a Disabled Students Allowance grant from the British government.

The participants’ views and actions related to accommodations reflect several values. In responding to the value prompt for “access,” Emily made it clear that accommodations should only be provided when she asks for it. It is her choice and decision as to when she needs it. Alan takes responsibility every term to contact his upcoming instructors about his disability and accommodation requests. Since he uses books-on-tape, advance lead-time is needed to make audio versions of the course text. For the computer animation course, however, the instructor made a last minute change in the course text. This led to Alan falling behind in the course and growing increasingly frustrated with the lack of respect and support the instructor was giving him. Eventually, his parents stepped in after seeing the anger and stress he was experiencing, which led to this 26 year old young man questioning if he was really capable and empowered enough to act on his own behalf.

Darren in particular articulated several fine points about having access to accommodations. As one of his accommodations is to take exams in private, his classmates quickly notice that he is absent during texts. When they ask, he explains to them about having an LD and receiving accommodations like extra time on tests. Some will joke that they would like that advantage as well, to which Darren sarcastically replies, “. . . if you want to struggle for twenty years with a learning disability.” He recognizes that some people question the fairness of giving accommodations. In response to the concern that some students may be lying about an RD/LD in order to receive the advantages that accommodations like extra time can provide, Darren questions why this is viewed as a problem:

I don’t see what we are losing by all this. If i get additional time and i do well, I have learned the stuff. I can demonstrate my knowledge of the material. Isn’t that what tests are really about?

You’re not making the tests shorter. You’re not testing me on material that’s easier. . . . The reality is that. . . 90% of Americans would fail. The reality is that giving me that extra hour of time is what helps me do it.

Darren’s argument directly challenges the concerns expressed by Zirkel (2000), Leef (2010), and Vickers

(2010) about the fairness of providing accommodations to students with LDs. Calling on his experiences as a teacher, he is arguing that the time component of these tests is irrelevant. Leef does raise the concern that extra time to make a decision is not a viable possibility for an emergency room doctor. However, Darren is talking about courses such as Calculus II and Freshmen English. These classes do not have the same time-sensitive risks as found in an emergency room. Fairness, as Darren suggests, requires a more nuanced perspective.

Unfortunately, Darren also lends some credence to the concern that some students do cheat the accommodations system. One of his classmates was struggling with passing a math course due to the combined pressures of memorizing formulas and not thinking efficiently enough during an exam. When this friend asked Darren about how to get accommodations, Darren provided advice as to how the friend could demonstrate a learning disability. When taking the neuropsychological batteries to diagnose an RD/LD, Darren advised the friend to do well on one section but intentionally do poorly on another. This way, he would demonstrate the inconsistent skill abilities commonly seen in people with RDs/LDs Edwards (1994). When asked why he helped his friend game the system in this way, Darren provided two reasons. From his own experiences and from teaching students with LDs, he recognized some LD-related traits in his friend. His second reason was his earlier argument that the extra time does not change the underlying importance of mastering the material. Regardless of his reasons, the implications of Darren's actions shows that the value tension and dam associated with instructors' concerns about the fairness of providing accommodations are not simply unfounded speculation. Such issues and concerns should be respected, and means of supporting and negotiating these issues is paramount to addressing the value tension and dam.

5 Discussion

The interviews used to develop the illustrative case studies / life stories of adults with reading disabilities presented in this chapter expand upon similar previous studies. Greater focus was placed on exploring their usage of technology and their reading practices. Most of the participants in this study have lived more than half of their lives after the passage of influential disability legislation such as the ADA (1990) and IDEA (1997). The participants' perspectives on living with RDs reflect in part the changes that such laws have made in society's perceptions and treatment of people with disabilities. Additionally, three of the participants in this study were not identified as having an RD until they were adults. This delay in diagnosis creates an important distinction in the role of disability in their lives. Instead of growing up with the disability, these individuals have to process and add a new facet to their identities and lives.

As an empirical investigation, these interviews provided insights about many of the observations made in previous chapters. Assistive technology usage was limited among the participants, and several participants specifically mentioned that TTS was not a useful tool for them. The conversations with the participants also

helped to reify and validate elements of the value-stakeholder framework. The value of awareness arose in these discussions just as they did in the online discussion forums. The hypothesized desire to control disclosure of one's disability was repeatedly demonstrated, although a disconnect was noted between their actions and their views of normalcy. As was also suspected in the earlier conceptual investigation (Chapter 6, Section 3.4.3), the communities these individuals belong to are not defined by their disability status. The reasons several individuals expressed for not belonging (or reluctantly belonging as in Kellie's case) invoked the problems associated with deviating from what is considered normal. The role of fairness in providing and receiving accommodations was further highlighted in both positive and negative ways.

6 Chapter Summary

This chapter presented an empirical investigation on the reading practices, technology usage, and the role of disability in the lives of adults with reading disabilities. Semi-structured interviews with ten participants were used to develop illustrative case studies. Using the words and experiences of these direct stakeholders, the ten life stories provided validation of the importance of privacy management and hiding as a means of addressing issues of identity and normalcy. Other aspects of the value-stakeholder framework were expanded upon, including the lack of a reading disability community and the complexity of the fairness of accommodations.

NOTES TO CHAPTER 8

- 1** In two cases, technical problems prevented successful audio recording. Excessive background noises made recording of the pilot interview with Kellie inaudible. Battery problems disabled the recorder early in the interview with Ashley as well.
- 2** The school Nigel attended was similar to the one that Edwards taught at and recruited students from for her interviews Edwards (1994).
- 3** Another example of this break with the Matthew effect is the previously mentioned Jonathan Mooney (Mooney, 2007). In his memoir, he frequently refers to books and essays that he has enjoyed reading on disability studies, including Foucault (1977/1995) and L. J. Davis (1995).
- 4** In the fall of 2010, Kellie moved her comic to a new server provider. In the course of the move, she updated the appearance of her website. Included in this change was the removal of the link to the page containing her statement about her spelling. The reason for this is not clear, although the spelling in her comic has improved significantly in the last year. It is possible that she has decided to step back from being visible about her disability, although I cannot confirm this at the current time.
- 5** Frankly, I find pithy statements such as, “We are all the same in that we are all different,” to be vacuous and rather belittling. The implication is that while one’s differences are recognized, they do not really matter since everyone else is also different. This begs the question as to why certain differences deserve recognition while others are passed over as unimportant.
- 6** Examples of this community ethos can be seen in various 12-step programs like Alcoholics Anonymous. Members of these groups admit and openly share their problems with each other as a means of establishing a community in which everyone is both a recipient and a provider of support.

CHAPTER 9

TECHNICAL INVESTIGATION: VALUE ANALYSES OF EXISTING READING TECHNOLOGIES

Outside of a dog, a book is man's best friend. Inside of a dog, it's too dark to read.

— Groucho Marx (attributed)

This chapter describes the first of three technical investigations performed as part of this dissertation. In Value Sensitive Design, technical investigations can be conducted in several ways. One approach is to use an existing value-stakeholder framework to review existing technologies in terms of how well they address various value-related concerns. In this chapter, various technologies that support the reading process (i.e., reading widgets) are described and evaluated relative to the value-stakeholder framework from Chapter 6. First, the review process and how the reviews are presented is discussed. Next, the first technology reviewed is the traditional book and other forms of printed text. The next section overviews the currently available assistive technology. Several electronic reading devices are then evaluated. A discussion of the insights from the different reviews concludes the chapter.

1 The Value-Based Reviewing Process

In the following sections, multiple forms of technologies related to reading are reviewed. Each review begins with a description of the relevant reading widget or component under consideration. This description includes relevant features of the widget, how it is used, and both monetary and usage costs.

The technology is then evaluated in terms of how well it supports a set of seven key values: access, choice, empowerment¹, fairness, literacy, normalcy, and privacy. For the reader's convenience, definitions of these seven values are listed in Table 9.1. These values were selected from the interactive framework presented in Figures 6.3(a) and 6.3(b) in Chapter 6 (page 125), and each represents a key factor theme identified in the previous conceptual and empirical investigations that influences technology usage or reading disability management. Certain key values, such as identity and community, are not specifically included in this review as relevant elements of these values can be discussed within other values when the need arises. For

Table 9.1: Definitions of values used in the reviews of different reading technologies.

VALUE	DEFINITION
Access	The ability of a person to use a system or service without experiencing barriers or difficulties.
Choice	The freedom and opportunity for a person to select among several options, including the option to choose none of them.
Empowerment	A person's ability to freely plan, decide, and act as she deems best.
Fairness	All individuals should be treated favorably and without bias, dishonesty, or injustice. The belief that reasonable steps should be made to ensure that all persons have an opportunity to succeed in life.
Literacy	The ability to consume and produce information in a prescribed way (reading and writing). The expectation that a member of society has received an education and can read and write.
Normalcy	The degree to which a person conforms to the ideals of a society and the accompanying acceptance, rejection, and psychological impact received due to the degree of conformity. An individual's conception of what the qualities and abilities (physical, mental, emotional, etc.) of other members of society are and how it compares to the individual's own qualities and abilities.
Privacy	The rights to be left alone and to control how information about oneself is disseminated.

example, the role of community in influencing technology adoption and one's sense of identity invoke values of normalcy and privacy.

When interpreting how well a widget supports the values, the viewpoints of different stakeholder groups are considered. Primarily, this view is that of the main direct stakeholder group: adults with RDs. Various other stakeholder groups are still relevant, of course, and are mentioned when applicable. In particular, the perspective of instructors in regards to the fairness of using the reviewed technology is of interest. As noted earlier, some college instructors have expressed doubt and distrust over providing accommodations to students with RDs/LDs (W. M. Williams & Ceci, 1999; Zirkel, 2000; Vickers, 2010). This vocal minority creates both a value tension and a value dam around issues of fairness (see Chapter 6, Section 4). as well as the need to evaluate how well any reading widget addresses potential fairness concerns.

2 The Book and Printed Text

To begin these technology reviews, the first reading widget under consideration might not be complex in terms of technology, but it has been refined and improved over the past centuries—printed text. Be it bound as a book, in a magazine, or several leafs of paper stapled together, printed text is typesetted text that is readily mass-produced (Knuth, 1999). One of the key attributes of this medium is that once it has printed, the text is essentially fixed in terms of its content and presentation. Other than through the use of external tools such a magnifying lens or a color overlay, no elements of the typography can be changed.

Moreover, printed text is not only about the content. How the text is presented is just as important (Bernhardt, 2004; Hill, 2004). Font choices, section headings, images, and even how text breaks across lines all shape the reading experience proffered by printed text (Tinker, 1963, 1965; Zachrisson, 1965; Frase & Schwartz, 1979; Santos Lonsdale et al., 2006). The differences in the usage experience of reading from a small paperback versus a heavy hardcover book are readily apparent. Printed text is both content and form, and both need to be considered when evaluating its support of the seven values in this review.

Foremost, the book/printed text is clearly supportive of the value of literacy. In many ways, the book is the symbolic embodiment of literacy, and separating the two is thereby difficult due to their shared history. The conventions of typography have shaped how people read, and how we read has similarly influenced how books are typeset. Typography began more as an art form, and the concept of the book as art is greatly exemplified in the illuminated tomes from the medieval ages (Knuth, 1999). Even after the printing press made mass production of books possible, great care was made in the design of typefaces and the laying out of each line of text (Sutherland, 1989; Knuth, 1999). These choices did not reflect only aesthetic goals, however, as readability and legibility were also desired. Centuries later, it would be determined by sensory psychologists like Tinker that their choices reflect the visual capabilities of the average reader (Tinker, 1963, 1965; Zachrisson, 1965; Sutherland, 1989).

Because both the book and the act of reading co-evolved, printed text also supports the notion of normalcy. Reading from a book, magazine, or stapled together pieces of paper will not make the user stand out in any particular way. Similarly, the privacy of a person with an RD is likely to be maintained when he or she reads silently from a book, even when in public. Only when reading has to be aloud or accomplished in a fast manner might there be some indications of deviance from normal on the part of a reading-disabled user. For example, reading a menu proved so challenging and distressing to one woman in the study by Tanner (2009) that she would insist on always eating at the same restaurant when dining with people who did not know about her RD.

This example also shows some of the limitations of printed text. Despite successfully supporting the values of literacy, normalcy, and privacy, printed text is not as supportive for the other values relevant to this review. For both empowerment and fairness, books are fairly neutral in their support of these values for the direct stakeholders. While the knowledge found in a book can empower the reader, this is true for any reader regardless of disability. Similarly, any concerns about fairness that an instructor may have about providing printed text to one student can be easily rectified by providing the same printed text to all students.

Access and choice, however, are negatively supported by printed text. Difficulties with access to printed text essentially create and define reading disability. Because text is the default state in which reading occurs, barriers to access are expected. Some texts are more accessible than others, however, such as large-print editions for readers with poor vision. Such large-print books are one of the few means by which the value of

choice is provided to the user. In general, printed text offers no freedom of choice to the user as the typography and content are fixed upon printing. Some choice can occur if different print formats are available, such as large-print editions or if the book is available from different publishers. However, this choice only exists at the time of purchase and only if multiple options are available to the consumer.

New options for printed text might change this scenario, however, in the form of personalized typesetting (Karow, 1998). Efforts like the Espresso Book Machine (On Demand Books, 2010) allow the consumer to purchase a book and have it printed using the purchaser's personally selected typographic settings. Although the printed book will still be fixed in its format, the user at least has greater freedom of choice at the purchasing level. Personalized typesetting may also increase empowerment on behalf of those with RDs given the possible usage of personalized typography to improve reading performance (Dickinson et al., 2002; Gregor et al., 2003).

3 Assistive Reading Technologies

Given that printed text presents some access difficulties to those with reading disabilities, several forms of assistive reading devices have been developed. These range from simple tools like the color overlay to the more complex and technical text-to-speech systems. In this section, several types of these assistive reading technologies are evaluated.

3.1 Overlays and Windows

Among the simplest forms of assistive reading widgets are the text window and the color overlay. The text window (described in Chapter 3, Section 1.4) is a piece of cardboard or other stiff material with a small window cut into it in order to hide surrounding text, lessen visual distraction, and prevent line skipping. Color overlays (Chapter 3, Section 1.3) are transparent plastic sheets tinted to various colors that have been found to reduce the effects of visual stress. Both are used in the same way: placed on top of the text and moved as necessary.

One strength of these tools is their simplicity. Each is designed to address a specific reading difficulty and only that. Moreover, each can be readily constructed by anyone from materials at home or a local office supply store. This also negates the need to consult an AT specialist.² This simplicity makes windows and overlays positively support several of the values. Both tools promote access, if only for a narrow range of difficulties. Empowerment is also readily encouraged as the user can act on his or her own in acquiring and configuring these tools. The simplicity of the reading intervention is unlikely to trigger fairness concerns as well.

Some degree of choice is also available with color overlays and text windows. The size of each is customizable. The two can be used separately or combined. However, the choice is inherently limited in terms of what is helpful. Not every color will help a person with visual stress. Too large of a window will fail to reduce the distraction of surrounding text, and too small of one will hinder reading.

Similarly, overlays and windows offer mixed support of the value of literacy. Both can improve reading

performance in the right user, so some positive support is there. However, because the window and the overlay are peripheral to printed text, their usage will interfere with the typical actions of reading. As mentioned in Chapter 2, Section 1.4, text windows may reduce comprehension due to obscuring the layout of text, which has been shown to affect recall and understanding (Frase & Schwartz, 1979; Wylie & McGuinness, 2004; Walker et al., 2005; Santos Lonsdale et al., 2006). Moreover, the action of reading is altered by usage of one of these widgets. Depending on its size, the window or overlay may have to be moved across a page. When the time comes to turn a page, extra steps are needed to remove and replace the widget. These interruptions, albeit minor, do interrupt the flow of reading.

The issue is that their usage deviates from the normal approach to reading. Because the vast majority of readers do not use windows or overlays, the use of one will be readily observed by those around. This usage may also suggest that the reader may be abnormal in some way. For example, in Britain, usage of color overlays for addressing dyslexia and related conditions is commonly known (Evans, 2001; D. Mills, 2005). At the same time, eye strain is common among people who must read frequently, so that reason could be given to explain using one. A text window or straightedge is sometimes recommended to improve pacing when skimming or speed reading. Thus, text windows and color overlays are limited in their support of the values of privacy and normalcy. Some negative implications of their usage exist due to associations with disabilities, but these negative aspects are ameliorated by the fact that more normal, more common reasons also exist for why they might be used.

3.2 Text-To-Speech Software

The next set of assistive reading widgets to evaluate are far more complex than the window and overlay. As described in Chapter 3, text-to-speech systems are the most common form of computer-based ATs for people with RDs. Multiple TTS software packages are available commercially, but for brevity, only two are evaluated here: Kurzweil 3000[®] and ReadPlease. These two systems represent the extremes in what is commercially available in text-to-speech for people with RDs in that the two are on opposite ends of the ranges for price and feature availability.

3.2.1 Kurzweil 3000

Kurzweil 3000 is one of the most popular TTS systems available today (Kurzweil Educational Systems, 2006; Laga et al., 2006). In addition to reading digital texts aloud, Kurzweil 3000 also comes with OCR software that allows a user to scan in any document of his choice. Documents can also be imported from files in several formats (e.g., PDF and Word). Additional tools to support the reading process include highlighting, magnification, a built-in dictionary, and pronunciation controls. The tools can be finely configured to meet the user's needs. Individual software licenses for Kurzweil 3000 are priced between \$1095 and \$1495, with the primary price difference being if documents are imported or scanned in grayscale or color.

3.2.2 ReadPlease

ReadPlease (2005) is another popular TTS system. Much simpler than Kurzweil 3000, it has no scanning or import features. Users either copy and paste or type in the text they wish to be read aloud. ReadPlease contains some additional tools, such as word highlighting and speed adjustment, that can be configured to meet the user's needs. ReadPlease is available as freeware, although a deluxe version is available for \$50. The deluxe version adds some additional tools and features, though not as many as found in Kurzweil 3000.

3.2.3 Value Evaluation

As these two systems are assistive technologies, they should readily promote the value of access, and, to a degree, both do so. The key component in both, text-to-speech, has been identified as a helpful accommodation for most people with RDs (Elkind et al., 1996; Sands & Buchholz, 1997). Kurzweil goes further in promoting access, however, due to its greater recognition of the value of choice. By providing additional features beyond TTS, it can address other sources of reading disabilities better than the more limited ReadPlease.

Another aspect of access concerns getting the texts to be read by the systems. Manual entry by typing or copy/paste, as with ReadPlease, is cumbersome and scales poorly. Kurzweil's scanning and file import features are clearly more efficient. Room for improvement still exists, though, as scanning is error-prone and can be a time-consuming, page by page process.

Similar to access are the systems' support of the value of empowerment—the ability for a person to act for herself. Neither system limits what types of readings can be used. With Kurzweil 3000, less effort is needed to input documents than with ReadPlease. However, this easier usage comes at a high monetary cost. The high software price for Kurzweil 3000 is prohibitive for many users, especially university students who are dealing with other major expenses like tuition. Due to its high price, Kurzweil 3000 is mostly purchased by institutions rather than individuals. The software is made available on certain computers in certain labs. The limited locations and time available further hinders the ability of the user to work at her own discretion (Laga et al., 2006). With its far lower price tag, ReadPlease's affordability promotes empowerment in its users but at the expense of greater difficulty with inputting documents to read. Moreover, since its basic version is free, it can be readily installed on any computer assuming the user has the appropriate administrative rights.

Unfortunately, both systems also further impair the user's empowerment due to lack of access in the configuration menus. Neither ReadPlease nor Kurzweil 3000 incorporate TTS in the configuration menus, thus making any text within them potentially inaccessible. Customizing the software to one's exact needs will be difficult and may require the help of another person. This is a particular concern for a feature-rich system like Kurzweil that may require the user to activate and adjust multiple software options.³ Kurzweil 3000 does at least incorporate TTS into the help menus, while ReadPlease does not.

Support of privacy is also problematic for the two software systems. Both require the user to wear

headphones or to have the text played aloud for all to hear. Playing the text aloud is likely to mark the user as having issues with reading. Headphones can solve this problem, but their usage is permissible and normal only in some situations. Thanks to the proliferation of MP3 players and iPods, headphones are frequently seen in libraries, computer labs, and many other public spaces. Wearing headphones in a lecture hall or while working with others is inappropriate, however. In these contexts, the user is forced to either not use the software or to relinquish her privacy around her RD.

Even without playing the speech aloud in public, TTS systems are still potential threats to the user's sense of normalcy. The TTS software's purpose is to provide assistance to people with reading difficulties. The presence of such an application on one's computer is a direct reminder and symbol of having an RD. In the case of Kurzweil 3000, the software may only be installed on certain computers. If these computers are somehow marked as for use only by people with disabilities, then using those computers will also label the user as not normal. Moreover, using TTS to read is a deviation from the normal practice of reading. Although audiobooks have been available for quite some time now, is hearing a text read aloud equivalent to reading the text visually? Both ReadPlease and Kurzweil do show the text when it is being spoken aloud, but the user is by no means obligated to follow along.

Finally, the question of fairness can arise in the use of these tools in academic settings. As these are assistive technologies, the goal is for the software to try to level the playing field so that a person with an RD could perform just as well as a person with no disabilities. The concern is that an AT could go beyond equalizing and instead enhance performance. The on-demand dictionary in Kurzweil 3000 is a feature that could provide an unfair advantage. TTS addresses the phonological processing deficit, while the dictionary is primarily a convenient tool to aid comprehension.

A greater concern for fairness, however, is not in the software but the computer running it. Consider the situation in which a student with an RD uses TTS in his classes. On a test, he will be using his computer as per his accommodations. The expectation will be that the computer will be used only for text-to-speech, but the software provides no guarantees that he might access other information stored on the computer or through a network connection. Trust and respect are important mediators of this concern, but the threats to fairness are there and can feed and enlarge doubts about providing accommodations.

3.3 Reading Pens

While ReadPlease and Kurzweil 3000 are software solutions that require a computer to run them, reading widgets can also take the form of specialized hardware. For example, reading pens integrate scanning, OCR, and TTS into a single device (WizCom, 2010). Shaped like a writing utensil, reading pens have a small optical scanner on one end. The user can run this scanner over individual words or lines of text and hear them read aloud. Some reading pens also come with built-in dictionaries or pronunciation guides for use when single

words are scanned.

Because of their design and implementation as specialized hardware, reading pens balance out many of the access issues seen in the TTS software just discussed. Because of the built-in scanner and OCR, any text can readily be digitized. However, the pen is designed for scanning and reading aloud only small segments of text at a time. If the user needs extensive TTS support, the pen will be an inefficient means to scan the entire text. This limitation is tempered somewhat by the lower price (averaging about \$250 (WizCom, 2010)) and device portability. Unlike the high expense of Kurzweil 3000, a person with an RD is more able to have a personal pen that is not restricted to usage in a particular computer lab. Thus, the user is offered a greater degree of empowerment by a reading pen.

As for supporting the other values, the reading pen performs similarly to the TTS software. As with Kurzweil 3000, the built-in dictionary may conflict with the value of fairness. Usage in public spaces also presents the user with the same challenges as text-to-speech in that playing the text out loud will disturb the user's privacy. The user does have the choice of using only the definition and pronunciation features, but such usage in public is still likely to be noticed and commented upon. However, because the pen is used only when needed, any threats to normalcy can be limited. By using the pen only when necessary, the flow of reading is also less interrupted than when using a text window.

3.4 Intel Reader

In 2009, a new reading widget became available—the Intel Reader (Intel, 2010a). The Intel Reader is similar to the reading pen in that it is a specialized piece of portable hardware that combines OCR and TTS, but instead of scanning words or lines at a time, a camera is used to capture an entire page at a time. The imaged text is then displayed on the device's screen (10.9 cm diagonal) as it is read. Most importantly, text capture is not limited to just books, but can include restaurant menus, brochures, and any other printed materials one encounters on a daily basis. By making it possible to digitize and hear any text at any time, the Reader is designed to provide text access to people with print disabilities. This includes RDs as well as visual impairments.

At this time and to the best of my knowledge, no formal adoption/user studies of the Intel Reader have been published. There has been one informal field study (Intel, 2010b), however, in which Readers were provided to adolescents with dyslexia in U.S. middle and high schools over a six week period. Since the scope of the study involved a relatively short time period and that the students were given lots of secondary technical support, little to no information is available for prediction about the Reader's adoptability by adults with RDs/LDs. However, using the value-stakeholder framework, a value evaluation can identify critical issues that will influence its rate of adoption among this primary direct stakeholder group.

Clearly, the Intel Reader succeeds in promoting the values of access and empowerment due to its combination of TTS and OCR. This support is similar to that provided by Kurzweil 3000, although the Intel

Reader does increase the portability of this approach as it can be used anywhere. The Reader also shares some of Kurzweil 3000's difficulties with promoting these values. Capturing a book page-by-page is still a time-consuming process. Furthermore, the Intel Reader is priced at \$1495 per device, making the expense out of reach for some consumers.

Because it is also based around text-to-speech, using the Intel Reader shares the same mixed support of literacy, normalcy, and privacy. Public usage will again require playing the TTS output aloud or using headphones. Moreover, since it is a specialized device, its novelty will also attract attention. Capturing text may involve a camera flash as well, further making the user stand out. Additionally, the Reader only captures the content of text; it does not maintain any of the formatting or layout of the captured text. Thus, the literacy experience using the Reader is considerably different than the original printed version.

The Reader also offers little support for the value of choice. It is only a TTS device and has no additional features like a built-in dictionary or notetaking tools like in Kurzweil 3000. Configuration options are limited to how the text is displayed on the screen: size and color. However, its text-capturing ability does allow the user complete freedom in whatever she wants to read.

Finally, since the Reader can store multiple documents at a time, it can raise some concerns about fairness in situations such as classroom usage and testing. Students will have to be trusted to only listen to appropriate, on-task materials. Similarly, accessing resources that could be construed as cheating is another concern. A more general concern may be the uniqueness of the reader. Unlike with a laptop or other portable computer device, most instructors will have little to no experience with the Reader. This unfamiliarity may breed distrust and concern regarding a student's use of the technology.

4 Electronic Reading Devices

Supporting reading through computer technologies is not limited to only providing access for people with disabilities, however. Nowadays, not all text is necessarily printed onto paper. In today's information society, more and more text is becoming available in digital formats. While printing onto paper is usually an option, reading can also take place from computer or other electronic displays.

The idea of reading from an electronic screen has been around for time and was predicted at least as early as 1945 (Bush). Empirical studies have explored the differences between reading from the screen and paper. While early studies suggested that reading from a screen was inferior to reading from paper, the ongoing evolution of display technologies and interface research has established the two as fairly equivalent mediums for reading (Mills & Weldon, 1987; Muter, 1996; Gujar et al., 1998; Price, Schilit, & Golovchinsky, 1998; B. L. Harrison, 2000; Dillon, 2004; Chen, Guimbretiere, Dixon, Lewis, & Agrawala, 2008). Differences still and will continue to exist between the two, however, due to the different affordances offered by the two

technologies. Texts printed on paper are easy to annotate, manipulate, and do not have a limited battery life. Digital texts allow the user to carry around a complete library in a condensed form. Moreover, search functions readily enable finding information in a text.

From the perspective of assistive technologies and reading disabilities, electronic reading devices provide another opportunity and venue in which assistive tools could be deployed. Although these devices have not been deployed or explored as potential reading widgets, the value-stakeholder framework can be applied to them just as with the Intel Reader. Three types of electronic reading devices are considered: e-book readers, tablet computers, and PDAs/smartphones. Each is described, and then the three are evaluated.

4.1 Dedicated E-Book Readers

The first type of electronic reading technology is the dedicated e-book reader. These readers are portable digital devices consisting primarily of a large display, data storage, and text presentation software. Although these devices have been around since as early as 1998 (Gujar et al., 1998; Price et al., 1998), the technology has only recently become popular among consumers (Siegel & Gallaga, 2009). Improvements in the technologies and services associated with e-books are responsible for this change. For example, the Amazon Kindle uses an electronic ink/paper display that mimics papers and enables the screen to be read in a wide range of light levels, including sunlight (Kroeker, 2009; Amazon, 2010). With a battery life up to seven days, this encourages ongoing usage of the reader on daily commutes, at home, and on vacations. Moreover, the Amazon store is set up to make purchasing and downloading of new texts easy for the consumer.

At the time of the writing, several models of e-book readers are available, including the Amazon Kindle, the Barnes & Noble Nook, and the iRex Digital Reader (Amazon, 2010; Barnes & Noble, 2010; iRex, 2010). Aside from the electronic ink displays and extended use batteries, other features are sometimes found in these readers. Texts can be uploaded to the device through a direct connection with a computer or wirelessly through by wi-fi, Bluetooth, or a cellular network connection. Some readers can accept different file formats, including the popular PDF format as well as the accessible DAISY and NIMAS standardized formats (NISO, 2005; National Center on Accessible Instructional Materials, 2006). Text can also be enlarged or changed to to a different font typeface. A few readers also include reading tools like a built-in dictionary, TTS, or annotation tools. Additionally, most readers remember the last page that the user read, thus solving the misplaced bookmark problem.

4.2 Tablet Computers

Another common feature among e-book readers is that they are a dedicated piece of hardware and only support the act of reading. Portable computers can replicate the functionality of an e-book reader and offer additional functionality as well. Although the most common form of a portable computer is the laptop, tablet computers are also available (Willis & Miertschin, 2004). Tablets are a fully functional computer in the form factor of

a slate in which a large display (22–32 cm diagonal) is the prominent feature. Interaction with the computer is performed primarily through a touchscreen or a pen device/stylus. Not all tablets come with a keyboard, and those that do have the option of detaching or moving the keyboard out of the way. Importantly, because they are computers, tablets can run a variety of software that can include various reading applications. These applications may include any of the features available in e-book readers, including AT tools such as TTS.

The availability of tablets increased significantly in 2002 when Microsoft released a version of Windows XP with support for digital ink (Microsoft, 2002). Tablets running this operating system were essentially the same as a desktop or laptop running regular Windows XP, save for some additional features utilizing the digital ink. This meant that tablets software interfaces supported multitasking across different applications each housed in their own separate window. Interface controls such as menus and buttons that were designed for usage with a mouse interface were unchanged, sometimes causing difficulties for pen-based interactions.

This approach was the norm for tablet computers until the April 2010 release of Apple's tablet—the iPad (Apple, 2010a). Emphasizing interaction through touchscreens, the iPad uses a specialized operating system, iOS, designed to facilitate working on a tablet. Functionality on the tablet is made extensible through the download of different applications. Multiple applications can be used at the same time, but only one application is viewable at a time. Interface controls have also been redesigned for easier use with a touchscreen or stylus. Although Apple was the first to produce touchscreen-based tablets using this approach, other companies have been developing similar products using the Android operating system with planned releases for late 2010/early 2011.

The iPad is particularly worth noting in this dissertation since as part of its success, the iPad has been receiving accolades as a platform for delivering assistive technologies (Hager, 2010; Harrell, 2010). The disabilities that have received this attention have primarily been severe cognitive disabilities such as autism or disabilities involving communication and the need for augmentative and alternative communication. Even though the iPad's potential of supporting users RDs/LDs has not been explored, the reasons for its success with other disabilities are worth noting. One of the reasons given by these users or their caregivers is that the iPad is a cheaper option (prices start at \$500 plus the cost of applications) than the specialized hardware options typical of most ATs. This is due in part to the economies of scale possible when manufacturing a product for the general population and not a small subset. Furthermore, the iPad offers additional functionality beyond the those specific to the assistive technology. Finally, the design of the hardware and software promotes an exploratory-style interface that greatly improves its usage learning curve.

4.3 PDAs and Smartphones

A third form factor of reading devices is distinguished by its smaller size. Unlike the vast majority of e-book readers and tablet computers, personal digital assistants (PDAs), and smartphones (cellular phones with

additional computing abilities) are small enough to fit into one's palm or pocket. Their smaller size naturally means a reduced display screen, but their computational capabilities are not. PDAs and smartphones can access networks, play music, display and adjust text, and data can be entered via stylus input or touchscreen. As such, the difference between a PDA and a tablet computer is somewhat unclear, but smartphones are distinguished by their primary role as a cellular phone.

Although I am unaware of any implementations of assistive reading aids onto PDAs or smartphones, it is certainly within the realm of possibility. In the case of the smartphone the iPhone (Apple, 2010b), TTS has been implemented on the iPad which uses the same underlying operating system as the iPhone. Moreover, reading on mobile devices like the PDA has been previously studied (Waycott & Kukulska-Hulme, 2003; Mustonen, Olkkonen, & Hakkinen, 2004; Vadas, Patel, Lyons, Starner, & Jacko, 2006). The study by Waycott and Kukulska-Hulme (2003) is particularly worth mentioning as it reports on the experiences of Masters students in an information technology course in which the course text was provided only on PDAs.

4.4 Value Evaluation

Overall, the three types of electronic reading devices perform similarly in their support of the various values. For example, in all three cases, the consumer has a rich set of devices to choose among. This support of the value of choice comes from the larger consumer market involved in catering to the general population as opposed to only people with RDs/LDs. Similarly, the consumer also has many options for obtaining electronic text due to the recent growth in e-book availability. Since more and more books are available already in electronic form, the user is empowered in that she does not need to spend as much effort.

Unfortunately, this support of choice and empowerment does not carry over into promoting access, however. While it is true that the larger consumer market makes devices more accessible in terms of purchase costs, very few reading accommodations are offered on these devices. Text-to-speech is available on some, but not all, e-readers. Tablets have the option of installing TTS applications. Otherwise, the various devices only provide options for how text is formatted.

In regards to the value of literacy, the form factor of tablets and e-book readers reflect the form factor of books and the printed page. Size, dimensions, and font size are all replicated to some degree. PDAs and smartphones are limited, however, due to their inherently smaller sizes. More importantly, though, is how these devices fit into a larger shift in society's perceptions of what literacy and reading entail. It is becoming more and more acceptable and normal for people to be seen reading from electronic devices like a Kindle or iPad. Because this is seen as normal, reading from one will not divulge the user as having a disability unless a noticeable reading accommodation like TTS is used. Privacy is thus promoted.

Despite the usage of these technologies becoming increasingly the norm, issues of fairness in their usage in scenarios like classrooms and testing are open questions. Time is needed for educators to react to the relatively

new technology. Since most of these devices can connect to networks, the specter of cheating does arise. This is particular true for smartphones due to concerns about their potential as tools for cheating (Campbell, 2006). However, policies will have to be developed due to the increasing rates of adoption of these technologies. As an example, if an instructor permits students to use their textbooks during exams, the eventual scenario in which some students use electronic versions of the textbook will force the instructor to address the fairness of using e-book readers.

5 Discussion

A summary of the value-based evaluations is presented in Table 9.2. These ratings are not absolute quantities but instead reflect the relative degree to which each technology promotes or detracts from the various values. For example, since printed text defines what is meant by literacy and normalcy in reading, printed text rates at the highest possible (+ + + +) for promoting these values.

In looking at Table 9.2, several patterns are readily noticed. As is to be expected, the assistive reading devices do a better job at promoting access than the other technologies, although the electronic reading devices do put in some effort as well. Similarly, the reading technologies all promote literacy to some degree. Due to their relative newness, the various reading technologies also raise concerns about fairness.

Perhaps most telling is the dynamic between access, normalcy, and privacy. While the assistive reading technologies in Section 3 do a good job at promoting access, their specific focus on disabilities and accommodations detracts from the values of normalcy and privacy. Conversely, the electronic reading devices in Section 4 offer far less access support for users with RDs/LDs, but their emphasis on the general population

Table 9.2: Summary of value-based reviews of existings reading technologies. Relative rating are represented as series of up to 4 minus signs (negative support) or 4 plus signs (positive support).

	Access	Choice	Empowerment	Fairness	Literacy	Normalcy	Privacy
Printed Text	--	--			++++	++++	++++
Text Window	+++	++	++++		++	--	--
Color Overlay	+++	++	+++	--	++	--	--
Kurzweil 3000	+++	+++	+++	---	+	----	----
ReadPlease	++	+	++	--	+	----	----
Reading Pen	++		++	--	+++	--	--
Intel Reader	+++	--	+++	--	+	----	----
E-Book Readers	+	++	+	--	+++	++	++
Tablet Computers	+	+++	+	--	+++	++	++
PDA's / Smartphones		++	+	----	++	++	++

makes their usage achieve better promotion of normalcy and the privacy of one's disability.

These reviews suggest several directions on how to build a reading widget that better supports these values. Clearly, policies or technical features that better support the fairness concerns associated with these technologies need to be developed. To address the mixed support of access, normalcy, and privacy, one approach may be to simply integrate assistive reading tools into e-book readers and tablet computers. While this would improve electronic reading devices' promotion of access for users with RDs/LDs, their support of privacy and normalcy may actually turn negative. The problem with systems like ReadPlease and Kurzweil 3000 are not the computers they are installed on but the visibility and resulting stigma risk of the accommodations they provide. Implementing a full TTS system like Kurzweil 3000 on an iPad or Kindle will not negate the value-based usage concerns.

This idea is not without merit, however, and a more refined approach at incorporating assistive reading tools into general electronic reading devices is detailed in Chapter 11. Before exploring that direction, the next chapter takes the findings from these reviews as well as previous chapters to formulate several design guidelines. These guidelines provide general recommendations for design goals, features, and tasks that should be considered when planning and implementing a reading widget for adults with RDs/LDs.

6 Chapter Summary

This chapter presented a technical investigation in which the value-stakeholder framework was used as a basis for evaluating existing reading technologies. Reviews were performed on printed text, various ATs for RDs, and computer-based reading devices. Support of several values were found to be lacking, including a failure to address fairness concerns and an inverse relationship between support of access and normalcy / privacy.

NOTES TO CHAPTER 9

- 1** Although empowerment was not discussed in great detail in Chapter 6, it is included in these technical reviews. One of the key goals of any assistive technology is the empowerment of its user to be able to live more independently with less difficulty and fewer barriers (King, 1999; Ladner, 2008). Thus, any assistive reading widget should clearly support the value of empowerment.
- 2** In the case of a color overlay, the user might be able to select a helpful tint on one's own. However, some studies have found that the wrong color may actually decrease reading performance (Jeanes et al., 1997; Dickinson et al., 2002). Moreover, studies have shown that to guarantee that a person can find a color that benefits reading, the set of available colors needs to sufficiently cover color space (Smith & Wilkins, 2007). If the user can only procure a small number of colored overlays, he may fail at finding one that benefits his reading. Overlay kits, such as the Intuitive Overlays (Smith & Wilkins, 2007), thus offer upwards of 30 color options in order to fine-tune the color to the user. The color transparencies available from a local office supply store may not offer the same range of options.
- 3** The complexity of configuring Kurzweil 3000's many features is also a source of concern for the validity and generalizability of studies of its effectiveness. In studies like Hecker et al. (2002), the study participants are given professional, customized advice and support in the installation and configuration of the system. Study results are therefore reflective of the best-case usage scenario. Real-life usage might involve a less-optimal configuration for the software, thereby lessening any benefits to reading. This concern suggests a need to replicate effectiveness studies in which the participants receive a lesser degree of technical support.

CHAPTER 10

TECHNICAL INVESTIGATION: DESIGN RECOMMENDATIONS AND GUIDELINES

In many of the more relaxed civilizations on the Outer Eastern Rim of the Galaxy, the Hitchhiker's Guide has already supplanted the great Encyclopaedia Galactica as the standard repository of all knowledge and wisdom, for though it has many omissions and contains much that is apocryphal, or at least wildly inaccurate, it scores over the older, more pedestrian work in two important respects.

First, it is slightly cheaper; and secondly it has the words DON'T PANIC inscribed in large friendly letters on its cover. — *The Hitchhiker's Guide to the Galaxy* (D. Adams, 1979, p. 2–3)

In addition to value evaluations of existing reading widgets, the value framework developed in this dissertation provides insight into the design of future reading widgets. This chapter presents several guidelines and recommendations for designing for adults with reading disabilities. First, some existing design recommendations are described. Then, a set of value-informed guidelines generated through a technical investigation are presented.

1 Designing for Users with Reading Disabilities

Because of the unique needs and situations of people with disabilities, designing assistive technologies can pose many challenges. As such, some technology researchers have developed guidelines to aid in this task. King (1999) in particular developed a framework of what he denoted as essential human factors that should be accounted in the design of any AT device. Although King considered all disabilities, other researchers have focused on specific disability groups. For example, both Robertson and Hix (2002) and Dawe (2006) discuss designing technologies for adults with moderate to severe cognitive disabilities/mental retardation.

In the case of reading disabilities, such efforts have focused primarily on the design of texts. Venable (2003) provide a comprehensive overview as to how complex texts may be simplified to reduce the difficulties commonly experienced by K-12 students with RDs/LDs. Their work is unique in that it concerns a wide range of texts, including books, magazines, and newspapers. Other design recommendations for texts tend

to focus on website design. Powell, Moore, Gray, Finley, and Reaney (2004) synthesized a set of twelve recommendations about the format and content of websites for dyslexic students. Other efforts have made recommendations for designing pages to be accessible for users with cognitive disabilities (Jarrett & Grant, 2010; WebAIM, 2010). Such efforts unfortunately concern the full range of cognitive disabilities, and thus the user is often assumed to be low or limited general intelligence which is not true of reading-disabled users.

When it comes to design recommendations for actual reading widgets and not just text design, the literature on designing for adults with RDs is quite sparse. To the best of my knowledge, the only such published work is that from the SeeWord project (Dickinson et al., 2002; Gregor et al., 2003). In their design of a dyslexia-friendly interface for Microsoft Word, user studies identified the importance of controlling or minimizing distractions such as the automatic spellcheck features. Direct manipulation interfaces were also identified as more desirable.

2 Value-Informed Design Recommendations

Given the lack of design recommendations for reading widgets for reading-disabled users, a technical investigation was performed as part of this dissertation. This effort draws upon the value-stakeholder framework developed and refined throughout the past chapters. Some of the insights may have been noted in previous AT design research (Dawe, 2006; King, 1999) but are repeated here with justifications from the VSD analysis. The ten recommendations are listed in Table 10.1 along with the value concerns they address.

2.1 Support the Reading Process and Reading Tasks

Although this recommendation may seem obvious, it is motivated by several reasons. First, this directly addresses and reinforces the explicitly supported value of literacy identified in Chapter 6, Section 4.1. This

Table 10.1: Recommendations for the design of assistive technologies for adults with reading disabilities.

DESIGN RECOMMENDATIONS	VALUES INVOLVED
1. Support the reading process and reading tasks.	Literacy
2. Support the acquisition of rich digital texts.	Access, Empowerment, Fairness
3. Provide multiple forms of accommodations.	Access, Choice, Fairness
4. Typography matters.	Choice, Fairness, Literacy, Normalcy
5. Recognize and control disclosure due to technology usage.	Choice, Identity, Normalcy, Privacy
6. Support and adapt to multiple usage contexts.	Community, Literacy, Privacy
7. Include support for fairness arbitration and usage negotiations.	Access, Fairness, Privacy
8. Bring expert knowledge to the end user.	Access, Choice, Empowerment, Fairness
9. Mitigate purchase and usage costs.	Access, Fairness
10. Design for all readers.	Fairness, Literacy, Normalcy

recommendation is about also recognizing one of the key findings of the life stories study in Chapter 8. Many of the participants clearly articulated how they regularly engage in various reading tasks, and several (Kellie, Clarissa, Calvin, and Emily) even described reading as one of their great passions in life. Moreover, as discussed in Chapter 3 and in the online discussions analyzed in Chapter 7, most of the tools recommended for people with RDs do not address reading but instead address related areas of difficulty: writing, organization, and mathematics (R. B. Lewis, 1998; Raskind & Higgins, 1998; Lange et al., 2006; C. K. Lewis, 2007). To summarize, This recommendation redirects the designer to emphasize key aspects of the user population: difficulty with the desired task of reading.

2.2 Support the Acquisition of Rich Digital Texts

Without material to read, the widget is simply not helpful. Thus, text access is a critical, first-mile issue and was therefore recognized as a value dam in Chapter 6, Section 4.3. Supporting this design recommendation requires recognizing the various means by which digital text may be acquired and any related barriers. The simplest approach is to use a copy of the text that has already been digitized, and, as discussed in the previous chapter, this is becoming increasingly more common due to the growing popularity of devices like the Kindle and the Nook. However, issues of copyrights, copying, and digital rights management are still being debated (Kocher, Jaffe, Jun, Laren, & Lawson, 2002; Doctorow, 2004; Stone, 2009; Bookshare, 2010a). As such, access to digital text comes in the form of entering the text manually or via scanning and OCR. This itself can be problematic due to the time involved. Depending on the scanner interface, the process could involve working word by word, line by line, or page by page. Such time costs have been identified as a factor in TTS abandonment (Elkind et al., 1996). Moreover, cost can be a further barrier to access as OCR software is expensive as in the case of Kurzweil 3000 (Laga et al., 2006) or requires specialized hardware (Laga et al., 2006; Intel, 2010a).

This recommendation also goes beyond just providing a copy of a text. The word ‘rich’ is included to remind the designer that the texts we read include more than words. Printing and typesetting have been refined over the centuries to produce well-crafted printed texts (Tinker, 1963, 1965; Knuth, 1999). Aspects of this craft include well-chosen paragraph formatting, font choices, and page layout to which we have grown accustomed. These features have been shown to influence reading comprehension, recall, and other interactions with text (Frase & Schwartz, 1979; Wylie & McGuinness, 2004; Walker et al., 2005; Santos Lonsdale et al., 2006).

Unfortunately, these features are rarely included in the standards for print disability friendly text formats. Neither the DAISY (NISO, 2005) nor NIMAS (National Center on Accessible Instructional Materials, 2006) standards mandate replicating all elements of typography. While bolding and italics are mentioned in NIMAS, elements of typesetting such as line breaks, page breaks, etc. are not explicitly required (features for these are provided and suggested for use with legal documents, however). The motivation behind these omissions is

two-fold. The first is a legacy of earlier technologies in which data size and memory limitations encouraged parsimony in markup languages, but the development of more efficient languages (e.g., cascading style sheets) and increased data storage capacities for lower costs has lessened the need for such parsimony. The second motivation for not including all typographical features is the scope of access issues faced by people with print disabilities. Most affected are those with visual impairments since seeing the text is an actual barrier for working with the text. Even if the DAISY and NIMAS standards replicated typographical features, these users would not benefit. This is symptomatic of a sadly common view in accessibility efforts. Dr. Wayne Dick, a computer science professor and active contributor to the Web Accessibility Initiative, has commented:

There is a very harmful myth concerning accessibility. It holds that once a problem is solved for blindness then it is also solved for other print disabilities. That is false. (Dick, 2010)

Current standards for accessible versions of texts are flawed copies in that they deliver the content but not the same visual experience. In a sense of fairness and to offer support to sighted people with print disabilities such as RDs/LDs, all aspects of a printed text should be made available to the reading widget user. It is then the user's choice as to which should be retained. This has design implications for reading widgets as well as file properties and contents of digital texts.

2.3 Provide Multiple Forms of Accommodations

As noted in Chapters 3 and 9, currently available assistive reading devices focus nearly exclusively on text-to-speech. This is problematic for several reasons. First, of the many difficulties associated with reading disabilities listed in Table 2.2 (page 24), TTS addresses only the difficulties associated with the phonological processing deficit. Many other traits are left unsupported. Second, both of the empirical investigations (Chapters 7 and 8), included individuals with RDs who reported dissatisfaction with using TTS systems. Finally, studies have shown that TTS provides reading benefits to only 80–90% of people with RDs (Elkind et al., 1996; Sands & Buchholz, 1997; Elkind, 1998/2001). For the remaining 10–20%, it is only fair that they have the option to receive reading support in forms other than text-to-speech.

Thus, a single reading widget will simply not suffice. Because of the complex diversity in how RDs manifest across individuals, a similar range should be seen in the available assistive technologies. This need is further motivated by the multiplicity of possible reading tasks. To truly provide a technology that supports the needs of the user, multiple options need to be provided.

2.4 Typography Matters

Connected to the previous two recommendations is the need to pay attention to typography. Mentioned already, centuries of typography efforts have refined how text is printed to the point that we take most typesetting and layout for granted (Tinker, 1963, 1965; Knuth, 1999). However, we know that reading performance in all readers can be manipulated by changing fonts, line widths, and other text features (Frase & Schwartz, 1979;

Dyson & Kipping, 1998; Santos Lonsdale et al., 2006). The effects are small but present. Moreover, growing evidence suggests that people who struggle with reading are even more sensitive to slight changes in text formatting (O'Brien et al., 2005; A. Wilkins et al., 2009). The SeeWord project further demonstrated the potential benefits from letting readers choose how text is rendered (Dickinson et al., 2002; Gregor et al., 2003), leading several to recommend that when designing texts for dyslexic individuals, typography choices should be left up to the reader (Powell, Moore, Gray, Finley, & Reaney, 2004; WebAIM, 2010).

Because of both the legacy of typesetting and the scientific findings, developers of a reading widget should prioritize text rendering. One form of accommodation should be the option to select type features such as fonts, sizes, spacings, and colors just like in the SeeWord system (Dickinson et al., 2002; Gregor et al., 2003). Additionally, prioritizing typography means that the care should be taken in selecting the software engine that handles text rendering should be high quality. Most of the default text display systems in programming languages like Java and C# are legacy software designed decades ago. Using little computation power, they display text without the finesse, style, or art seen in traditional printing efforts. In fact, Knuth (1999) resolved to develop the $\text{T}_{\text{E}}\text{X}$ and Metafont typesetting languages after becoming disgusted by the results of other computer typesetting efforts. These systems allow for digital typography to approximate and at times replicate the quality seen in text typeset by skilled humans. His systems do require additional computation time to achieve such quality. Given that readers with RDs seem to be more sensitive to typography and the goal of a reading widget is to provide an equitable experience to the “normal” experience of reading from printed text, the implementation effort and computation costs of Knuth-like text rendering is more than justified.

2.5 Recognize and Control Disclosure Due to Technology Usage

Another design recommendation concerns the value flow regarding privacy. If the user desires to maintain an appearance of normalcy, any reading widget that broadcasts to others about the user's disability will not be adopted by such a user. For example, during the interviews described in Chapter 8, Calvin and Nigel were adamant about controlling disclosure to employers.

Designers thus must remain conscious of the social impact or weight (Toney et al., 2003) that a widget may bring to bear on the user. This is by far not an easy task, however. Different users will differ in their personal perceptions of what is too revealing or too labeling. How to best allow users to select their level of disclosure requires a concerted research and development effort. One solution may be the previous design recommendation to provide an array of accommodations. The user could then select the tool that, according to his opinion, discloses the least while still meeting his needs.

2.6 Support and Adapt to Multiple Usage Contexts

To truly realize the previous design recommendation, such disclosure controls must also be flexible to the context. Reading can take place in many contexts. Sometimes the user will be alone, with trusted friends,

with fellow classmates or employers, or with complete strangers. Depending on the situation, different levels of disclosure will be tolerated. One could design for the worst case: usage in a public venue where privacy and stigma are rampant concerns to the user. If the resulting tool only provides a small benefit to the reader, it becomes wasteful if the user is limited to only that tool. A more helpful but also more labeling tool may not be used in the worst case, but may be used in other contexts. Nigel stated this explicitly in his interview when he stated that while he would feel comfortable using TTS in the privacy of his own home, he would not use it at work due the impact it would have on his disability disclosure (Chapter 8, Section 4.3.1). Designers should thus provide users with the ability to adjust to different contexts in order to best meet the users' needs and comfort levels. Such adjustments could be manual or could be automated as usage contexts tend to be correlated with locations and times.

2.7 Include Support for Fairness Arbitration and Usage Negotiations

One potential usage context deserves specific attention—the university classroom. Due to the value dam around fairness, some instructors object to providing accommodations to students with RDs/LDs. This can occur even if the students are within their legal rights (W. M. Williams & Ceci, 1999; Zirkel, 2000; Vickers, 2010). Such resistance is likely to deter the student from using a reading widget in the classroom context and could negatively influence overall usage and adoption. Although this research found that this issue primarily arose in university classroom situations, such fairness debates are likely to occur in other contexts as well.

This design recommendation suggests that efforts should be made to identify mediation approaches to prevent such situations. Ideally, aspects of the widget or its deployment could be implemented to aid in such a negotiation process. Negotiation outcomes could include successfully demonstrating the legitimate need for a particular widget or finding an alternative accommodation that both parties find acceptable.

2.8 Bring Expert Knowledge to the End User

This research also identified that not all adults with RDs/LDs seek out help from disability services. Reasons for this include a desire to hide from or escape the disability label (Cory, 2005), the costs associated with formal evaluation (Gross, 2002; Vickers, 2010), and lack of knowledge of available ATs (mentioned by many of the participants in Chapter 8). Regardless of the motivation, not working with disability services comes at a significant cost for a reading-disabled person. Disability services and experts have backgrounds and the knowledge to help identify what tools are most likely to help an individual. They also support configuring and fine-tuning a device to the user's needs, a task known to be difficult and prone to mistakes (Dickinson et al., 2002; Dawe, 2006).

If the users will not go to the experts, then perhaps the widget can bring the experts or their knowledge to the users. Expert knowledge systems (Bobrow, Mittal, & Stefik, 1986) and recommender systems (Montaner, López, & Rosa, 2003; Adomavicius & Tuzhilin, 2005) should be explored as a means of empowering adults

with RDs/LDs in their search and configuration of reading widgets (Deibel, 2007a). Involving disability personnel in the design process is one potential way to get at this expert knowledge.

2.9 Mitigate Purchase and Usage Costs

One of the more common complaints about the commercial systems reviewed in the previous chapter was regarding their costs. Due to the small economic markets associated with disability, AT prices tend to remain high and thus pose a major barrier to adoption and usage (Dawe, 2006; Bigham et al., 2008). To better promote access, designers should explore ways of reducing or eliminating such costs. One approach may be to go the route of WebAnywhere and provide reading support as a free web service that requires only a normal computer and browser software (Bigham et al., 2008). Another approach would be to focus on and encourage the development and use of open-source components (Bigham et al., 2008; Frost et al., 2008). Another advantage of open-source is that it would allow other people, including direct stakeholders, to add to the technology and promote choice, community, and communication among people with RDs (Bigham & Ladner, 2007).

2.10 Design For All Readers

A final recommendation for the design of a reading widget for adults with RDs/LDs is to take a universal design approach (Newell & Gregor, 2000; Burgstahler & Cory, 2008) and stop focusing solely on reading disabilities. Instead, designers should consider developing reading widgets for everyone and not just people with RDs/LDs. Not only does this latch on to the recent popularity of electronic reading devices, it takes advantage of the pervasive value of normalcy in our society. By designing a technology desirable and useful to everyone, the widget would no longer be an assistive device associated with RDs. Its usage would no longer be potentially stigmatizing, and, by being used publicly and openly by the general population, diffusion of the technology would occur more readily.

However, this recommendation does not mean that a general purpose reading widget is sufficient for users with RDs. People with RDs experience difficulties with reading distinctly different than those experienced by the general population. Designers must still consider these needs as well as the needs of the general reader when designing a widget.

3 Chapter Summary

This chapter concerned design recommendations for technologies for people with reading disabilities. After a brief review of existing design guidelines, ten design recommendations were described. These recommendations are grounded in the value framework and analyses conducted and discussed in this dissertation.

CHAPTER 11

TECHNICAL INVESTIGATION: DESIGNING A SOCIALLY-FLEXIBLE READING WIDGET

What is an insidious occultist without a Book of Evil? These sorcery handbooks are conduits of unbridled power. . . . The only real problem with studying your Book of Evil is that weaker minds tend to go insane upon glancing at the contents. — *How to be a Villain* (Zawaki, 2003, p. 108)

The previous two chapters have presented technical investigations regarding the value-based design of ATs for adults with RDs. The first reviewed the technologies currently available and identified aspects they were lacking, and the second provided general guidelines for the design and implementation of a reading widget. This chapter brings together the results of the two technical investigations as well as the other VSD investigations presented in Chapters 6–8. The resulting synthesis is a design proposal for a specific reading widget. This widget—Calico—is a platform for delivering socially-flexible reading tools that support self-advocacy in reading-disabled users while also providing normalcy and privacy management.

This chapter begins with a reiteration of the identified challenges that hinder the successful deployment and adoption of ATs for adults with RDs. Two potential solutions are then proposed and discussed. The second is then expanded upon and Calico’s system architecture is proposed. The various components of Calico are described, including its extensible layered architecture, reading tools, and meta-tools. Examples of both kinds of tools are given. Further aspects of Calico are then discussed regarding implications of its usage as well as details about its implementation.

1 Challenges and Barriers to Deployment and Adoption

The preceding chapters have shown that there are multiple dams, barriers, and obstacles to successful AT usage among adults with RDs. Some of these are value-based; others are more in line with traditional notions associated with usability, accessibility, and adoptability. At the center of these various issues is society’s adherence to normalcy and literacy. For a person with a reading disability, the desire to hide or prevent others from knowing about one’s RD limits the use of any technology in public that may be seen as “labeling” or

“stigmatizing” due to how it delivers assistance (e.g., text-to-speech). If an assistive reading device is used at all, it is only used in carefully chosen contexts that are invariably only when alone or among a few select allies. Otherwise, places such as work and school inspire stealth tactics to preserve the privacy of one’s disability.

The consequences of hiding and the preservation of a sense of normalcy among adults with RDs has direct consequences on the value of community and for the technology adoption process. Because reading disabilities are invisible, the only means of knowing if a person has an RD is if she discloses. Two people with RDs may be close friends and interact frequently but never know about each other’s disability. This hiding prevents the development of an RD community that can perform group advocacy, including demands for better assistive reading tools. Moreover, the primary driving force of technology diffusion and adoption is communication about the technology. Stealth usage and the absence of conversations among people with RDs about their RDs both hinder the spread of knowledge about assistive reading technologies.

These issues of normalcy and community are not the only factors that hinder successful AT usage among adults with RDs, however. For example, people with reading disabilities exhibit a diverse range and severity of difficulties with reading and other cognitive tasks. Thus, offering a single form of accommodation will unlikely meet the diverse needs of the user population. Unfortunately, the current AT offerings attempt to do this via such a single approach, namely text-to-speech systems. As noted in Chapter 3, Section 1.1, the benefits of TTS require strong auditory skills not possessed by all users with RDs. Moreover, several of the participants in Chapter 8 expressed negative experiences with using TTS (see Section 4.2.1 in that chapter).

Access issues are another source of problems. The pricing for ATs are often high due to the small consumer markets, thus making it difficult for some potential users to acquire an assistive device. Another access barrier is procuring digital versions of the materials to read. This is becoming less of an issue due to the growing popularity of e-book readers and our increasing transition into an information society. Some universities and schools are even moving towards only using digital textbooks due to the cost benefits (Young, 2010).

Moreover, introducing a new digital technology into an educational settings can raise concerns about honesty, cheating, trust, and fairness (Campbell, 2006). Debates about the fairness of providing accommodations to university students with RDs/LDs is already a common area of debate (Vickers, 2010). Combined, these concerns about fairness are another obstacle to successful AT deployment. Adults with RDs in college engage in reading on a regular basis, and assistive reading tools are likely to be helpful. If instructors reject the technologies due to fairness concerns, a major context and impetus for using such technologies will be lost.

2 Addressing the Challenges: Two Proposals

The unfortunate conclusion from all this is that technologies specifically designed and marketed as ATs for reading disabilities are unlikely to be adopted into common, widespread usage. However, this resistance does

not mean that better ATs for RDs should not be explored nor developed, though. The participants interviewed in Chapter 8 all engaged in reading in their daily lives, some even to an avid extent. They also discussed the negative implications their RDs have on their daily lives, including reading tasks. Two participants, Tara and Calvin, volunteered for the study partially in the hope of learning about new or better reading widgets that did not rely on TTS.

Although no claims can be made about the representativeness of the 10 participants relative to the reading-disabled population, the views of these individuals is compelling. Admittedly, not every adult with an RD will engage in reading as frequently or as determinedly as do these individuals. Regardless, there is a subpopulation of adults with RDs who are underserved by the available assistive reading technologies. With these individuals in mind, I propose two solutions that can address the identified challenges to adoption.

2.1 Proposal 1: Massive Social Change

As noted, a key source of difficulty for promoting AT adoption among users with RDs is society's role in defining what is normal. Quite simply, these barriers can be eliminated by effecting massive social change. Society's perceptions of disability and difference need to be changed to reduce the negative implications and stigmas. At the same time, the reactions of people with disabilities to the pressures and effects of normalcy should also be tempered. Of course, changing long-entrenched values and beliefs in a society cannot happen overnight nor is it a realistic goal for a dissertation. Long-term, ongoing efforts are needed that may take decades or centuries to completely come to fruition.

Still, this proposed solution merits mentioning because the process is underway. The disability rights movement has been active for several decades now (P. Williams & Shoultz, 1982; Charlton, 1998; American Association of People with Disabilities, 2010). One major impact of those efforts has been that many governments have legally recognized the rights of people with disabilities to live productive lives just as much as the other members of a society (ADA, 1990; Disability Discrimination Act, 1995; IDEA, 1997; Special Educational Needs and Disability Act, 2001; ADAAA, 2008). The Americans with Disabilities Act itself was passed 20 years prior to this dissertation. While these laws have not solved all of the ills associated with disability in today's society, they have brought disabilities more and more into the forefront. People with disabilities are no longer kept hidden away at home or sequestered into institutions. Increasing numbers of students with disabilities are now enrolling in college (Scott et al., 2003; Burgstahler & Cory, 2008; N. Matthews, 2009).

While these efforts have addressed disability at the societal level, there have been similar efforts targeted at people with disabilities, with two specifically focusing on younger individuals. The DO-IT program (DO-IT, 2010) has established ongoing mentoring efforts and information resources for promoting the use of ATs to increase the participation of people with disabilities in higher education and employment. By providing

knowledge, support, and encouragement about the potential helpfulness of assistive technologies, DO-IT helps students become comfortable using ATs. Project Eye-to-Eye (2010) focuses on establishing mentoring/role model relationships between elementary school children and adults with learning and cognitive disabilities. While sharing past experiences, the mentors not only provide advice and guidance, but helps the children identify and enjoy their personal strengths. In particular, Project Eye-to-Eye works to challenge the notion that literacy and school performance are the absolute measures of a person's worth and work to broaden its participants' concepts of self-worth and personal meanings of success. Through these efforts, both DO-IT and Project Eye-to-Eye are empowering young people with disabilities with the skills and mindsets to lead successful lives and at the same time positively influence society.

2.2 Proposal 2: Build a Better Reading Widget

Since such progress is being made with respect to the impact of disabilities in society, maybe someday the challenges identified in this dissertation will no longer be a concern. For the time being, however, support should still be given to adults with RDs. One approach would be to take the insights from the VSD investigations and design a reading widget that better addresses the challenges and barriers to successful diffusion and usage. To accomplish this, three primary design goals must be achieved:

- Provide multiple forms of reading support to meet the diverse access needs of adults with RDs.
- Recognize and support the user's sense of normalcy and right to privacy up to and including helping to hide the presence of the RD from others.
- Establish a deployment approach that will promote diffusion and communication of the technologies.

These design goals are in line with the guidelines recommended in the previous chapter. Furthermore, a means of achieving them was suggested by an observation in Chapter 9. As noted there, most assistive reading devices do a good job at promoting access but fail at preserving privacy and normalcy. Electronic reading devices, however, poorly address access issues, but as their target population is the general populace, they are less threatening to issues of normalcy and privacy regarding RDs. Plus, diffusion of these technologies is more achievable due to the larger consumer market and greater likelihood of visual usage. What is needed is a means of combining the strengths of the assistive reading technologies and electronic reading devices to address their mutual weaknesses. This is not as simple as implementing TTS on a tablet computer, however. Text-to-speech is greatly visible when used and thus induces threats to normalcy and privacy when used in public contexts. Putting TTS on an electronic reading device will incur the same negative value impacts.

The unfortunate truth is that any assistive reading tool will be potentially labeling and stigmatizing. Different ATs do differ in their visibility, and what ultimately matters is the user's degree of comfort in regards to those different visibilities. One person with an RD may be comfortable using in public a colored text background mimicking an overlay. Another person may be worried about people asking why the e-book

device's display is tinted purple. Each individual may react in a different way as it is ultimately a personal choice. The most direct means of recognizing and supporting this diversity of stigma concerns and reactions is to implement multiple assistive reading tools on a reading widget like a tablet and then let the user choose what assistance is active in specific contexts. This way, every user can select the tools that he or she feels most comfortable using in that context.

There is still a problem with this approach, however. A reading device loaded with many assistive options is unlikely to be perceived as a device for the general population. By providing a large number of built-in features that provide assistance to users with RDs, the design of the device implies that the primary user population are people with RDs and not the general population. The problem here is how the features are presented. Including assistive features in a device does not automatically signify it as a device for people with disabilities. The Amazon Kindle (2010) has a built-in TTS option, but the device itself is marketed and largely viewed as a technology for everyone (Siegel & Gallaga, 2009). The Intel Reader (Intel, 2010a), however, is also a portable reading device with TTS but is marketed and targeted to users with disabilities.

The distinction here is that the Kindle's TTS feature is not presented to the user as the device's most important, beneficial aspect. From a certain perspective, one could characterize that the main problem with most ATs for people with RDs is that the tools they provide are specific to providing assistance for people with RDs only. Instead, what if a reading device provided other forms of reading help that were not limited to just RD-related difficulties? A reading device that provides customized support for multiple reading tasks and issues faced by all types of readers could be construed as a general purpose device and not just an AT meant only for people with RDs. As first proposed in last design recommendation (Section 2.10) in the previous chapter, this universal design approach is the basic idea behind the proposed Calico system.

3 The Calico Reading System

Although the intent of Calico is to provide help for people with reading disabilities, the primary universal design goal of the Calico¹ system is to provide support for the reading needs of all readers, not just those with RDs. Promoting the successful adoption of assistive reading widgets for people with RDs is achieved as a consequence of the design of Calico. Its design is relatively simple: a software application purposed for displaying and reading text on a variety of digital devices. This includes e-book devices, PDAs, and all computer form factors: tablets, laptops, and computers. As shown in Figure 11.1, Calico consists of three components: the document viewer, reading tools, and meta-tools. Each component is described below.

3.1 The Basic Document Viewer

The first and primary component of Calico is its basic document viewer. True to its name, this viewer can load documents from files, display them, and perform simple navigation such as turning a page or going to a

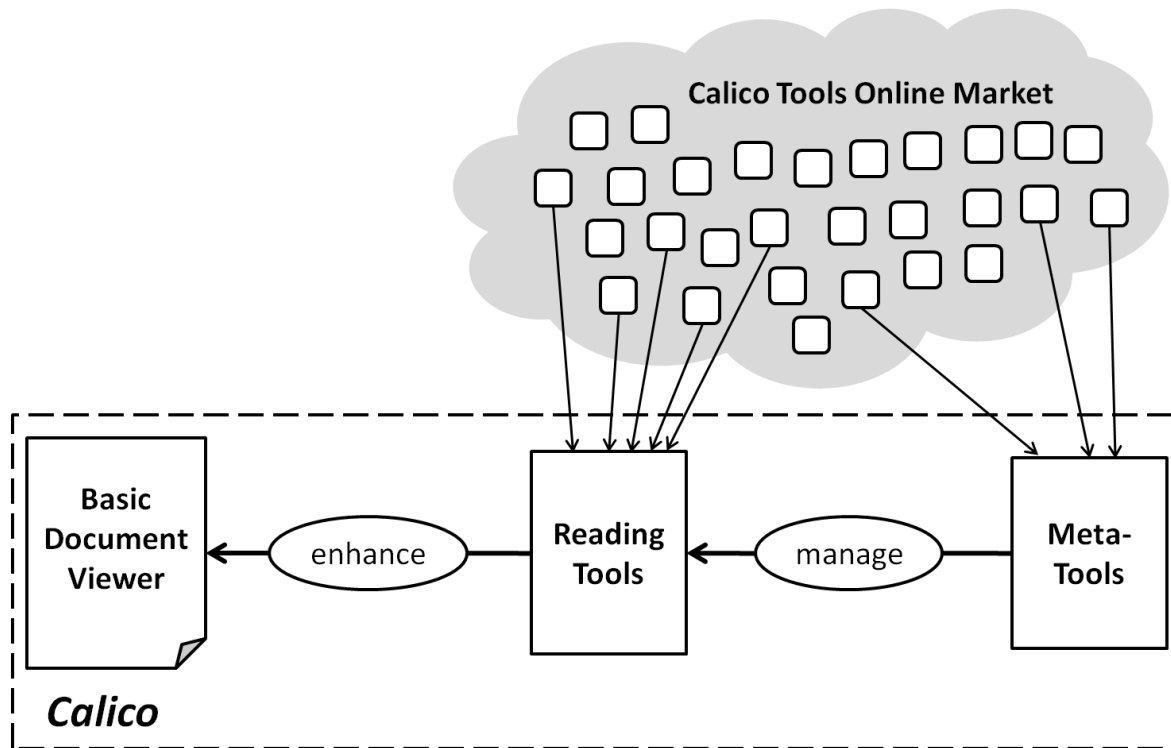


Figure 11.1: The system architecture for Calico is composed of three components: a basic document viewer, reading tools, and meta-tools. Reading tools and meta-tools are available online.

specified page. Given that Calico is meant to provide support for a variety of reading needs, this functionality may seem inadequate. However, the simplicity of the basic document viewer's design is intentional as Calico is based on a multi-layer interface design.

Shneiderman (2003) proposed the multi-layer interface as a means of supporting novice users in mastering complex software applications. Modern word processing software comes with multiple features and tools, ranging from basic font manipulation to design templates for letters and fax cover sheets. This array of choices can be intimidating to a beginning user. A multi-layer interface scaffolds the learning by controlling the number of features at one time. Starting with a basic version of the application, interface features are added with the addition of new "layers." Continuing with the example of a word processing application, the base of a multi-layer word processor would contain only features that are absolutely necessary: load a file, save a file, and print. The next layer may add a few simple features such as boldface, italics, and spellchecking. With each additional layer, the application grows in complexity as more and more features are added. Although this description might suggest that layers come in strict, hierarchical orders, Shneiderman suggests that layers can also branch in order to provide modular functionality in order to provide features more specific to certain tasks. For example, letter and fax templates would be features in a layer for office assistants, while equation and chart editors would be included in a layer for scientists and researchers.

The key aspects of a multi-layer interface design are that the application starts off with a simple, easy-to-grasp interface with limited functionality and new features are only added when necessary. One of the open questions about multi-layer interfaces is determining when new feature levels should be introduced. Another question is which features belong in which levels. For the most part, Calico sidesteps these questions by leaving these choices to the user.² New features are only added by the user through the deliberate installation of extensions known as reading tools.

3.2 Reading Tools

To achieve its goal of meeting the reading needs of a diverse set of readers, Calico must recognize the multiple forms that literacy can take and provide means for supporting them. This viewpoint is taken from the theory of multiliteracies (New London Group, 1996) in that reading skills and tasks differ across genres, fields, and purposes. Reading a physics research paper invokes different practices than reading a scholarly law article. Both are different from reading a short story as well as biographies, romance novels, and user manuals. These various reading tasks all share some elements of the reading process but also bring in their own cognitive demands. Calico's purpose is to provide support for all of them.³

Reading tools are installable extensions to Calico that provide additional functionality. The features added by extensions help streamline Calico to meet the explicit needs of its user. If a person is using Calico to read medical articles, extensions can make Calico into software specialized for reading medical articles. If a person reads primarily news articles, the tools can be focused towards that purpose instead. Moreover, these tools are composable. This means that multiple tools can be running and interacting at the same time. As an example, a person with an RD could be using a personalized typographic rendering, a text window, and on-demand TTS. Calico's design allows these three different reading tools to interact seamlessly.

This composable extension framework is based on the one used by the Mozilla Firefox web browser (Mozilla Foundation, 2010). Firefox provides the standard functionality needed for navigating the web but also offers extensibility through extensions called add-ons that are available for download online. Add-ons can be for general purposes such as blocking advertisements on websites or can be specialized tools such as real-time currency conversions, online shopping support, and integration with social networking sites. Importantly, Mozilla is not the sole developer of these browser add-ons. By providing tools and programming languages to build add-ons, Mozilla has enabled a community of Firefox users to develop the tools that they want and need. The usage of community developers is also seen with the applications built for Apple's iPhone and iPad. Such efforts promote user self-advocacy by as they provide the means users to develop extensions desired by the various user communities. For Calico, the same approach is used. Reading tools (and meta-tools) are available for download online, and interested users with the necessary skills are able to implement their own tools as well for use by others.

3.2.1 Examples of Tools Unrelated to Reading Disabilities

A demonstration of the potential diversity of reading tools is shown in Table 11.1. The tools listed are not specific to reading disabilities but address both general and specific reading needs. Search, dictionary lookup, notetaking, and annotation tools are examples of features already available on many electronic reading devices (Amazon, 2010; Apple, 2010a). One means of enhancing dictionaries would be to search a subject-specific dictionary such as a medical or a French-to-English dictionary. Depending on the setup, the dictionary could be accessed online or installed on the device. The latter is how the Kindle provides its dictionary features.

Table 11.1 also provides two examples in which a reading tool uses network access to provide specialized support to the user. The first is a tool for a person working in investment and finance. When reading an article that mentions a company that she is unfamiliar with, the Investment Lookup tool would access records from the NYSE or NASDAQ to provide information about the company and its economic performance. While this is an example of a tool for non-fiction reading, the Potter Pensieve is an example of providing support for fiction reading. The *Harry Potter* series by J. K. Rowling is an example of a fictional universe encompassing multiple characters, terminology, trivia, and history that is distributed across multiple books. As keeping track of every tidbit of knowledge can be difficult, therefore some fans created online resources with information about the series. The Pensieve would be a tool created by this fandom to connect to these online resources.

Moreover, reading tools can do more than simply looking up information from other sources. The last two examples in Table 11.1 manipulate document content to aid the reader. Both tools help prevent the need to repeatedly flip back and forth across pages in order to find some information. For example, when reading Chapter 6 of this dissertation, a reader would likely need to refer back to Figure 6.1 several times. The Information Clip tool would allow the user to select a section of the document (Figure 6.1) that would be stored as a thumbnail on a tool bar for later access as shown in Figure 11.2. This usage of clipping to isolate specific information for more convenient access later is derived from the WinCuts (Tan, Meyers, & Czerwinski, 2004) and Clipping Lists (T. Matthews, Czerwinski, Robertson, & Tan, 2006) interfaces.

Bibliographies and endnotes can be another cause of readers flipping back and forth between pages. To read a note or identify what paper is being referenced, the reader has to mark his current reading location, flip ahead in the document, read, then return to where he was. This can be a tedious effort.⁴ The Reference/Endnote Fetcher simplifies this effort by identifying footnotes and paper references and then retrieving the text when requested. An example of this is shown in Figure 11.3. In the figure, the document being read is Deibel (2008), which uses a bibliography format in which numbers represent the cited papers. The fetcher tool recognizes the format of an in-text reference, associates it with the corresponding entry in the bibliography, and provides that entry when requested by the user. The success of this tool is contingent on having an algorithmic process that can correctly identify and map references to their later entries. This can be achieved by using

Table 11.1: Examples of Calico reading tools unrelated to reading disabilities.

TOOL	DESCRIPTION
Search	Find all instances of a given text in the current document.
On-Demand Dictionary	Get the meaning of the selected word from a general purpose dictionary.
On-Demand Medical Dictionary	Get the meaning of the selected word or phrase in a medical dictionary.
Margin Annotations	Allow the user to write or type notes to be stored as notes in the margins.
Underliner / Highlighter	Mark text that the reader indicates as important and allow the user to control the style and visibility of the markings.
Investment Lookup	Retrieve information about a company's current and past stock performance.
Potter Pensieve	Look up selected text on an online encyclopedia about the Harry Potter Universe (http://harrypotter.wikia.com/)
Information Clips	Select a portion of a page to keep as a readily retrieved thumbnail, allowing ready access to tables, figures, and other frequently referred to items.
Reference / Endnote Fetcher	Retrieve the text of a footnote or reference without having to move to the page location of the footnote or reference.

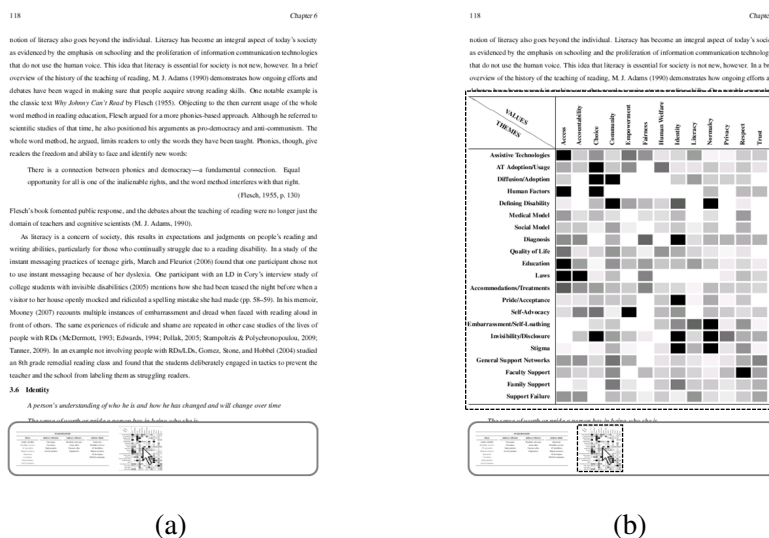


Figure 11.2: Example usage of the Information Clips reading tool. (a) The clip bar at the bottom contains two previously clipped items. (b) The user selects a clip thumbnail for re-viewing.

participation were posted to the courses' mailing lists and message boards (see [4] for more specific information on the recruitment process). The choice for focus by two reasons. First, K. Deibel. Studying our inclusive practices: Course experiences of students with disabilities. In *Proceedings of the 12th annual ITiCSE Conference*, pages 266–270, New York, 2007. ACM Press.

Figure 11.3: Using the Reference / Endnote Fetcher to retrieve a bibliography entry in Deibel (2008).

the by-example data scraping approach in the *reform* web enhancement system (Toomim et al., 2009). By having the user provide a few examples from the document of what a reference looks like and the mapping between these references and the later entries, this properly trains the machine learning component sufficiently to ensure high classification accuracy.

3.2.2 Examples of Tools Addressing Reading Disabilities

Although the majority of reading tools in Calico are not expected to specifically concern reading disabilities, such tools would also be available. Table 11.2 lists several reading tools that address some of the various difficulties experienced by people with RDs. As can be seen, many of the assistive technologies discussed in Chapter 3 can be implemented in Calico. Some of these are direct replications, such as recreating the SeeWord project (Dickinson et al., 2002; Gregor et al., 2003) with the Personalized Digital Typography tool. Overlays, TTS, and highlighting are also included in the table. The text window is also replicated but improved upon. As shown in Figure 11.4, the opacity of the window frame can be adjusted to obscure but not hide the surrounding text. In this example, the surrounding text is lightened, but other approaches (e.g., blurring or distorting) could also be implemented. This approach addresses some of the concerns about windows hindering reading comprehension due to its suppression of information about the overall text layout and formatting.

Some of the reading tools in Table 11.2 are new applications of computer science research, particularly natural language processing. Research on reading level detection and text simplification (Schwarm & Ostendorf, 2005; Petersen & Ostendorf, 2009) drive tools that simplify or summarize selected sections of text. Another example is the Smart Dictionary. This tool is an advanced version of the On-Demand Dictionary reading tool in that it uses word sense disambiguation to return the most appropriate definition/word sense (W. Kintsch, 1998; Navigli, 2009). For people with RDs, having to sift through several returned definitions and identify the best one can be a source of difficulty as well as a marked increase in the amount of text needed to be read. By providing the most appropriate definitions first, these issues are addressed.

This approach of using composable extensions is a direct means of addressing the diversity of reading disabilities as directed by the design recommendation in Section 2.3 of Chapter 10. The list of tools in Table 11.2 addresses many of the RD-related difficulties described in Chapter 2. The user can choose tools that address her reading weaknesses or augment her reading strengths while ignoring tools that are ineffective. This level of choice in assistive tools was rarely seen in the technologies reviewed in Chapter 9. Kurzweil 3000 was the rare exception, but the multiple forms of assistance it offers are fixed options built-in to the system itself. If a tool is not helpful, a Kurzweil user's only option is to disable the tool. Unlike with Calico, alternative forms of help cannot be added to Kurzweil.

Calico's ability to provide alternative versions of assistance is also a means of addressing concerns about stigma and normalcy. With Calico, several reading tools can provide essentially the same form of assistance

Table 11.2: Examples of Calico reading tools addressing reading disabilities.

TOOL	DESCRIPTION
Smart Dictionary	Get the most likely meaning of the selected word using word sense disambiguation.
Translucent Text Window	Simulate a text window of configurable size and transparency.
Automated Highlighting	Provide an automated moving word and line highlighting.
TextLens	Use a fisheye lens to reduce visual clutter around the text currently being read similar to the idea behind TableLens (Rao & Card, 1994).
Intelligent Bookmark	Remind the user of the last page, line, and word read by requiring the user to move a pointer (e.g., stylus or finger) across the text when reading.
Personalized Digital Typography	Let the user select how the text should be rendered: font, sizes, line spacing, colors, etc.
Virtual Overlays	Change the background color of the displayed text as a replication of the effects of a color overlay.
Text Simplification & Summary	Provide an easier-to-read summary of a selected section of text.
Outside the Lines Skimmer	Provide support for the text skimming practices suggested by Mooney and Cole (2000) for college students with RDs/LDs.
Text-to-Speech	Read the text aloud.
Word Aloud	Replicate a reading by reading only small selections of text aloud.
Phonetic Respeller	Provide a phonetic respelling of the selected word.

notion of literacy also goes beyond the individual. Literacy has become an integral aspect of today’s society as evidenced by the emphasis on schooling and the proliferation of information communication technologies that do not use the human voice. This idea that literacy is essential for society is not new, however. In a brief overview of the history of the teaching of reading, M. J. Adams (1990) demonstrates how ongoing efforts and debates have been waged in making sure that **people acquire strong** reading skills. One notable example is the classic text *Why Johnny Can’t Read* by Flesch (1955). Objecting to the then current usage of the whole word method in reading education, Flesch argued for a more phonics-based approach. Although he referred to scientific studies of that time, he also positioned his arguments as pro-democracy and anti-communism. The

Figure 11.4: Demonstration of the Simulated Text Window tool using translucence to obscure but not hide the surrounding text.

<foh-toh-graf>
 The photograph showed the theft...

Figure 11.5: Using the Phonetic Respeller to get a phonetic spelling of the word ‘photograph.’

but differ in the visibility of their usage. For example, the last three tools in Table 11.2 all address difficulties related to the phonological processing defect that impacts word recognition. Text-to-Speech is the standard approach, but as previously noted, listening to an entire text can attract undesired attention. Reading pens allow the user to be more selective and minimize the amount of text that is read aloud, thereby incurring less risk of being noticed. The Phonetic Respeller further reduces threats to normalcy by eliminating the speech component. Instead, as shown in Figure 11.5, this tool transcribes a selected word into a more easily parsed phonetic spelling. The respeller does require the reader to still visually parse text as opposed to completely bypassing the phonological processing deficit by hearing the word. However, the assistance offered by the respeller requires a brief moment to use and is less likely to disturb others and attract their attention. Thus, the likelihood of the respeller being adopted into regular use is higher. Even if the assistance provided is less effective, this is of course far better than receiving no assistance due to the tool being rejected outright.

3.2.3 The Consequences of Too Many Reading Tools

Although this approach to providing reading tools allows Calico to successfully meet the first two design goals on page 206, the multitude of reading tools introduces problems for achieving the third goal of promoting diffusion. Foremost among these issues is the vast number of reading tools that might be available for Calico. Consider that the perceived visibility and stigma threat of using a reading tool likely differs from user to user and from context to context. To help ensure that there is at least one tool option that a user is willing to use, several variations of the same approach (as in the just mentioned example of TTS and respelling) are necessary. Even more reading tools are needed to address the diversity seen with RDs. Moreover, Calico's purpose is to be a reading support for all types of users and literacies, further swelling the number of reading tools that Calico can make available. Sorting through this morass of available tools naturally creates a problem for users. Not only does it involve the user correctly identifying what he needs, he then has to search through the available tools to find the most tools most relevant and appropriate for those needs.

This need to help with technology selection is fortunately not a new problem, and various approaches for addressing this issue have been used previously. For example, King (1999) states that the role of an AT specialist is to use one's expert knowledge of available ATs and the nature of disabilities to help the intended user search through the available technology options. Mozilla uses a community-approach for add-ons on the Firefox browser. All of the add-ons available for download on Mozilla's website have user ratings and written reviews, and the most popular add-ons (by rating or number of downloads) are featured prominently.

Unfortunately, both of these approaches have limitations when it comes to users with RDs. Mozilla's community approach might work for recommending general reading tools, but it has been previously demonstrated that people with RDs are unlikely to act cohesively as a community due to the emphases placed on hiding and normalcy. Assistive reading tools are therefore unlikely to receive many ratings or reviews.

Table 11.3: Examples of Calico meta-tools.

TOOL	DESCRIPTION
The Johnny Recommender	Evaluate the reading strengths and weaknesses of the user and recommend appropriate reading tools. Only recommends tools that fulfill a design contract.
Chaney Profile Manager	Create, manage, and apply profiles that determine which reading tools are activated based on different contexts.
Lockdown	Allow an external authority to limit access to certain Calico features during set times and tasks (e.g., academic testing).
Course Tools	Provide, manage, and update reading tools that an instructor has suggested as useful or necessary for a course or class.
Company Tools	Provide, manage, and update reading tools that a company has determined as required or useful for its employees.
Version Manager	Keep up with new versions of a document still in the editing process.

Similarly, the common behavior to hide makes a user with an RD unlikely to seek out advice from an AT or disability specialist. Even if a user with an RD is willing to disclose and seek out help, contacting such a specialist may not be possible. A university may not have an AT specialist, and even if the school does, that specialist may not be aware or trained in ATs for RDs. Furthermore, the user may not be a student, and university disability services are rarely available to people not in school due to resource demands. Thus, access to the expert knowledge provided by disabilities specialists is problematic and leads to many users with RDs having to instead go through the AT selection and configuration process alone.

3.3 Meta-Tools

To address these issues and to help Calico promote diffusion and self-advocacy among users with RDs, a different approach called the Johnny system (discussed below) was developed. The idea behind Johnny was to introduce a new type of tool into Calico—the meta-tool. A meta-tool is an extension to Calico that aids in the management of other tools. As shown in Figure 11.1, reading tools enhance the performance of the basic document viewer, while meta-tools interact only with the reading tools. This interaction includes recommending new reading tools, helping configure installed reading tools, and enabling or disabling Calico features and components. Table 11.3 lists several examples of meta-tools.

3.3.1 The Johnny Recommender

The first meta-tool conceived of was the Johnny system. It was designed to promote self-advocacy in users with RDs by providing an alternative to contacting an AT expert. As suggested in Section 2.8 in the previous chapter, Johnny uses a combination of expert knowledge systems (Bobrow et al., 1986) and recommender systems (Montaner et al., 2003; Adomavicius & Tuzhilin, 2005) to best replicate the knowledge and expertise possessed by such personnel.⁵ Beginning with a simple assessment of the user’s reading abilities, this meta-

tool provides suggestions on what tools will be the most effective. Additionally, it informs the user about these tools by providing demonstrations and also helps the user properly configure any tools chosen for adoption.

The implementation of Johnny is motivated from insights from semiotic engineering. Developed by Souza (2005), semiotic engineering interprets interfaces as a communication between the system designer and the user. User difficulties are caused by a breakdown in this communication. As I identified in Deibel (2007a), this approach suggests several means for supporting the adoption and configuration processes. Reasons for failed AT adoption often include a failed understanding of what the technology actually does, why it should be helpful, and uncertainty about how to use and configure the technology (Dawe, 2006). A well-designed system should clearly convey the answers to such questions.

Johnny ensures that any reading tool it recommends is capable of clearly articulating these questions. This is accomplished through a contract that must be fulfilled if Johnny is to include the tool in its recommendations. First, this contract requires the tool to provide both a demonstration of what it does and a configuration wizard. The demo addresses the issue of needing to understand what the tool does, while the wizard is a surrogate for the disability expert who would normally help in configuring the tool. The second part of the contract requires the tool to report to Johnny measures of its effectiveness on different reading tasks. For example, the Smart Dictionary tool would highly support word sense disambiguation but would provide little benefit to phonological processing.

With a collection of reading tools that meet this contract, an example usage of Johnny would be as follows. It would begin by conducting an automated reading assessment of the user. Using an adaptive format, this assessment would aim to provide both a broad understanding of the user's needs (Perkins & Cohene, 2006) as well as in-depth understandings of particular problem areas (Protopapas & Skaloumbakas, 2007; Singleton & Henderson, 2007; Singleton et al., 2009). The user has the option to skip questions or stop at any time, but the system would encourage later continuation in order to provide better recommendations.

Johnny would then use the results from assessment and each tool's contractual measures of its effectiveness to provide recommendations. As an example, assume the questionnaire identifies a user as having significant difficulty with phonological processing. Explaining this finding, Johnny suggests three tools: Text-to-Speech, Word Aloud, and the Phonetic Respeller. Using the provided demos, the user decides against the two audio tools, but decides to give the respeller a try. Johnny then activates the respeller's configuration wizard to help the user adjust tool to his needs. As the user wants to avoid having the text look childish, the system guides him to have the respeller appear only on demand and to use the international phonetic alphabet for the respellings.

3.3.2 Chaney Profile Manager

Another example of a meta-tool is Chaney which helps the user manage which tools are active at different times. This is a means of addressing one of the other weaknesses of Calico's usage of reading tools. Consider

a Calico user who uses the system to read science articles at work but read fiction for pleasure in her off times. For each of these reading activities, she will have different tools installed. Some, but not all, are applicable for both tasks. To avoid having unnecessary tools clutter the interface, a profile manager would allow Calico to have multiple usage modes. In the case of this example, Chaney would include a mode for fiction reading and a mode for scientific reading, effectively creating two distinct versions of Calico installed on one device.⁶

Chaney's ability to offer easy control of what reading tools are active in certain contexts has particular benefits for users with RDs. For each reading difficulty experienced by the user, there is a reading tool that provides the greatest benefit. However, usage context can hinder if adoption of such a tool if the visibility of its use is overly stigmatizing. This leads the user to choose a suboptimal tool that offers less benefits to reading but better promotes normalcy and privacy. A context manager like Chaney allows the user to still use the more stigmatizing reading tool in contexts where the user feels more comfortable. The Phonetic Respeller, for example, would be active in the default case, but TTS could be used when the user is alone. The context manager would allow the user to make sure that TTS is never active in certain contexts but is still available to provide its greater performance benefits when the user was willing to use it.

How Chaney determines what profile to use can be implemented in several ways. The most direct and safest approach is to always start in a default state and only change profiles when the user indicates to do so. Context usage shifts could also be automatically determined based on available information. Automated detection of the type of document being currently read could also activate specific profiles. If the device has the ability to detect its location as with the GPS units in iPads and smartphones, certain an AI system could learn what usage profiles are associated with what location and time contexts. When used at the office, Calico would switch to its business mode but would return to a fiction reading mode when taken home.

3.3.3 Examples of Other Meta-Tools

Other uses of meta-tools as mentioned in Table 11.3 include supporting multiple users of Calico working together in some way. In a college course, a meta-tool can be used to ensure that all students have the same reading tools available as recommended by the instructor. When the course is over, such a meta-tool would also help students remove said tools if they are no longer desired. Management of shared documents could also be supported through a meta-tool.

Most importantly, meta-tools provide a means for addressing the academic fairness concerns that dominated most of the value-based technology reviews in Chapter 9. As a reminder to the reader, both assistive and general-purpose digital reading technologies are relatively new to classrooms. Usage policies have yet to be codified or standardized for these technologies, particularly in high-stake situations such as performance exams. Even if students are permitted to consult their textbooks during a test, a student using one of these devices would raise concerns of fairness. Search functions would make it easier for the student to look up

information in the textbook. The device could also have other useful documents already stored within it. Network connectivity could also give students unfair access to more knowledge resources.

A meta-tool like Lockdown can prevent such actions. Prior to the start of the exam, the instructor would require that this meta-tool be installed and activated. Temporary restrictions would then be placed on Calico limiting access to certain documents, which reading and meta-tools are activated, and other features such as network connectivity. The user could even be restricted from switching to other applications on the device. Lockdown would only deactivate after a set time period or if a security code is entered by the instructor. This meta-tool thus provides instructors with a modicum of control in regards to the usage of electronic reading technologies in their classrooms, thereby addressing value issues related to trust and fairness.

4 Discussion

The Calico system just described is a system for delivering reading assistance to everyone, not just adults with RDs. It is only a proposal, however, and has not yet been fully implemented. Because of this, how successful Calico is at achieving the goals of successfully promoting the adoption of assistive reading technologies by adults with RDs cannot be determined at this time. Still, there are several reasons to be optimistic about Calico's potential. At the same time, there are some open questions to consider as well.

4.1 Promoting Diffusion

A key aspect of Calico's design is that it is targeted at the general population and not just adults with RDs. As this is a significantly larger population, the amount of communication about the technology can be greater than it would be otherwise. Moreover, the general population is more likely to engage in public usage of a reading technology than the far more invisible RD community. According to Roger's theory on the diffusion of innovations, these social and communication elements are exactly what is needed for technology adoption to occur (Rogers, 2003).

Calico is also not reinventing the wheel. Ten years ago, introducing software for supporting reading on a digital device would not have been successful as reading from digital devices was still in its infancy. The recent surges in the popularity of e-book readers and tablet computers demonstrates that a shift in how people read is beginning. Calico makes only a few assumptions about the hardware it would run on. The only expectations are that a computational device is available for performing the various functions of the reading tools and that the device can somehow connect to resources online. Thus, Calico should be implementable on whatever portable technologies are currently popular for displaying documents to be read and can thereby latch on to the diffusion rates of those technologies.

Diffusion of assistive reading tools is also supported by Calico. The successful adoption of Calico by the general reading populace helps place the technology in the hands of users with RDs. The range of reading

tools can address the diverse difficulties associated with RDs, and if such a need is unmet, the ability of users with the necessary skills to design and implement new tools can address such a gap. The Johnny system meta-tool also demonstrates an alternative to having to consult with a disability expert to learn about the AT options, thus addressing the challenges associated with hiding and lack of disclosure.

4.2 Navigating Normalcy

Due to its basis in universal design, Calico helps a person with reading disabilities navigate the issues surrounding disability, normalcy, and stigma. This is because Calico is framed as a technology for the general population of readers. If reading from an electronic device attracts any attention from others, it is not because such an act is unusual and distinctive. Kindles, iPads, and tablets are now common tools for reading in public. Attracting attention from others will likely indicate interest in the device itself—a critical aspect of the diffusion process.

However, it is possible that simply using a reading tool might indicate that the user has a reading disability. Calico addresses this possibility in several ways. First, the range of reading tools available allows the user to pick assistive approaches that are lower in their conspicuousness and less likely to lead to embarrassment if noticed. Profile management as offered by Chaney provides further power to control the potential threat of disclosure from AT usage, thus making Calico flexible to the user's various social interactions.

The Johnny meta-tool is a potential concern, however, as it does have strong links to the concept of reading disabilities. Fortunately, Johnny is not used continuously. Unlike an assistive device that is always present like a wheelchair, white cane, or Kurzweil 3000, Johnny is only used when a recommendation is desired by the user. Thus, any risks associated with its usage are constrained to narrow moments of time. Moreover, rather than having the meta-tool permanently installed and visible in Calico, only the user's assessment data needs to be stored. Thus, another person is even less likely to accidentally discover that the user is hiding an RD.

4.3 Open Design Questions

Unfortunately, many implementation issues must be addressed before Calico and its various components can be realized as an actual application. Some are easily resolved, such as achieving the design recommendation that quality typographic rendering needs to be implemented (Chapter 10, Section 2.4). The legibility of print research by Tinker (1963, 1965) and the digital typography algorithms developed by Knuth (1999) provide guidelines and solutions for implementing text rendering in Calico. Support for getting access to documents is also needed, including the ability to import and convert various file formats. Implementing these features can draw upon previous efforts in text digitization, OCR, and file conversions, but additional work will be required to ensure that the digital texts used by Calico to ensure a "rich" text experience as described in one of the design recommendations from the previous chapter (Chapter 10, Section 2.2).

Several components of the Johnny Recommender meta-tool are also in need of further development. The

design contract that recommended tools must meet needs to be codified, including a specification of how reading tools report their effectiveness on different reading tasks to Johnny. These effectiveness measures will also have to be mapped to the diagnostic component of Johnny that utilizes expert knowledge to characterize the user's reading strengths and weaknesses needs to be constructed. Implementing some of this automated questionnaire will be derived from previous efforts at computer-based disability screening (Perkins & Cohene, 2006; Protopapas & Skaloumbakas, 2007; Singleton & Henderson, 2007; Singleton et al., 2009). Once constructed, the assessment will still need several iterations of refinement to test its validity and reliability as well as to ensure that completing it does not require the user to spend an excessive amount of time.

Several aspects are also open areas for computer science research. Foremost among these are the human-computer interactions issues regarding the usability of Calico's extensible, multi-layer interface with particular emphasis and concern for users with RDs. For example, how users will respond to the framework is uncertain, but studies of similar systems offer some promise. In studying the potential of multi-layer interfaces, Shneiderman (2003) found that participants with little to no computer experience quickly grasped the concept and rated it positively. Hanson and Richards (2004) developed a package of interoperable tools that allows Internet Explorer to transform web pages to be more accessible. One year after the public release of the software, they reported that several thousand people with disabilities, including RDs/LDs, had become users of their system. Both studies suggest that the general design concepts of Calico can be implemented successfully, but care must be taken to ensure that the overall system and its components provide a smooth and easy user experience.

Similarly, software engineering issues abound in regards to providing Calico's extensible framework and user development opportunities. The internal document model will need to provide enough structure and information to allow reading tools to perform reading enhancements efficiently. Computer security is also a concern. Meta-tools like Lockdown will need the ability to control system access and prevent workarounds while also not providing opportunities for malicious tools to be implemented. A more general concern about reading tools and meta-tools concerns how to guarantee that multiple tools compose rather than interfere with each other. Lerner and Grossman (2010) have analyzed and proposed approaches for addressing similar concerns with the composition and programming languages behind web browser extensions. Applications of their insights is planned.

5 Chapter Summary

Using the insights gained from previous chapters, this chapter recognized that multiple obstacles currently exist that prevent successful diffusion of any technologies designed specifically as ATs for adults with RDs. An alternative approach to providing assistive reading tools was proposed. This system—Calico—focuses on

providing reading support to all readers of all abilities. Specific reading needs, including those associated with RDs, are addressed through an extensible framework of reading tools, and further control for these reading tools is provided through the use of meta-tools. Arguments were then discussed as to how this infrastructure addresses the design goals of supporting literacy, promoting the user's sense of normalcy, and encouraging successful technology adoption.

NOTES TO CHAPTER 11

- 1** I originally chose the name ‘Calico’ essentially at random when it became too cumbersome to constantly refer to “my proposed system” or “the reading system.” The name itself was inspired by my beloved cat Susie. Although it was initially selected as a placeholder until I came up with a more appropriate name, the eventual development of a backronym made it official. Calico, after all, stands for “Computer-Assisted Literacy Interface via Composable Orthotics.”
- 2** Although Calico does not inherently provide support for selecting what tools may benefit the user, Calico can be extended to provide this functionality through the use of a meta-tool. These are discussed in Section 3.3 of this chapter.
- 3** Naturally, some literacies are more difficult to support than others. One particular challenge would be the literacies associated with comics and graphic novels. Because of their tight integration of text and images, the reading experience is very different than the traditional printed text. Many of the reading tools mentioned in this chapter cannot be readily applied to comics. Manipulating the size or formatting of text would have to integrate with the visual flow of the comics, for example.

Because comics and graphic novels are so different, they are not supported in any of the upcoming planned implementations for Calico. I do hope to explore this issue of supporting comics for users with RDs in the future, however. This is particularly motivated by the interest in comics seen by some people with RDs/LDs as evidenced by some of the interviewed and recruited participants for the life stories study in Chapter 8.
- 4** The frequent usage of chapter endnotes in this dissertation is admittedly intentional in order to provide an example of this back and forth reading task.
- 5** The Johnny system is hence named after *Why Johnny Can’t Read* by Flesch (1955) as part of its purpose is to identify the user’s reading needs.
- 6** Due to its ability to transform Calico into different systems, the Chaney profile manager is named after silent film actor Lon Chaney, Sr. Known as the “Man of a Thousand Faces,” he pioneered the usage of makeup and costumes to transform himself into memorable film characters such as the Phantom of the Opera and the Hunchback of Notre Dame.

CHAPTER 12

CONCLUSIONS AND FUTURE WORK

Lalo: You've been reading 'Belondweg' this summer—

Amy: I DIDN'T EVEN FINISH IT!

Lalo: That's OK. I'm talking about the beginning. What happens at the very beginning of 'Belondweg?'

Amy: The Mordondey kill her da and burn. . .

Lalo: Not quite. That happens before the beginning. When we first see Belondweg, father's dead. Her city's burning. She's out on the plain crying. . . . Now say you were Belondweg at that moment. Right then. If somebody asked you, would you say you were at the beginning or the end of a story?

Amy: It. . . it would feel like the end of everything.

Lalo: Exactly, but for us, reading the book, it's different. We know it's the start of the book. . . . We can feel from the weight of the book that there's a lot of story left to come.

— *Amy Unbounded: Belondweg Blossoming* (Hartman, 2002, p. 197–198)

This dissertation presented an overview of the the many sociocultural, economic, political, technical, and environmental factors that influence the adoption and usage of assistive technologies by adults with reading disabilities. The inherent broadness of this topic was approached through the application of Value Sensitive Design. By using this methodology's principled emphasis on human values and recognition of different stakeholder groups, several multidisciplinary investigations were completed that provided detailed insights as to why certain reading technologies tend to be rejected or abandoned. These investigations also led to the development of new approaches for designing reading-support tools that better address the identified barriers to adoption, diffusion, and long-term usage.

This chapter concludes the dissertation. A summary of the contributions is presented. These include the research findings from the individual chapters and investigations as well as wider contributions that transfer beyond the dissertation's focus on reading disabilities and related ATs. Directions for future work are then discussed for refining the VSD analysis and for applying and implementing the identified insights. The chapter and dissertation then ends with some final reflections.

Table 12.1: Replication of Table 1.1: Summary of research contributions from this dissertation.

CONTRIBUTION	CHAPTER(S)
Applying value sensitive design to adults with reading disabilities, assistive technologies, and technology adoption	
<ul style="list-style-type: none"> Development and refinement of a value-stakeholder framework to describe factors influencing adoption of assistive technologies by adults with reading disabilities 	6–8
<ul style="list-style-type: none"> Analyses of online discussions about reading disabilities, technology, and society 	7
<ul style="list-style-type: none"> Interviews with young adults with reading disabilities about their literacy practices, social interactions, disability impact, technology usage, and values 	8
<ul style="list-style-type: none"> Value-based reviews of existing reading technologies 	9
<ul style="list-style-type: none"> Value-based recommendations for designing assistive reading technologies 	10
<ul style="list-style-type: none"> Proposal for socially-flexible reading tools that support users by promoting self-advocacy with the aid of meta-tools 	11
Insights about assistive technology design and adoption	
<ul style="list-style-type: none"> Identification, analyses, and discussions about the lack of assistive technologies for adults with reading disabilities 	3
<ul style="list-style-type: none"> Synthesis of the PATTC framework for understanding technology usage 	4, 5
<ul style="list-style-type: none"> Applying semiotic engineering to assistive technology design 	11
Contributing to and expanding the value sensitive design methodology	
<ul style="list-style-type: none"> Introduction of theme-value literature analysis as a tool for value identification in conceptual investigations 	6
<ul style="list-style-type: none"> Expansion of the concept of indirect stakeholders to include individuals who affect the usage of technology by the direct stakeholders 	6
<ul style="list-style-type: none"> Generalization of the value dams and flows methodology 	6

1 Summary of Findings and Contributions

This dissertation was about understanding the many factors influencing the adoption of assistive technologies by adults with reading disabilities. In order to identify and characterize these influences and propose solutions, an extensive research effort was conducted. The list of contributions reported in Chapter 1 (reproduced in Table 12.1) provides an overview of the primary studies and development that was conducted. In this section, these as well as other research activities conducted as part of their contributions are recounted.

1.1 Synthesis of Research Disciplines

One of the challenges involved in this dissertation was due to its multidisciplinary nature and breadth. Detailed reviews of the literature from multiple fields had to be conducted and presented. This included the need to describe the diverse nature of reading disabilities in both its symptoms and implications on the lives of people

with RDs. To do this, Chapter 2 pulled together literature from reading science, cognitive psychology, and disability studies.

Studies and findings from educational technology and computer science research were then compiled to summarize the various assistive technologies that have been made available for people with RDs (Chapter 3). A lack of AT options was noted and demonstrated from both a commercial and research perspective. An analysis of the technologies recommended by leading RD/LD advocacy websites showed that only a narrow range of ATs for RDs are available in today's market. A literature review of computer science efforts to develop ATs for people with RDs further suggested that research into developing new or improving existing technologies is limited. Reasons for this lack were then proposed and discussed.

The literature on reading disabilities and relevant assistive technologies only provided two-thirds of the necessary background for this dissertation. To understand why or why not different technologies are adopted and used, various theories and studies on technology adoption were brought in (Chapter 4). Drawing from communication research, Rogers's model of the diffusion of innovations was described. Specific models for the adoption of assistive technologies as well as studies of AT adoption were presented. In particular, research on the adoption of ATs by people with RDs only focused on a narrow range of ATs (Figure 12.1(a)).

1.2 Reading Disabilities, Assistive Technology Adoption, and Value Sensitive Design

From these three literature overviews were distilled the two key research questions for this dissertation: What factors influence the adoption of ATs by adults with RDs? and How can one support and promote the adoption of said technologies? Value Sensitive Design was selected as the overarching framework to address these questions. As a methodology for explicitly accounting for human values in the design and study of technologies, VSD had been utilized for a range of technologies and topics but had not yet been applied to assistive technologies nor AT adoption. This dissertation marks the first such application. The utility of VSD for such work was demonstrated both abstractly and concretely. Aspects of VSD were highlighted as relevant and salient to the issues surrounding AT adoption (Chapter 5), and the ensuing VSD investigations demonstrated how such a VSD study can be conducted. Thus, this dissertation establishes VSD as a valuable and effective research approach for studying AT adoption.

A total of six VSD investigations were conducted for and described in this dissertation. A conceptual investigation started the VSD process by identifying relevant stakeholders and values (Chapter 6). To provide insights and structure for understanding the array of literature consulted for this investigation, a theme-value coding was developed and applied. Various interactions and tensions were then identified among the recognized values with issues of normalcy, privacy, and identity playing dominant, central roles.

Two empirical investigations were then conducted to challenge, validate, and refine this value-stakeholder framework. The first was an observational study of online discussions involving RDs (Chapter 7). Analysis

of the three selected threads provided insights about the opinions and views of multiple stakeholder groups on various issues related to RDs, technology, and society. The second empirical investigation was an interview study of ten reading-disabled adults about the impact of their disabilities on their education, relationships, and other aspects of their lives (Chapter 8). Inquiries were also made about their literacy practices and technology usage. Both investigations reified aspects of the value-stakeholder framework and provided insights into the desire to hide and pass as normal.

The value-stakeholder framework and the findings of the previous investigations were then applied in three technical investigations. Existing reading technologies were evaluated in terms of how well they promoted or worked against various values (Chapter 9). General design guidelines and recommendations for building better ATs for adults with RDs were then derived from the insights of the value-stakeholder framework (Chapter 10). The final technical investigation (Chapter 11) utilized these design guidelines as the basis for the Calico reading system. Through its use of an extensible framework and support through the original notion of meta-tools, Calico promotes self-advocacy as well as flexible features to manage and control disability visibility across multiple contexts.

These VSD investigations fill in a gap in the research earlier noted in a review of AT adoption studies (Section 3 in Chapter 4). As shown in Figure 12.1, this dissertation focused exclusively on reading disabilities and considered multiple types of assistive reading technologies. This combination was not previously seen in

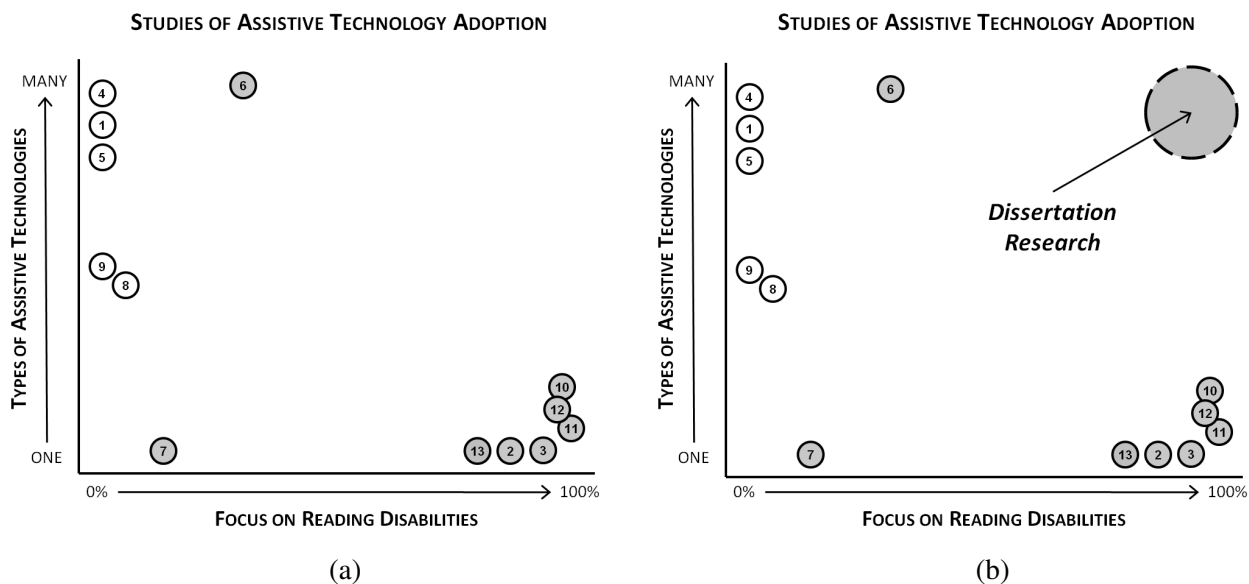


Figure 12.1: Distributions of previous and this dissertation’s research studies on AT adoption. Numbers correspond to the studies listed in Table 4.2. A greyed circle indicates the study involved participants with LDs or RDs. (a) Plot showing focus on reading disabilities versus number of ATs in the study. (b) Previous plot with the dissertation studies shown.

the AT adoption literature. By addressing this gap, the process of AT adoption was found to be reflective of the decision process to hide or disclose one's disability. Due to the values our society places on literacy and normalcy, many people with RDs feel compelled to hide their disabilities from others. In keeping the disability private, this includes not disclosing to others about the disability but also influences the choice of what ATs, if any, are adopted into regular use. Technologies that signal to others that the user has an RD may not be used in public situations. To thus manage this appearance of normalcy and avoid stigma risks, technologies need to provide multiple options in order to allow the user to continually choose the most appropriate technology for the pertinent contexts. Unfortunately, the current diversity of available AT options is insufficient to permit such choices and actions. Technologies must be developed that acknowledge and support these value issues of normalcy, privacy, identity, and choice in order to promote successful technology diffusion.

1.3 General Insights about Assistive Technology Design and Adoption

The contributions and findings from this dissertation are not specific to reading disabilities and assistive reading technologies. Several of the findings generalize to broader issues concerning disabilities and assistive technologies. As previously mentioned, Value Sensitive Design has been demonstrated as an effective methodology for studying the social aspects of assistive technology usage. VSD could be readily applied to other disability types in order to discover the aspects and nuances that influence AT adoption and usage. Semiotic engineering was also identified as a means of designing AT interfaces that better communicates to the user the purpose of a technology, how to use it, and how to configure it (Section 3.3.1 in Chapter 11 and Deibel (2007a)). The PATTC framework (Person, (dis)Ability, Task, Technology, and Context) was derived from previous AT adoption studies and existing AT adoption models to scaffold understanding of the various facets influencing AT adoption and usage (Section 4 in Chapter 4). Though derived with ATs and disabled users in mind, the PATTC framework is applicable to all ranges of use abilities, technologies, and tasks.

Specific elements of the value-stakeholder framework are also applicable beyond the reading disability scope of the dissertation. The importance of the value of normalcy and role of indirect stakeholders who stigmatize people of disabilities in influencing technology adoption apply to other disability types. People with other types of disabilities will also sometimes opt to hide their disabilities from others if possible (Kuusisto, 1998; Cory, 2005; N. Matthews, 2009). Issues of normalcy and stigma have also been identified with other disability types, such as deafness (L. J. Davis, 1995; Lane, 1997), conditions requiring the use of a wheelchair (Scherer, 2005), and psychological conditions (Cory, 2005; Brown, 2009; L. J. Davis, 2009). People who demonstrate difficulties with reading but not necessarily due to an RD also experience stigmas related with normalcy and literacy. For example, the remedial reading students in Gomez et al. (2004) engaged in deliberate tactics to resist being labeled as such by their teacher and school. The findings and methodologies in this dissertation can apply to these various groups for understanding their reactions to technologies, educational

policies, and other value-influenced aspects of our society.

1.4 Refinement of Value Sensitive Design Methodologies

As an exercise in Value Sensitive Design, this research also contributed to VSD methodology in several ways. On a high level, the topics to which VSD can be applied was expanded to include disabilities and assistive technologies. As a result, the values of normalcy and literacy were added to the larger list of values that have been explored in early VSD studies. Insights were also made about VSD's relevance and compatibility with models of technology adoption (Roger's diffusion of innovations and my PATTC framework) and the medical and social models used in disability studies (Section 4 in Chapter 5).

Methodologies used within VSD were also refined and improved. Although the literature review is not a new technique, the dual-coding and the density mapping used in the theme-value analysis in the conceptual investigation in Chapter 6 provides a new means of managing and understanding the role of different values in literature that spans multiple disciplines. Another improvement on a VSD technique involved the value flows and dams introduced by Miller et al. (2007). The concept was expanded such that dams and flows could be identified in more than just empirical investigations. An example was given of identifying dams and flows during a conceptual investigation (Section 4.3 in Chapter 6).

Most notable among the refinements to VSD was the introduction of a new type of indirect stakeholder—those who affect technology usage (Section 1 in Chapter 6). Originally, the VSD methodology concerned supporting values of those who use a technology as well as those who are affected by such usage. Because society influences the usage of and values associated with a technology, some members of society influence the usage and impact of that technology due to actions and decisions informed by their value system(s). In recognizing the various stakeholders and their values that promote or dissuade technology adoption, designers using VSD can thus make more nuanced decisions about which values should or should not be supported in designing a technology or policies regarding its use.

2 Future Work

The above contributions and findings do not mark the end of the research presented in this dissertation, however. The work is ongoing, and several directions are planned for the future. These include continuing some of the VSD investigations already conducted as well as new studies to address gaps in the current understanding and research coverage.

2.1 Continuing the Theme-Value Literature Review

New work and insights are continually taking place in the various, multiple disciplines involved in this dissertation. When new publications relevant to this dissertation are found and read, they can be coded and

integrated into the theme-value mapping. Although the papers included in this review are not meant to be a statistical sampling of all of the relevant research, the addition of more papers does help to strengthen and better define any of the patterns that informed the initial value identification. The use of the theme-value coding framework also supports my ongoing understanding of the many nuances and issues involved in the broad scope that this line of research entails.

2.2 Addressing Missing Values

In continuing the theme-value literature analysis, new themes and values may be identified and folded into the framework. Two such values have already been recognized. As mentioned in Chapter 6, Section 4.4, one audience member inquired about the absence of diversity as a value in the framework. As part of the empirical investigation presented in Chapter 7, analyses of online discussions involving RDs also found mentions of the importance of diversity. Another missing value identified in the two empirical investigations (Chapters 7 and 8) was characterized as awareness of how people differ in their experiences and issues faced in life. Reviews of the literature will be conducted to identify instances of these values within the existing set of 57 papers as well as any new papers brought into the review.

2.3 Conducting and Continuing Additional Empirical Investigations

The importance of diversity and awareness as well as the other elements of the value-stakeholder framework will be validated and further explored through future empirical investigations. One direction will be to continue the empirical investigations presented in Chapters 7 and 8. More online forms and discussion threads will be selected for analysis. The life stories of the interviewed participants will be composed, and additional insights will likely be noticed during that process. Additional interviews may also be conducted by recruiting more adults with RDs.

2.3.1 Additional Interviews of Individuals with Reading Disabilities

In particular, certain subsets of this direct stakeholder population will receive greater focus. One group of interest will consist of individuals like Harold, Ashley, and Calvin who received their RD/LD diagnosis as adults. As mentioned in Chapter 8, Ashley and Calvin struggled in school and only finally understood the reason for their difficulties later in life. Meanwhile, Harold only began to experience difficulties while in college. The experiences of these three individuals offer a different perspective on living with a disability, what it means to be normal, and how literacy difficulties shapes one's identity.

Another group of interest will be individuals who have participated in disability advocacy activities like DO-IT (2010) and Project Eye-to-Eye (2010). As mentioned in Chapter 11, Section 2.1, these groups are part of a larger social movement to change social aspects of disability. DO-IT provides information and social networks to promote the use of ATs, enrollment in higher education, and employment for all people with

disabilities. Project Eye-to-Eye establishes mentoring efforts between children and adults with RDs/LDs in order to challenge conventional views of what is normal. Adults who participated in these programs will likely have different reactions to issues related to social stigma and the value of normalcy. These differences may also be reflected in their usage of reading support technologies in that concerns about being labeled by their usage would be lessened. Thus, this subgroup would offer an interesting and different perspective from the participants already interviewed.

2.3.2 Interviews with Indirect Stakeholder Groups

One weakness of the research presented in this dissertation has been the heavy emphasis on the direct stakeholder group of adults with RDs. Considering the viewpoints of other stakeholder groups is already a key concept within Value Sensitive Design, but the importance of this was demonstrated especially in recognizing the omission of the values of diversity and awareness. The audience member who queried during the defense about the whereabouts of diversity in the framework is a disability advocate and AT developer. Of the three online discussion threads analyzed in Chapter 7, awareness and diversity were the most prevalent in the thread involving college writing instructors discussion disability (Section 2.2). These two examples primarily involve indirect stakeholder groups, thus demonstrating the need to bring in more of their insights.

Several directions will be used to explore the viewpoints of various indirect stakeholder groups. One approach will be to find more papers that express the concerns and views of other indirect stakeholders. Examples that are already in the theme-value literature review include studies like Dawe (2006) that emphasizes the opinions of parents and teachers and the study by Kaehne and Beyer (2009) on the role of school counselors in helping students with RDs/LDs transition beyond K-12. More such papers need to be incorporated into the review. This will include articles that express the concerns of instructors and education policy makers questioning the fairness of accommodations such as the already included Zirkel (2000) as well as the more recent reports by Leef (2010) and Vickers (2010).

A new empirical investigation will also be conducted. Using again a semi-structured approach, assistive technology specialists, disability counselors, and special education teachers will be interviewed to gain their insights about various topics. Similar to the review of AT recommendations given by RD/LD advocacy websites (Section 2.1 in Chapter 3), these individuals will be asked to discuss what technologies they suggest and recommend for supporting people with RDs/LDs. The participants will also be asked to describe the factors they believe influence AT adoption. Their reactions to the value framework will also be a critical focus of the interviews, and participants will be expressly asked to indicate gaps and problems with it.

2.4 Implementing and Evaluating Calico

The final direction for planned future work is to continue with the development of the Calico reading system. This will entail both software development as well as user evaluations of Calico's features and approach to

delivering accommodations. Development of the Calico's primarily infrastructure of a document viewer and extensible framework. Doing so will require making software engineering decisions to address the open design questions about the internal document model and computer security as described in Section 4.3 in Chapter 11. Individual reading tools and meta-tools will also be developed to demonstrate the breadth of reading help that Calico can provide.

User evaluation will occur alongside development through an incremental process using medium-fidelity prototypes. A medium-fidelity prototype is a realization of a proposed system that demonstrates its intended functionality but does not fully implement all of the intended features. Essentially a proof-of-concept, this prototyping approach allows the designer to get user feedback without fully implementing or over specifying a system (Lin, Newman, Hong, & Landay, 2000). For instance, a prototype of the Calico system may only ever load and display the same document but still fully demonstrate multiple reading tools being used in parallel. Similarly, a demonstration of the Johnny meta-tool would perform only a simplified RD assessment making answers to the map directly to directly to a limited set of reading tools. For example, if the user highly agrees to the statement "Words become blurry and move if I read for longer than 10 minutes at a time," then the prototype Johnny would highly recommend a color overlay tool.

Usability evaluations will be conducted with various stakeholder groups. With adults with RDs, the evaluations will explore usability issues of Calico and the effectiveness of different reading tools. Inquiries will also be made about what contexts the user would freely consider using Calico with particular tools activated. Other evaluation studies will involve AT specialists and disability service personnel to gain their insights about how to provide better support with Calico, including identifying ways to better integrate with accommodation policies and how to improve the process by which Johnny assesses a user's reading performance. To ensure that Calico's extensibility framework readily allows third-party development of new reading tools and meta-tools, studies involving AT developers will also be conducted.

3 Concluding Thoughts

Although the research work is ongoing, this dissertation has reached its conclusion. Thousands of pages have been read and distilled into 12 chapters encompassing 232 pages of their own. From beginning to end, this work has been about one thing—literacy. Literacy pervades our modern information society, but a significant portion of the population experience difficulty with reading and writing due to being born with a reading or learning disability. Recognizing a fundamental right for all members of society to have an opportunity to succeed in life, society strives to provide accommodations to people with disabilities, sometimes through assistive technologies. This was my original motivation to study reading disabilities and computer technologies, for I wanted to ensure that everyone has the chance to share in my own passion for reading.

I eventually came to realize that providing assistive technologies for reading was not sufficient for achieving this goal. For any accommodation to actually help someone, that person must adopt and use it. This dissertation has shown that despite the existence of assistive reading technologies, adults with RDs tend not to use them despite having the interest and desire to engage in reading. Reasons for this non-use were explored, and it was found that society's own embracing of literacy discourages those who struggle from reading to demonstrate said struggles publicly.

Essentially, the same literacy that enabled me to complete this dissertation is the same literacy that makes difficulties with reading a disability and stigma in our society. In looking back at the quote that began Chapter 1, Socrates was correct in that the invention of reading and writing would have consequences. He was wrong about the nature of those consequences. Despite his concerns, literacy has allowed us to accrue great knowledge about ourselves and our universe. Unfortunately, literacy has also created a false truth by which we judge members of our society on their abilities relative to the ill-defined notion of normalcy. To make sure that we benefit from literacy, we must understand and address the problems it helps create. This dissertation is one such step toward that goal.

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APPENDIX A

AT RECOMMENDATIONS FROM RD/LD INFORMATION WEBSITES

This appendix contains specific details about the analysis described in Chapter 3, Section 2.1 of the assistive technologies recommended by prominent websites providing information on reading and learning disabilities.

1 Web Sites

Listed in Table A.1 are the six websites chosen to be surveyed for their AT recommendations. As sites for major organizations involved in research, education, and advocacy work regarding disabilities, they have a strong reputation of being informative and reliable. These sites have also been recommended or referred to by peers and colleagues who work in disability-related fields.

In September 2009, each website was read through for any recommendations or comments about assistive technologies or the use of computers for supporting people with RDs/LDs. When possible, I used a site's search engine to find pages mentioning "computers," "accommodations," or "assistive technologies." Pages that were found to be particularly fruitful at mentioning ATs are included in Table A.1.

2 AT Recommendations

Multiple, independent passes were made on each site to generate lists of recommended technologies. These passes were combined and then reduced for clarity. One reduction was to combine spelling checkers and grammar checkers into a single term as well. Mentions of different fonts or other aspects of typography were all referred to as typography. Also, initial passes listed specific brands (e.g. Kurzweil 3000[®]) separately. For the final analysis, brands were collapsed into a single descriptive category (i.e. Text-to-speech).

The complete list of identified ATs is listed in Table A.2. The technologies are separated into two categories: tools for supporting reading and tools for other tasks such as writing and organization. Note that the International Dyslexia Association (IDA) did not suggest any technologies.

Table A.1: Descriptions and specific pages of RD/LD websites used in the survey.

<p>LD Online</p> <p>Leading website and information storehouse that serves parents, teachers, and other professionals who work with learning disabilities and ADHD. Contains multiple articles written by experts that are regularly updated to reflect the most recent research and practices.</p> <p><i>Specific pages:</i></p> <p>.../article/Blogs,_Wikis_and_Text_Messaging:_What_are_the_Implications_for_Students_with_Learning_Disabilities</p> <p>.../article/Assistive_Technology_at_Work</p>	<p>http://ldonline.org/</p>
<p>Disabilities, Opportunities, Internetworking, and Technology</p> <p>DO-IT is an organization dedicated to bringing people and information together to promote the success of people with disabilities in higher education and professional careers. This includes specific interest in supporting people with disabilities in the fields of science, technology, engineering, computing, and mathematics.</p> <p><i>Specific pages:</i></p> <p>.../Brochures/Technology/tech.html</p> <p>.../Brochures/Technology/atpworld.html</p> <p>.../Stem/ld.html</p>	<p>http://www.washington.edu/doi/</p>
<p>Learning Disabilities Association of America</p> <p>The LDAA provides support to people with LDs and their parents, teachers, and other professionals through providing practical information and resources targeted at local, state, and national levels.</p> <p><i>Specific pages:</i></p> <p>.../pdf/college_success.pdf</p> <p>.../pdf/assistive_tech.pdf</p> <p>.../aboutld/adults/post_secondary/transitioning.asp</p> <p>.../aboutld/parents/ld_basics/dyslexia.asp</p>	<p>http://www.ldanatl.org/</p>
<p>The British Dyslexia Association</p> <p>As a UK national organization, the BDA campaigns for positive change in the lives of people with dyslexia through ongoing efforts in legislation, education, information dissemination, and research.</p> <p><i>Specific pages:</i></p> <p>.../about-dyslexia/it-information/supporting-literacy-with-ict.html</p> <p>.../about-dyslexia/it-information/small-and-portable-devices.html</p> <p>.../about-dyslexia/it-information/speech-recognition-software.html</p> <p>.../about-dyslexia/adults-and-business/reasonable-adjustments-in-the-workplace.html</p>	<p>http://www.bdadyslexia.org.uk/</p>
<p>International Dyslexia Association</p> <p>The IDA supports and disseminates research on understanding and treating dyslexia and related LDs to educators, researchers, parents, and those with dyslexia.</p> <p><i>Specific pages:</i></p> <p>none</p>	<p>http://www.interdys.org/</p>
<p>National Center for Learning Disabilities</p> <p>NCLD works to ensure that every child, teenager, and adult with LDs has the information and opportunity to succeed in school, work, and life.</p> <p><i>Specific pages:</i></p> <p>.../at-school/general-topics/accommodations/accommodations-and-modifications-for-teens</p> <p>.../at-school/general-topics/accommodations/accommodating-students-with-dyslexia</p> <p>.../at-school/general-topics/accommodations/accommodations-for-students-with-learning-disabilities</p>	<p>http://www.nclld.org/</p>

Table A.2: AT recommendations by website. Listings are separated into tools specific for reading and tools for other tasks.

Tools for Reading	Websites						Total
	LD Online	DO-IT	LDAA	BDA	IDA	NCLD	
Audio books	X	X					2
Color overlays				X			1
Electronic dictionary	X			X			2
Highlighting		X		X			2
Magnification		X					1
Optical character recognition	X	X					2
Online reference materials	X						1
Reading pen	X			X			2
Text-to-speech	X	X	X	X			4
Typography				X		X	2
Tools for Other Tasks							
Audio/visual recorders	X	X	X	X			4
Brainstorming software		X		X			2
Laptop	X						1
Personal organizers	X	X	X	X			4
Portable word processor	X	X	X	X		X	5
Speech recognition	X	X		X			3
Spelling/grammar checkers	X	X	X	X			4
Visualization tools	X						1
Word prediction software	X	X		X			3
Total	14	12	5	13	0	2	

APPENDIX B

LITERATURE SEARCH AND LABELING OF ACM DIGITAL LIBRARY

This appendix contains the specific details about the search described in Chapter 3, Section 2.2 of the ACM Digital Library to identify the degree of computer science research efforts in regards to assistive technologies for reading and learning disabilities.

1 Search Terms

The search of the ACM Digital Library (<http://portal.acm.org/dl.cfm>) was conducted on August 17, 2009. Through trial and error, it was determined that the library's search engine ignored punctuation, meaning that the search term "learning disabled" would return the same results as "learning-disabled." It was also determined that the search engine did not automatically perform stemming. This necessitated manual inclusion of both singular and plural terminology among the search terms. Additionally, adjective forms ("dyslexic" and "disabled") were included in the search terms. With the results shown in Table B.1, four separate searches using the following search terms were conducted:

- **Reading Disability Search (RD only)**

This search sought to find all papers referring to reading disabilities. Several variants of both dyslexia and RDs were used as search terms: dyslexia or dyslexic Or dyslexics or "reading disability" or "reading disabilities" or "reading disabled".

Table B.1: Results for the four searches of the ACM Digital Library.

Search	Results	% Disability	% Total
RD only	161	2.43%	0.06%
LD Only	151	2.28%	0.06%
RD + LD	286	4.32%	0.11%
Disability	6,621	-	2.58%
Total Searched	255,808	-	-

- **Learning Disability Search (LD only)**

Given the high co-occurrence of learning disabilities and reading difficulties, a separate search was conducted for papers concerning LDs using the terms: “learning disability” or “learning disabilities” or “learning disabled”.

- **Reading and Learning Disability Search (RD + LD)**

Another was conducted using the search terms from the two above searches.

- **Disability Search**

As the ACM Digital Library contains all publications by the ACM, not all papers involve disability or assistive technologies. To establish a baseline of how common such topics are in the library, a search of terms related to disability was also conducted: disability or disabilities or disabled.

2 Analyzing the Search Results

To further understand the ACM search results, the 286 papers in the RD + LD search were analyzed using an open coding analysis (Taylor & Bogdan, 1998) to identify common themes. The themes evolved throughout the analysis process, leading to tags being consolidated or split. A total of three passes were conducted that led to the development of the following labels that were assigned to the search results. Note that a paper could be labeled with multiple tags, although an attempt was made to limit the number of tags as much as possible.

- **Acquired Cognitive Disability**

This tag applies to any papers regarding cognitive disabilities that were acquired via disease or trauma as opposed to developmental conditions present at birth. This tag was initially two separate tags: acquired dyslexia and other acquired conditions. This tag is exclusive and if applied to a search result, no other tags may be applied to the same result.

- **Assistive Reading Technology**

This tag refers to any publication that discusses in depth any technology for supporting reading for users with RDs or LDs. If multiple papers were found to be part of an extended research effort, those papers were categorized separately. Thus, the tags Deibel and SeeWord were developed.

- **Brief Mention Only**

This tag applies when a paper briefly mentions a search terms but for only a few sentences.

- **Deibel**

These refer to papers written by myself, which were part of an ongoing research effort.

- **Diagnosis**

Papers with these tags describe systems for diagnosing a disability. Due to the scope of the search,

the diagnosis systems are not necessarily for RDs or LDs.

- **Experiment Control**

Some studies screen their participants for RDs as that might negatively impact their findings. For example, a study of a tool for supporting text entry on cell phones would want to exclude participants with language difficulties. Thus, the paper mentions RDs but is otherwise about a completely different topic. This tag is another exclusive tag and if applied to a search result, no other tags may be applied to the same result.

- **In Poor Taste**

This tag refers to any paper in which the choice of language or perspective was viewed as potentially insulting. In most cases, the slight was unintentional on the part of the authors. For example, a paper on a programming assignment for students might include the theme of a dyslexic clerk who constantly mixes up his letters. Other times, an author directly associates an RD with being bad, unfortunate, or problematic.

- **Includes Other Disabilities**

This tag applied to a paper if the scope of the paper was beyond a single disability. In most cases, such a paper would dedicate sufficient time to RDs or LDs and then another class of disability as well (i.e., blindness).

- **Non-Reading LDs**

This tag applies to any paper that focused on a learning disability in which reading was not a major concern. Examples include a paper regarding ADD/HD or dyscalculia.

- **Not a Paper**

The ACM Digital Library also includes entries for the table of contents of conference proceedings and workshops, calls for participation, and other non-research publications. This tag applies to such search results.

- **Participant Has RD/LD**

In some papers, reading or learning disabilities are not in the scope of the study. However, one or more participants has an RD/LD and has some bearing or insight worthy of mention. This tag is another exclusive tag and if applied to a search result, no other tags may be applied to the same result.

- **Position Paper**

This tag applies to papers that are not straightforward research or experimental reports. Instead, such papers serve primarily to inform others about or express a philosophical view involving disabilities.

- **Possible Application**

This tag applies when the authors suggest the technology or technique investigated in the paper may be useful for people with RDs/LDs. Note that such a paper does not study the actual effectiveness of said approach and only suggests that it may be effective.

- **RDs as an Example**

This tag applies when a paper uses RDs or LDs as a motivating example, but the primary focus is on a different topic. This may involve citing and discussing a paper about RDs. A case study involving a person with RDs is another example.

- **Referenced Paper**

This tag refers to any paper where the search hit comes from only the bibliography section of the paper. A cited paper's title or journal involves one of the search terms, but otherwise, the search term is not mentioned anywhere else in the paper. This tag is another exclusive tag and if applied to a search result, no other tags may be applied to the same result.

- **Related Work Only**

This tag refers to any paper in which the only mention of RDs or LDs occurs only in the discussion of what other researchers have done (i.e. the related work sections). This tag is distinct from *RDs as an Example* in that the presence of the search term does serve any motivating purpose for the paper. The goal of the paper is targeted elsewhere.

- **Search Error**

This tag applies when a search result is in error. For example, the idiosyncrasies of the digital library's search engine causes "...learning. Disability..." to be matched with the search term "learning disability". This tag also applies if a paper uses terminology in an atypical fashion, such as referring to blindness as a reading disability. This tag is another exclusive tag and if applied to a search result, no other tags may be applied to the same result.

- **SeeWord**

This tag was branched from *Assistive Reading Technology* to highlight any paper regarding the SeeWord project (Gregor et al., 2003) from the University of Dundee.

- **Severe LD**

This tag refers to any paper that primarily focus on learning disabilities in which intelligence is severely impacted. This tag is a union of previous tags separating conditions such as mental retardation and autism spectrum disorders. This tag is another exclusive tag and if applied to a search result, no other tags may be applied to the same result.

Table B.2 lists the occurrence and frequency of the above tags across the 286 search results. Note that a high number of papers were tagged with *Brief Mention Only* and only a relatively few papers were labeled *Assistive Reading Technology*. Moreover, as suggested by the above tags, there have been only two concerted, ongoing efforts involving ATs for RDs: the SeeWord project and my own efforts.

3 Labeled Search results

Listed below in order of most recent publication are the 286 returned results. For each entry, the labels I assigned to it are listed in closed brackets [. . .]. Also include is a label indicating which of the three searches returned the item: LD only, RD only, or RD + LD.

ACM Search Results

- R. Varma (2009). *Attracting Native Americans to computing*. DOI: 1536616.1536650. [LD only, Brief Mention Only]
- D. Ginat (2009). *Interleaved pattern composition and scaffolded learning*. DOI: 1562877.1562915. [LD only, Brief Mention Only]
- E. I. Konstantinidis, M. Hitoglou-Antoniadou, A. Luneski, P. D. Bamidis, and M. M. Nikolaidou (2009). *Using affective avatars and rich multimedia content for education of children with autism*. DOI: 1579114.1579172. [LD only, Severe LD]
- C. Skourlas, P. Belsis, F. Sarinopoulou, A. Tsolakidis, D. Vassis, and C. Marinagi (2009). *A wireless distributed framework for supporting assistive learning environments*. DOI: 1579114.1579167. [RD only, Assistive Reading Technology, Includes Other Disabilities]
- V. M. Leirer, F. Glöckner, T. Elbert, and I. T. Kolassa (2009). *An auditory computer-based training for mild cognitive impairment and mild Alzheimer's disease: German prototype of the Brain Fitness program*. DOI: 1579114.1579168. [RD only, Related Work Only]
- P. Marti, A. Pollini, A. Rullo, L. Giusti, and E. Grönvall (2009). *Creative interactive play for disabled children*. DOI: 1551788.1551871. [LD only, Severe LD]
- M. Cavazza, D. Pizzi, F. Charles, T. Vogt, and E. André (2009). *Emotional input for character-based interactive storytelling*. DOI: 1558013.1558056. [LD only, Related Work Only]
- G. Walsh (2009). *Wii can do it: Using co-design for creating an instructional game*. DOI: 1520340.1520722. [LD only, Non-Reading LD]
- P. O. Kristensson and L. C. Denby (2009). *Text entry performance of state of the art unconstrained handwriting recognition: A longitudinal user study*. DOI: 1518701.1518788. [RD only, Experiment Control]
- D. Sloan, C. Asakawa, and H. Takagi (2009). *Proceedings of the 2009 International Cross-Disciplinary Conference on Web Accessibility (W4A)*. DOI: 1535654. [LD only, Not a Paper]
- S. Harada, J. O. Wobbrock, J. Malkin, J. A. Bilmes, and J. A. Landay (2009). *Longitudinal study of people learning to use continuous voice-based cursor control*. DOI: 1518701.1518757. [RD only, Participant Has RD/LD]
- A. C. Cavender, R. E. Ladner, and R. I. Roth (2009). *The summer academy for advancing deaf and hard of hearing in computing*. DOI: 1508865.1509043. [LD only, Brief Mention Only]
- C. H. Gonzales, G. Leroy, and G. de Leo (2009). *Requirements engineering using appreciative inquiry for an online community of caregivers of children with autism*. DOI: 1529282.1529310. [LD only, Severe LD]
- T. N. Arvanitis, A. Petrou, J. F. Knight, S. Savas, S. Sotiriou, M. Gargalakos, and E. Gialouri (2009). *Human factors and qualitative pedagogical evaluation of a mobile augmented reality system for science education used by learners with physical disabilities*. DOI: 1502539.1502576. [LD only, Brief Mention Only, Includes Other Disabilities]
- P. G. Neumann (2009). *Risks to the public*. DOI: 1507195.1517460. [LD only, Brief Mention Only]

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APPENDIX C

ENHANCED BAKER'S BASIC ERGONOMIC EQUATION

As noted in Chapter 4, Section 2.2, Baker's Basic Ergonomic Equation (Baker, 1986; King, 1999) is a useful heuristic for determining the likelihood of an AT being used. However, as noted in that section, several limitations to it exist due to its failure to account for stigma and necessity. This appendix presents an enhanced version of Baker's equation.

1 Accounting for Stigma

As stated earlier, the desire to hide one's disability and avoid stigma can influence the usage of an assistive technology. In the study by Cory (2005), students with invisible disabilities were enrolled in college and had clear motivation to receive an education and achieve future career goals. Yet, many chose to avoid seeking out help or support, due in part to their desire to control the impact of being labeled as having a disability. Refusing to use an assistive device is one form of control, so it seems appropriate to include a perception of stigma due to using the device in Baker's equation. A simple modification to the denominator does just that:

$$\text{Likelihood of Usage} \propto \frac{\text{Motivation}}{\text{Time} + \text{Physical Effort} + \text{Cognitive Effort} + \text{Stigma Cost}}$$

Note that the above is based on Baker's original version of his equation (Baker, 1986) and does not include King's addition of *Linguistic Effort* (King, 1999). King's influence is still present, though, as the equation is being applied to any and all AT and not just alternative communication equipment.

We can generalize the equation further, however, by using the notion of *social weight*. As proposed by Toney et al. (2003), social weight is the attention a device attracts when used in social situations. As a bit of an extreme example, a thermos typically has a low social weight when used to pour a cup of coffee during a business meeting. Using an espresso machine to make a cup of coffee in the same meeting, however, attracts a high amount of attention and thus has a high social weight. Toney et al. (2003) encourage the minimization of social weight when designing a device. For an assistive technology, social weight includes the perception of stigma as it is the user's opinion of the obtrusiveness of the device in a social situation. Moreover, social

weight can capture the opinions of people other than the user in terms of the device's desirability. Considering the social weight of an assistive device as perceived by the user thus enhances Baker's equation by including a previously missing social component:

$$\text{Likelihood of Usage} \propto \frac{\text{Motivation}}{\text{Time} + \text{Physical Effort} + \text{Cognitive Effort} + \text{Social Weight}}$$

2 The Need for Context

By introducing social weight to the equation, though, a new problem is introduced. The stigma of using a device depends on the context of where it is used. Consider a text-to-speech system being used in a private room versus a lecture hall. By playing the text aloud or wearing headphones in a lecture hall, the user is likely to attract the attention of the lecturer as well as the other students. In a private room, no one is around to notice, so the perceived stigma risk is likely lower. Ergo, context should be accounted for in the equation.

Context actually impacts other elements in the equation. A noisy background may increase the cognitive difficulty of a task. A context such as taking a timed examination or a work deadline could affect both the time permitted and the level of motivation. Because of this and the fact that context is not readily quantified, it makes sense to add context as a functional parameter:

$$\text{Likelihood of Usage}(c) \propto \frac{\text{Motivation}(c)}{\text{Time}(c) + \text{Physical Effort}(c) + \text{Cognitive Effort}(c) + \text{Social Weight}(c)}$$

where c stands for context.

3 Accounting for Necessity

Also influencing the usage of a technology is the perceived necessity of the technology for the desired task. The example given back in Chapter 4 considered a person with paraplegia and a person with a reading disability. Without some form of assistance, the person with paraplegia is for all practical purposes immobile. However, even without an assistive device, a person with a reading disability can usually still read, albeit slowly and problematically. Thus, the necessity of using an AT could be less for that individual.

In my own work, I have encountered an example of how the perception of necessity can influence the usage of an AT. Alan was a student with a reading disability from my studies on the experiences of students with disabilities in computer science courses (Deibel, 2007b, 2008). At the time of the studies, he preferred books-on-tape over using a TTS system as the unnatural sounds of computerized speech made it difficult for him to follow along. As he noted, though, books-on-tape take a while to prepare, and this has made him fall behind in courses at times. Text-to-speech typically has a much shorter preparation time. About a year later, I ran into Alan on campus, and he informed me that he was now using TTS because he was highly motivated to

For user u , assistive device d , task t , and context c , the likelihood of the user using the assistive device to perform the task given the context is defined as:

$$\text{Likelihood of Usage}(u, d, t, c) \propto \frac{\text{Necessity}(u, d, t, c) \times \text{Motivation}(u, t, c)}{\text{Time}(u, d, t, c) + \text{Effort}(u, d, t, c) + \text{SocialWeight}(u, d, t, c)}$$

where

$$\text{Effort}(u, d, t, c) = \text{Physical Effort}(u, d, t, c) + \text{Cognitive Effort}(u, d, t, c)$$

Figure C.1: Revised, parametrized form of Baker's Basic Ergonomic Equation.

graduate this year (Personal communication with Alan from Deibel (2007b), October, 2007). To achieve this goal, he realized that although he prefers books-on-tape, the faster delivery time of TTS is a necessity if he wants to keep up in his courses and graduate.

Necessity clearly depends on the task and the user, though. Alan would have unlikely used TTS for casual reading. Another reading-disabled student with the same opinion of the unnaturalness of TTS would likely prefer books-on-tape, especially if there was not a time concern as in Alan's case. Thus, we need to add additional parameters for the task and user. Moreover, necessity appears to be tied strongly to the device being considered, requiring a further parameter.

4 Putting It All Together

Figure C.1 shows the revised form of Baker's equation with the addition of context, social weight, necessity, and other parameters. Several of the elements in this revised equation are worth discussing. First, I deliberately chose to limit the parameters of *Motivation* to the user, task, and context with the idea that motivation being device-independent makes motivation more about wanting to do an action than wanting to use a device. Second, context was included as a parameter for all aspects of the numerator. This is meant to reflect the perspective that a disability is only a problem when the socioenvironmental context is not accommodating (Sears & Young, 2003). Finally, the numerator is framed as *Necessity* \times *Motivation* instead of *Necessity* + *Motivation* deliberately emphasize how the perception of the necessity of the device for the task can overpower either a high or low motivation to perform a task.

At this point, however, the equation in Figure C.1 is no longer a simple to remember heuristic. A simplified version would read as follows:

$$\text{Likelihood of Usage}(\text{context}) \propto \frac{\text{Necessity}(\text{context}) \times \text{Motivation}(\text{context})}{\text{Time}(\text{context}) + \text{Effort}(\text{context}) + \text{SocialWeight}(\text{context})}$$

This would read as:

The likelihood of an assistive device being used is a product of the user's motivation to perform the task and the necessity of the device for the task. This product is reduced by the sum of the

time the task will take, the effort involved in using the AT, and the social weight of the device. All of this is further shaped by the context of the user at the moment.

Although this is still weighty, the rules of thumb are there. Motivation and necessity improve the likelihood of usage. Social weight, time, and greater effort all reduce the likelihood. Finally, there is the reminder to always consider that context of the user.

APPENDIX D

VALUE-ANNOTATED BIBLIOGRAPHY

Adelman, P. B. & Vogel, S. A. (1990). College graduates with learning disabilities: Employment attainment and career patterns. *Learning Disability Quarterly*, 13(3), 154–166.

A survey of college graduates and nongraduates with LD is conducted regarding their experiences in college and employment. Findings include the importance of acceptance and understanding of one's disability,

Themes	Values
Assistive Technologies	Access, Accountability, Choice, Community, Identity
AT Adoption/Usage	Access
Quality of Life	Access, Community, Identity
Education	Fairness
Accommodations/Treatments	Access
Pride/Acceptance	Accountability, Empowerment, Identity
Self-Advocacy	Accountability
General Support Networks	Access, Accountability, Choice

Alexander-Passe, N. (2006). How dyslexic teenagers cope: An investigation of self-esteem, coping and depression. *Dyslexia*, 12(4), 256–275.

This study discusses how issues of depression, low self-esteem, avoidance, and stress management impact the lives of dyslexic teenagers. Particular emphasis is given to the relationship with teachers and school and the implications for later success in life.

Themes	Values
Assistive Technologies	Community, Identity, Normalcy, Privacy, Trust
Quality of Life	Identity
Education	Accountability, Identity, Privacy
Self-Advocacy	Normalcy, Privacy
Embarrassment/Self-Loathing	Identity, Literacy, Normalcy
Invisibility/Disclosure	Community, Normalcy, Privacy
General Support Networks	Community
Support Failure	Normalcy, Trust

Armstrong, D. & Humphrey, N. (2009). Reactions to a diagnosis of dyslexia among students entering further education: Development of the 'resistance-accommodation' model. *British Journal of Special Education*, 36(2), 95–102.

This article is a study of how adolescents react to a diagnosis of dyslexia. Interviews with students identified patterns of resistance, denial, coping, and acceptance.

Themes	Values
Assistive Technologies	Access, Choice, Community, Empowerment, Identity, Normalcy
AT Adoption/Usage	Fairness, Identity, Literacy, Normalcy, Privacy
Diagnosis	Fairness, Identity, Literacy, Normalcy, Privacy
Quality of Life	Choice, Empowerment
Education	Identity, Literacy, Normalcy
Pride/Acceptance	Identity, Literacy, Normalcy
Embarrassment/Self-Loathing	Community, Identity, Literacy, Normalcy
Stigma	Identity, Normalcy
General Support Networks	Access, Community

Brown, S. (2009). Learning to read: Learning disabled post-secondary students talk back to special education. *International Journal of Qualitative Studies in Education*, 22, 85–98.

This study interviewed four post-secondary students who had been identified as learning-disabled. The participants discuss the tension between that label and participating in an academic meritocracy. Issues of normalcy, class, identity, and disability policies are discussed.

Themes	Values
Assistive Technologies	Access, Fairness, Literacy, Normalcy
AT Adoption/Usage	Access, Fairness, Identity, Normalcy, Respect
Defining Disability	Identity, Normalcy
Social Model	Normalcy
Diagnosis	Access, Fairness, Identity
Quality of Life	Normalcy
Education	Access, Literacy, Normalcy
Laws	Access
Accommodations/Treatments	Access, Fairness, Respect
Pride/Acceptance	Identity
Embarrassment/Self-Loathing	Choice, Normalcy, Respect

Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA, USA: University of California Press.

This books presents an analysis of how different societies treat people with disabilities and discusses the philosophies of the disability rights movement. Arguments are made against the views of disability as a tragedy and the segregation of the disabled voice from society, especially in regards to their treatment.

Themes	Values
Assistive Technologies	Access, Accountability, Community, Empowerment, Respect
AT Adoption/Usage	Accountability, Community, Empowerment, Respect
Defining Disability	Community, Empowerment, Respect
Social Model	Access, Accountability, Empowerment, Respect

Quality of Life	Accountability, Community
Accommodations/Treatments	Accountability, Choice, Community, Respect
Pride/Acceptance	Community, Empowerment, Identity, Respect

Clough, P. & Corbett, J. (Eds.) (2000). *Theories of inclusive education: A student's guide*. London: Paul Chapman Publishing.

This book presents a historical overview of inclusive education practices, including how disability models have shaped policy decisions.

Themes	Values
Assistive Technologies	Community, Empowerment, Human Welfare, Trust
AT Adoption/Usage	Community, Normalcy
Defining Disability	Community, Normalcy
Social Model	Human Welfare
Quality of Life	Community, Human Welfare
Pride/Acceptance	Human Welfare, Identity
Self-Advocacy	Empowerment, Human Welfare
Embarrassment/Self-Loathing	Identity
General Support Networks	Community, Empowerment, Trust
Faculty Support	Community
Family Support	Community

Cory, R. C. (2005). *Identity, support and disclosure: Issues facing university students with invisible disabilities*. PhD thesis, Syracuse University, Syracuse, New York, USA.

Cory's thesis is about access to accommodations and the barriers that students with invisible disabilities face. Her work is also about the role of universities in providing these students a quality education. She includes discussions of disability policies, disability theories, acceptance of one's disability, reasons for disclosing or not, opinions from peers and others, and personal stories of students with invisible disabilities

Themes	Values
Assistive Technologies	Access, Accountability, Choice, Community, Empowerment, Human Welfare, Identity, Literacy, Normalcy, Privacy, Respect, Trust
AT Adoption/Usage	Access, Accountability, Choice, Fairness, Identity, Normalcy, Privacy
Social Model	Community
Quality of Life	Accountability, Human Welfare, Identity, Privacy
Education	Access, Accountability, Empowerment, Identity, Literacy
Laws	Access, Accountability
Accommodations/Treatments	Access, Accountability, Choice, Fairness, Identity, Normalcy, Privacy
Self-Advocacy	Accountability, Choice, Empowerment, Identity, Normalcy, Privacy, Trust
Embarrassment/Self-Loathing	Human Welfare, Literacy, Normalcy, Privacy, Respect
Invisibility/Disclosure	Accountability, Choice, Empowerment, Identity, Normalcy, Privacy, Respect, Trust
Stigma	Human Welfare, Identity, Literacy, Normalcy, Privacy, Respect, Trust
General Support Networks	Access, Accountability, Choice, Empowerment, Privacy, Respect, Trust

Faculty Support	Fairness, Privacy, Respect, Trust
Family Support	Identity, Respect, Trust
Support Failure	Accountability, Human Welfare, Privacy, Respect, Trust

Dawe, M. (2006). Desperately seeking simplicity: How young adults with cognitive disabilities and their families adopt assistive technologies. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 1143–1152). New York: ACM Press.

Interviews about assistive technologies with parents and teachers of young adults with severe cognitive disabilities highlight the past experiences and multiple issues of allowing students some ability to interact with others on their own while meeting the various needs of the user and relevant caretakers (family and teachers).

Themes	Values
Assistive Technologies	Access, Choice, Community, Empowerment, Human Welfare, Literacy
AT Adoption/Usage	Access, Choice, Human Welfare
Diffusion/Adoption	Choice, Community
Quality of Life	Access, Community, Empowerment
Education	Access
Accommodations/Treatments	Access, Human Welfare
Family Support	Empowerment
Support Failure	Access, Human Welfare, Literacy

Deibel, K. (2008). Course experiences of computing students with disabilities: Four case studies. In *Proceedings of the 39th SIGCSE conference on technical symposium on computer science education* (pp. 454–458). New York: ACM.

Students with disabilities taking computer science courses were interviewed to identify successful inclusive teaching practices. 3 of 4 students were not registered with disability services due to personal choices that they were in charge of that decision. Students discussed if they considered themselves as disabled.

Themes	Values
Assistive Technologies	Accountability, Choice, Empowerment, Identity, Literacy, Normalcy, Privacy, Respect, Trust
AT Adoption/Usage	Access, Accountability, Choice, Identity, Trust
Defining Disability	Choice, Identity
Diagnosis	Identity
Education	Access, Fairness
Accommodations/Treatments	Access, Accountability, Choice, Trust
Pride/Acceptance	Choice
Self-Advocacy	Accountability, Choice, Empowerment, Identity, Privacy
Embarrassment/Self-Loathing	Normalcy
Invisibility/Disclosure	Accountability, Choice, Identity, Normalcy, Privacy, Trust
Stigma	Identity
General Support Networks	Accountability
Faculty Support	Access, Fairness, Respect, Trust
Family Support	Identity

Support Failure Accountability, Empowerment, Literacy, Respect

Dickinson, A., Gregor, P., & Newell, A. F. (2002). Ongoing investigation of the ways in which some of the problems encountered by some dyslexics can be alleviated using computer techniques. In *Proceedings of the fifth international ACM conference on assistive technologies* (pp. 97–103). New York: ACM.

This paper discusses the development and early evaluation of a new AT to address specific weaknesses associated with reading disabilities. Design guidelines for addressing the strengths and weaknesses of dyslexic users are also included.

Themes Values

Assistive Technologies	Access, Choice, Fairness, Literacy
Human Factors	Access
Medical Model	Access

Edwards, J. H. (1994). *The scars of dyslexia: Eight case studies in emotional reactions*. London: Cassell.

Case studies of apparently successful high school graduates with dyslexia showed a history of negative experiences in their childhoods and education. Examples of mockery and mistreatment from peers and teachers are discussed. Ramifications of these experiences include self-doubt, difficulty trusting others, senses of isolation, and avoidance of situations where their dyslexia would evidently manifest itself.

Themes Values

Assistive Technologies	Accountability, Community, Empowerment, Human Welfare, Identity, Normalcy, Respect, Trust
Quality of Life	Community
Education	Access, Accountability, Human Welfare, Literacy
Laws	Accountability
Embarrassment/Self-Loathing	Community, Identity, Literacy, Respect, Trust
Invisibility/Disclosure	Empowerment, Identity, Normalcy, Trust
Stigma	Community, Human Welfare, Identity, Normalcy, Respect
General Support Networks	Accountability
Faculty Support	Accountability, Human Welfare, Identity, Normalcy, Respect, Trust
Family Support	Human Welfare, Identity, Normalcy

Edyburn, D. L. (2006). Cognitive prostheses for students with mild disabilities: Is this what assistive technology looks like? *Journal of Special Education Technology*, 21(4), 62–65.

This thought piece about what assistive technologies for mild cognitive and learning disabilities might look like discusses additional concerns about fairness to others, over-reliance on a device, and when should an intervention be delivered.

Themes Values

Assistive Technologies	Access, Fairness, Human Welfare, Identity, Literacy
Quality of Life	Access

Elkind, J., Black, M. S., & Murray, C. (1996). Computer-based compensation of adult-reading disabilities. *Annals of Dyslexia*, 46, 159–186.

The development and testing of a new AT to address specific deficits seen in reading-disabilities is framed as providing better access to reading for adults with dyslexia. A long-term usage study was also performed to understand the needs of the user population.

Themes	Values
Assistive Technologies	Access, Empowerment, Fairness, Literacy
AT Adoption/Usage	Choice, Human Welfare, Literacy
Medical Model	Access
Laws	Access
Stigma	Access, Empowerment

Gerber, P. J., Ginsberg, R., & Reiff, H. B. (1992). Identifying alterable patterns in employment success for highly successful adults with learning disabilities. *Journal of Learning Disabilities*, 25(8), 475–487.

Surveys of highly and moderately successful adults with LDs are conducted to identify behavioral patterns that lead to vocational success. Self-advocacy, taking control of one's disability, disclosure, and mentoring are key findings.

Themes	Values
Assistive Technologies	Access, Accountability, Choice, Community, Identity, Respect, Trust
Quality of Life	Access, Community, Identity
Pride/Acceptance	Accountability
Self-Advocacy	Choice
Invisibility/Disclosure	Accountability, Choice
General Support Networks	Access, Choice, Identity, Respect, Trust

Goffman, E. (1962). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

This treatise on labeling theory (how society identifies and reacts to minority populations and deviant groups) discusses the relationship between normalcy and stigma. Goffman also discusses the actions that a stigmatized person may take to better achieve normal interactions with others. Definitions of disability and the disabled community are also discussed.

Themes	Values
Assistive Technologies	Access, Choice, Community, Identity, Normalcy, Privacy
AT Adoption/Usage	Community, Privacy
Defining Disability	Community
Quality of Life	Choice, Community
Education	Human Welfare
Laws	Access
Accommodations/Treatments	Privacy
Pride/Acceptance	Choice, Community, Identity, Normalcy
Embarrassment/Self-Loathing	Community, Human Welfare, Identity, Normalcy, Privacy
Invisibility/Disclosure	Choice, Identity, Normalcy, Privacy
Stigma	Community, Identity, Normalcy

Gomez, M. L., Stone, J. C., & Hobbel, N. (2004). Textual tactics of identity. *Anthropology and Education Quarterly*, 35(4), 391–410.

The study in this article looks at 8th grade students in a remedial reading class and analyzes the various, deliberate tactics they use to resist being labelled as 'remedial.' Issues of race, identity, and choice are discussed.

Themes	Values
Assistive Technologies	Community, Identity, Literacy, Normalcy, Respect
Education	Choice, Community, Identity, Literacy, Normalcy, Respect
Pride/Acceptance	Choice
Embarrassment/Self-Loathing	Identity, Literacy
Stigma	Identity, Literacy, Normalcy, Respect
General Support Networks	Community
Faculty Support	Choice, Identity, Literacy, Respect
Family Support	Community
Support Failure	Literacy

Kaehne, A. & Beyer, S. (2009). Transition partnerships: The views of education professionals and staff in support services for young people with learning disabilities. *British Journal of Special Education*, 36(2), 112–119.

This article presents results from a survey of disability specialists in regards to their views on supporting the transition of students with LD into the workplace and/or higher education.

Themes	Values
Assistive Technologies	Access, Accountability, Empowerment
AT Adoption/Usage	Access, Accountability
Quality of Life	Access, Empowerment
Education	Access, Accountability, Empowerment
Accommodations/Treatments	Access, Accountability
Pride/Acceptance	Access
Self-Advocacy	Access, Accountability, Empowerment
General Support Networks	Access, Accountability, Empowerment

Kim, K. (2005). Challenges in HCI: Digital divide. *Crossroads: The ACM Student Magazine*, 12(2), 3–7.

In this discussion of the changing nature of the digital divide, the growing divide involving disabled users is discussed in detail along with other aspects of the divide.

Themes	Values
Assistive Technologies	Access, Community
AT Adoption/Usage	Community
Diffusion/Adoption	Access
Education	Access
Laws	Access, Community
Accommodations/Treatments	Community
General Support Networks	Access
Support Failure	Access, Community

King, T. W. (1999). *Assistive technology: Essential human factors*. Boston: Allyn and Bacon.

Formulated from years of experience in disability services, this book is an overview of various human factors identified as important to AT adoption. Social aspects of ATs are an important highlight.

Themes	Values
Assistive Technologies	Access, Accountability, Choice, Identity, Respect
AT Adoption/Usage	Accountability, Choice, Human Welfare, Identity, Normalcy, Respect, Trust
Human Factors	Access, Choice, Normalcy, Respect, Trust
Quality of Life	Access
Laws	Accountability
Embarrassment/Self-Loathing	Respect
Stigma	Choice, Identity
General Support Networks	Identity
Support Failure	Accountability, Respect

Kintsch, A., & DePaula, R. (2002). *A framework for the adoption of assistive technology*. Paper presented at SWAAC 2002: Supporting learning through assistive technology, Winter Park, CO, USA.

This paper presents a framework for assistive technology adoption that focus on the collaboration of the multiple stakeholders involved in an assistive technology's life cycle. Characteristics of these stakeholder groups and the communications between them are discussed.

Themes	Values
Assistive Technologies	Accountability, Choice, Community, Human Welfare, Normalcy, Respect, Trust
AT Adoption/Usage	Accountability, Community, Human Welfare, Normalcy
Social Model	Normalcy, Respect
Accommodations/Treatments	Accountability, Community
General Support Networks	Accountability, Community, Trust

Kist, W. (2004). The new literacies movement: Reading and writing in the digital age. *Independent School*, 63(4), 28–36. This article provides an overview of the different digital literacies in existence today and the implications for students, success in life, and teaching.

Themes	Values
Assistive Technologies	Literacy, Normalcy
Diffusion/Adoption	Literacy, Respect
Quality of Life	Literacy
Education	Community, Literacy, Normalcy
Embarrassment/Self-Loathing	Normalcy
Stigma	Normalcy

Klare, G. R. (2000). Readable computer documentation. *ACM Journal of Computer Documentation*, 24(3), 148–168. This published article makes the following dyslexia joke: "Reading is fun... Dyslexics have more fnu."

Themes	Values
Assistive Technologies	Respect
Education	Community

Pride/Acceptance	Respect
Embarrassment/Self-Loathing	Literacy, Normalcy
Stigma	Respect

Kriscenski-Perry, E. & McColm, G. L. (2001, January 26). Who really has learning disabilities, and How can we help them? *Chronicle of Higher Education*. (letters to the editor)

These are two letters to the editor in response to the article by Zirkel (2000). The first criticizes Zirkel's argument that some people buy the diagnoses and instead argues that wealthier communities have greater resources to identify and address LDs in early education. The second article agrees with Zirkel and adds that current accommodation policies depend on what is and is not classified as a disability. Test anxiety is provided as an example of a non-disability that could benefit from accommodations.

Themes	Values
Assistive Technologies	Access, Community, Fairness, Normalcy, Trust
AT Adoption/Usage	Access, Community, Fairness
Diagnosis	Access, Community
Quality of Life	Access, Community
Education	Access, Community, Fairness
Accommodations/Treatments	Access, Community, Fairness
Invisibility/Disclosure	Normalcy, Trust
Faculty Support	Choice, Fairness
Support Failure	Fairness

Kuusisto, S. (1998). *Planet of the blind*. New York: Delta.

This book is an autobiography of a man born legally blind but who did actively hid his blindness until his early 30s. Kuusisto discusses his family's denial, how he pretended to be able to see in childhood, his avoidance of using a white cane, and his struggle between being independent and relying on help from others.

Themes	Values
Assistive Technologies	Access, Choice, Community, Empowerment, Human Welfare, Identity, Literacy, Normalcy, Privacy, Respect, Trust
AT Adoption/Usage	Accountability, Choice, Identity, Normalcy
Diagnosis	Accountability, Identity
Quality of Life	Access, Human Welfare, Literacy, Respect
Education	Access, Human Welfare
Accommodations/Treatments	Identity, Normalcy
Pride/Acceptance	Choice
Self-Advocacy	Choice, Empowerment, Identity
Embarrassment/Self-Loathing	Identity, Respect
Invisibility/Disclosure	Choice, Community, Identity, Normalcy, Privacy, Respect
Stigma	Normalcy
General Support Networks	Normalcy, Trust
Family Support	Identity, Normalcy, Privacy

Ladner, R. E. (2008). Access and empowerment: Commentary on “Computers and people with disabilities”. *ACM Transactions on Accessible Computing*, 1(2), 1–5.

This high-level, historical review of computer science efforts regarding disabilities since 1992 discusses issues of access, research communities, and the potential for technology to empower the lives of disabled users.

Themes	Values
Assistive Technologies	Access, Community, Empowerment
Quality of Life	Access
Education	Access, Community
Self-Advocacy	Empowerment

Laga, K., Steere, D., & Cavaiuolo, D. (2006). Kurzweil 3000. *Journal of Special Education Technology*, 21(2), 79–81. Targeted towards people working in special education, this article reviews the Kurzweil 3000 software system. The variety of features is praised, although aspects of cost and licensing are criticized.

Themes	Values
Assistive Technologies	Access, Choice, Community, Empowerment, Literacy
AT Adoption/Usage	Literacy
Human Factors	Access, Choice
Education	Access, Literacy
Accommodations/Treatments	Literacy
Support Failure	Literacy

Lane, H. (1997). Construction of deafness. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 153–171). New York: Routledge.

This paper argues that being deaf is not a disability and is instead a language minority. Arguments about the social construction of disability, that disabilities are a bad thing, treatments for children born deaf, and social policy changes are discussed.

Themes	Values
Assistive Technologies	Access, Empowerment, Identity, Normalcy
AT Adoption/Usage	Community, Identity, Normalcy
Defining Disability	Community, Identity, Normalcy
Social Model	Identity
Quality of Life	Access
Education	Access, Community, Empowerment, Identity
Pride/Acceptance	Community
Self-Advocacy	Empowerment
Stigma	Identity, Normalcy
Family Support	Community

March, W. & Fleuriot, C. (2006). Girls, technology and privacy: “Is my mother listening?”. In *CHI '06: Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 107–110). New York: ACM.

A study of teenage girls and how they use communication technologies (phones, IM, etc.) to control their personal space and privacy. One study participant had dyslexia and actively avoided using instant messaging.

Themes	Values
Assistive Technologies	Choice, Literacy, Normalcy
Diffusion/Adoption	Choice, Community, Identity, Literacy, Normalcy, Privacy
Embarrassment/Self-Loathing	Literacy
Invisibility/Disclosure	Choice, Literacy
Stigma	Normalcy

Martin, B. & McCormack, L. (1999). Issues surrounding assistive technology use and abandonment in an emerging technological culture. In C. Bühler & H. Knops (Eds.), *Assistive Technology on the Threshold of a New Millenium*, Assistive technology research series (pp. 413–420). Amsterdam: IOS Press.

This is an AT usage and abandonment study from Ireland. Key elements identified include user independence, involvement in selection process, and factors such as environment, income, and gender.

Themes	Values
Assistive Technologies	Choice, Empowerment
AT Adoption/Usage	Choice, Empowerment
Human Factors	Choice
Social Model	Choice

Matthews, N. (2009). Teaching the 'invisible' disabled students in the classroom: Disclosure, inclusion and the social model of disability. *Teaching in Higher Education*, 14, 229–239.

Using perspectives from disability studies, this paper argues for greater usage of inclusive teaching practices in university education. Particular emphasis and discussion is given on the issue of disclosure for students with invisible disabilities. Student decisions, university policies, and teaching concerns are framed in relation to the medical and social models of disability.

Themes	Values
Assistive Technologies	Access, Accountability, Choice, Community, Fairness, Identity, Normalcy, Privacy, Respect
AT Adoption/Usage	Access, Community, Normalcy, Privacy
Defining Disability	Community, Normalcy
Medical Model	Fairness, Normalcy, Respect
Social Model	Community, Identity
Quality of Life	Access
Education	Access, Community, Fairness, Trust
Laws	Access, Accountability, Privacy
Accommodations/Treatments	Access, Normalcy, Privacy
Pride/Acceptance	Normalcy, Privacy
Embarrassment/Self-Loathing	Community, Identity, Normalcy, Respect
Invisibility/Disclosure	Choice, Community, Identity, Normalcy, Privacy
Stigma	Community, Identity, Privacy
General Support Networks	Accountability
Faculty Support	Access, Accountability, Community, Privacy

Support Failure Accountability, Community

McDermott, R. P. (1993). The acquisition of a child by a learning disability. In S. Chaiklin & J. Lave (Eds.), *Understanding Practice* (pp. 269–305). New York: Cambridge University Press.

This article is a case study of a young boy with a reading disability across four situations in which the knowledge of the boy's RD by others varies. Demonstrates the impact of social and cultural aspects of how disability manifests in an individual and how a disabled person can live up or down to the expectations made by others.

Themes	Values
Assistive Technologies	Community, Identity, Literacy, Normalcy, Respect
AT Adoption/Usage	Community, Normalcy
Defining Disability	Community, Normalcy
Quality of Life	Literacy
Embarrassment/Self-Loathing	Literacy, Normalcy
Invisibility/Disclosure	Community, Identity, Respect
Stigma	Community, Literacy, Normalcy, Respect
General Support Networks	Community, Identity, Respect
Faculty Support	Community, Identity, Respect
Support Failure	Identity

Mooney, J. (2007). *The short bus: A journey beyond normal*. New York: Henry Holt and Company, LLC.

This book is both an autobiography of the author's experience growing up with dyslexia and a travelogue about visiting others who are going or have gone through the special education system. Discussions of feelings of normalcy, belonging to communities, defining disability, and societies views towards disability are included.

Themes	Values
Assistive Technologies	Access, Accountability, Choice, Community, Empowerment, Human Welfare, Identity, Literacy, Normalcy, Respect, Trust
AT Adoption/Usage	Access, Choice, Community, Empowerment, Fairness, Identity, Normalcy
Defining Disability	Choice, Community, Empowerment, Fairness, Identity, Normalcy
Medical Model	Community
Social Model	Community
Quality of Life	Empowerment, Human Welfare, Literacy
Education	Access, Empowerment, Literacy
Laws	Access, Accountability, Community, Respect
Accommodations/Treatments	Access, Fairness
Pride/Acceptance	Empowerment, Human Welfare, Normalcy
Embarrassment/Self-Loathing	Human Welfare, Identity, Literacy, Normalcy
Invisibility/Disclosure	Choice, Identity, Normalcy
Stigma	Identity, Literacy, Normalcy
General Support Networks	Empowerment, Human Welfare, Literacy, Respect, Trust
Faculty Support	Literacy, Respect
Family Support	Literacy, Trust

Mooney, J. & Cole, D. (2000). *Learning outside the lines: Two ivy league students with learning disabilities and ADHD give you the tools*. New York, NY, USA: Fireside.

This survival guide for college students with LDs emphasizes working within the university community and culture to meet one's individual needs to acquire a quality education. Discussions include notions of normalcy and difference, taking pride in one's abilities, working with others (peers and teachers), and taking responsibility. Connecting with others with disabilities is also discussed.

Themes	Values
Assistive Technologies	Access, Accountability, Community, Empowerment, Fairness, Human Welfare, Identity, Literacy, Respect, Trust
AT Adoption/Usage	Access, Choice, Empowerment, Fairness, Normalcy
Social Model	Access, Accountability, Literacy
Quality of Life	Access, Human Welfare, Identity
Education	Access, Accountability, Community, Empowerment, Fairness, Human Welfare, Respect
Laws	Access, Accountability, Fairness
Accommodations/Treatments	Access, Choice, Empowerment, Fairness, Normalcy
Pride/Acceptance	Identity
Self-Advocacy	Accountability, Empowerment, Identity
Embarrassment/Self-Loathing	Human Welfare, Literacy
Invisibility/Disclosure	Empowerment
Stigma	Identity
General Support Networks	Community, Respect, Trust
Faculty Support	Human Welfare, Respect, Trust

Newell, A. F. & Gregor, P. (2000). "User sensitive inclusive design"—in search of a new paradigm. In *Proceedings on the 2000 conference on Universal usability* (pp. 39–44). New York: ACM.

In proposing an approach for AT development different from universal design, this paper argues for great sensitivity and inclusion of user voices in the design process. Paper recognizes that the opinions of people with disabilities are as valid if not more so as other people.

Themes	Values
Assistive Technologies	Access, Choice, Literacy, Respect, Trust
Social Model	Respect
Self-Advocacy	Choice, Respect, Trust
Support Failure	Access, Literacy

Phillips, B. & Zhao, H. (1993). Predictors of assistive technology abandonment. *Assistive Technology*, 5, 36–45.

AT usage and abandonment survey that emphasizes importance of user involvement in selection and supporting user independence.

Themes	Values
Assistive Technologies	Access, Empowerment, Human Welfare, Respect, Trust
AT Adoption/Usage	Choice, Empowerment, Respect
Medical Model	Respect

Quality of Life	Empowerment, Human Welfare
Support Failure	Empowerment, Trust

Pollak, D. (2005). *Dyslexia, the self and higher education: Learning life histories of students identified as dyslexic*. Stoke-on-Trent, UK: Trentham Books.

Multiple life histories of adults with dyslexia who attend or attended higher education are analyzed regarding the how dyslexia shapes an individual's sense of self. Identity issues, labelling, and accommodation strategies are discussed. How the adults define and frame dyslexia is related to strategies for success in life.

Themes	Values
Assistive Technologies	Accountability, Choice, Human Welfare, Identity, Normalcy
AT Adoption/Usage	Accountability, Choice, Empowerment, Human Welfare, Normalcy
Defining Disability	Choice, Empowerment, Human Welfare, Normalcy
Quality of Life	Accountability, Choice, Human Welfare, Identity
Education	Access, Accountability, Respect
Accommodations/Treatments	Accountability, Normalcy
Pride/Acceptance	Choice
Self-Advocacy	Choice, Human Welfare, Identity
Embarrassment/Self-Loathing	Choice, Literacy, Normalcy
Stigma	Normalcy

Poplin, M. S. (1995). The dialectic nature of technology and holism: Use of technology to liberate individuals with learning disabilities. *Learning Disability Quarterly*, 18(2), 131–140.

This article applies both a holistic and reductionistic lens to technologies for learning disabilities and discusses the need to go beyond remediation and instead embrace the user's strengths and wants. Issues of the digital divide due to race, economic status, and disability are also discussed.

Themes	Values
Assistive Technologies	Access, Empowerment, Fairness, Identity
Medical Model	Identity
Social Model	Identity
Quality of Life	Access
Education	Access, Fairness
Laws	Fairness
Self-Advocacy	Empowerment

Raskind, M. H., Herman, K. L., & Torgesen, J. K. (1995). Technology for persons with learning disabilities: Report on an international symposium. *Learning Disability Quarterly*, 18(2), 175–184.

An analysis of a 1993 symposium on ATs for LDs highlights various factors the attendees viewed as important. This includes concerns about ethics, socialization, remediation versus accommodation, respect of different cultures and opinions, and independence.

Themes	Values
Assistive Technologies	Access, Accountability, Community, Empowerment, Fairness, Respect
Medical Model	Accountability

Social Model	Accountability, Respect
Quality of Life	Community
Laws	Access, Accountability, Fairness
Support Failure	Accountability

Riemer-Reiss, M. & Wacker, R. (2000). Factors associated with assistive technology discontinuance among individuals with disabilities. *Journal of Rehabilitation*, 66(3), 44–50.

This AT adoption and abandonment study highlights important of the user's involvement in the selection process and how rehabilitation practices draw on a medical model view in which the expert knows best.

Themes Values

Assistive Technologies	Choice, Human Welfare, Respect
AT Adoption/Usage	Choice, Human Welfare
Diffusion/Adoption	Choice
Medical Model	Choice, Human Welfare, Respect
Quality of Life	Human Welfare

Rogers, E. M. (2003). *Diffusion of innovations* (5th ed.). New York: Free Press.

This seminal book is about the sociology behind technology adoption. Community drives technology diffusion but adoption and usage ultimately comes down to decisions by the interested party.

Themes Values

Assistive Technologies	Trust
Diffusion/Adoption	Choice, Community
Support Failure	Trust

Sacks, O. (1985). Wicky Ticky Ray. In *The man who mistook his wife for a hat* (pp. 92–101). New York: Harper & Row.

This case study of a young man with Tourette's syndrome discusses how a disability can be an integral part of one's identity and that treatment can have serious implications on one's sense of self.

Themes Values

Assistive Technologies	Choice, Human Welfare, Identity, Normalcy
AT Adoption/Usage	Choice, Human Welfare
Medical Model	Choice
Quality of Life	Identity, Normalcy
Accommodations/Treatments	Choice, Human Welfare
Pride/Acceptance	Human Welfare, Identity, Normalcy
Self-Advocacy	Human Welfare, Normalcy
Embarrassment/Self-Loathing	Normalcy
Stigma	Identity, Normalcy

Scherer, M. (2005). *Living in the state of stuck: How technologies affect the lives of people with disabilities*. Brookline, MA, USA: Brookline Books.

This book places emphasis on how choosing the right device can remove limitations for a person with a disability. Aside from the repercussions of the disability, other difficulties can include difficulty with achieving happiness, finding

employment, and socializing with others. How disability affects one's identity and relationships with others is a major focus as well.

Themes	Values
Assistive Technologies	Access, Empowerment, Fairness, Human Welfare, Identity, Normalcy, Respect, Trust
AT Adoption/Usage	Access, Empowerment, Fairness, Human Welfare, Identity, Normalcy
Defining Disability	Fairness, Identity, Normalcy
Medical Model	Access, Identity
Quality of Life	Empowerment, Fairness, Human Welfare, Identity, Respect
Laws	Access
Accommodations/Treatments	Access, Human Welfare, Identity
Pride/Acceptance	Identity
Stigma	Normalcy, Respect
General Support Networks	Identity
Family Support	Identity

Scott, S. S., McGuire, J. M., & Shaw, S. F. (2003). Universal design for instruction: A new paradigm for adult instruction in postsecondary education. *Remedial and Special Education, 24*(6), 369–379.

This paper discusses applying universal design to instruction in higher education. The discussion includes specific tactics, aspects of the university community, and implications for accommodation policies.

Themes	Values
Assistive Technologies	Access, Community, Fairness, Literacy
AT Adoption/Usage	Community, Fairness
Social Model	Access, Community
Quality of Life	Access
Education	Access, Community, Fairness, Literacy, Respect
Accommodations/Treatments	Community, Fairness
Invisibility/Disclosure	Fairness
General Support Networks	Access, Literacy
Faculty Support	Access

Shinohara, K. & Tenenberg, J. (2007). Observing Sara: A case study of a blind person's interactions with technology. In *Proceedings of the 9th international ACM SIGACCESS conference on Computers and accessibility* (pp. 171–178). New York: ACM.

This technology biography is of a young, blind woman discussing the technologies she uses in her life. She describes her desire to fit into the sighted world smoothly and to avoid calling attention to her blindness.

Themes	Values
Assistive Technologies	Access, Choice, Empowerment, Privacy
AT Adoption/Usage	Access, Choice, Privacy
Self-Advocacy	Choice, Empowerment
Embarrassment/Self-Loathing	Choice, Normalcy

Sitbon, L. & Belloc, P. (2008). How to cope with questions typed by dyslexic users. In *AND '08: Proceedings of the second workshop on analytics for noisy unstructured text data* (pp. 1–8). New York, NY: ACM.

This research article is about language classifiers for improving the effectiveness of spellcheckers for dyslexic users due to the different nature of their misspellings. Much of the terminology is negative (likely unintentionally) towards dyslexia and people with the condition. A strong example is in the title with the word 'cope.'

Themes Values

Assistive Technologies	Normalcy, Respect
Embarrassment/Self-Loathing	Normalcy, Respect

Spekman, N. J., Goldberg, R. J., & Herman, K. L. (1992). Learning disabled children grow up: A search for factors related to success in the young adult years. *Learning Disabilities Research & Practice*, 7(3), 161–170.

This study presents an analysis of factors that lead to success in adulthood for people with LDs. While challenges persisted into adulthood, success is possible with acceptance of disability and use of support systems.

Themes Values

Assistive Technologies	Community, Empowerment, Human Welfare, Trust
Social Model	Human Welfare
Quality of Life	Community, Human Welfare
Pride/Acceptance	Human Welfare, Identity
Self-Advocacy	Empowerment, Human Welfare
Embarrassment/Self-Loathing	Identity
General Support Networks	Community, Empowerment, Trust
Faculty Support	Community
Family Support	Community

Stampoltzis, A. & Polychronopoulou, S. (2009). Greek university students with dyslexia: An interview study. *European Journal of Special Needs Education*, 24(3), 307–321.

Sixteen Greek university students with dyslexia are interviewed regarding their experiences with dyslexia, life, and higher education. Discussions include negative childhood experiences, the benefits of successes outside of school settings, feelings pre- and post-diagnosis, and disclosure to others (intentional or not).

Themes Values

Assistive Technologies	Access, Accountability, Choice, Human Welfare, Identity, Literacy, Normalcy, Privacy, Trust
AT Adoption/Usage	Choice, Empowerment, Identity, Normalcy, Privacy
Diagnosis	Identity, Normalcy
Quality of Life	Access, Choice, Identity, Normalcy
Education	Privacy
Accommodations/Treatments	Choice, Empowerment, Privacy
Self-Advocacy	Accountability, Trust
Embarrassment/Self-Loathing	Literacy, Normalcy, Respect
Invisibility/Disclosure	Choice
General Support Networks	Human Welfare, Privacy, Trust
Faculty Support	Privacy

Family Support Community, Human Welfare, Respect, Trust

Strange, C. (2000). Creating environments of ability. *New Directions for Student Services*, 91, 19–30.

This article argues for greater recognition of different abilities on college campuses. Achieving this is framed in terms of environmental, social, and community factors. Safety and feelings of inclusion are specifically highlighted.

Themes	Values
Assistive Technologies	Community, Human Welfare, Respect
Social Model	Community
Quality of Life	Community, Human Welfare, Respect
Education	Access, Community, Human Welfare
Pride/Acceptance	Access, Respect
General Support Networks	Community
Faculty Support	Community

Swisher, J. R., Hyden, P. D., Jacobson, S. H., & Schruben, L. W. (2000). Simulation optimization: A survey of simulation optimization techniques and procedures. In *WSC '00: Proceedings of the 32nd conference on winter simulation* (pp. 119–128). San Diego, CA, USA: Society for Computer Simulation International.

In one of the author biographies, the author states that he is glad that he is not dyslexic as a joke since he has several titles with very similar acronyms.

Themes	Values
Assistive Technologies	Normalcy, Respect
Education	Trust
Pride/Acceptance	Respect
Embarrassment/Self-Loathing	Normalcy
Stigma	Normalcy, Respect
Faculty Support	Respect

Tanner, K. (2009). Adult dyslexia and the 'conundrum of failure'. *Disability & Society*, 24(6), 785–797.

This paper discusses dyslexia among adults using a framework of different kinds of failure. Failure is considered at a system (community) level, as a social construction, public versus private, in terms of family and support systems, and as a personal concept.

Themes	Values
Assistive Technologies	Access, Accountability, Community, Identity, Literacy, Normalcy, Privacy, Respect
AT Adoption/Usage	Community, Identity
Defining Disability	Community
Social Model	Normalcy
Diagnosis	Community, Identity
Quality of Life	Literacy
Education	Access, Accountability, Empowerment, Identity, Normalcy
Pride/Acceptance	Community, Identity
Embarrassment/Self-Loathing	Literacy, Normalcy, Respect

Invisibility/Disclosure	Community, Identity, Literacy, Normalcy, Privacy, Respect
Stigma	Literacy
General Support Networks	Accountability
Family Support	Accountability, Literacy
Support Failure	Access, Accountability, Community, Literacy, Normalcy

Tewey, B. P., Barnicle, K., & Perr, A. (1994). The wrong stuff. *Mainstream*, 19, 19–23.

This overview of AT abandonment emphasizes the importance of the end user's opinions and needs.

Themes	Values
Assistive Technologies	Access, Choice, Empowerment, Human Welfare, Trust
AT Adoption/Usage	Choice
Support Failure	Access, Empowerment, Human Welfare, Trust

Vance, A. (2009). Insurers fight speech-impairment remedy. *The New York Times*.

This newspaper article is about a woman and her conflicts with Medicare to get an augmented communication device. Multi-purpose technologies such as a computer are required to be stripped of functionality according to current policies, so she purchased an iPhone out of her own pocket due to the desire to have multifunctionality.

Themes	Values
Assistive Technologies	Access, Accountability, Choice, Community, Empowerment, Fairness
AT Adoption/Usage	Access, Choice, Community, Empowerment
Diffusion/Adoption	Community
Human Factors	Access, Choice
Quality of Life	Access
Laws	Access, Accountability, Choice, Community, Fairness
Support Failure	Access, Community

Weinberg, N. & Williams, J. (1978). How the physically disabled perceive their disabilities. *Journal of Rehabilitation*, 44(3), 31–33.

Adults with physical disabilities (both developmental and acquired) are surveyed in regards to how they view their disabilities. Discussions of regret, wanting a cure, advantages, and disadvantages are included.

Themes	Values
Assistive Technologies	Choice, Community, Fairness, Human Welfare
AT Adoption/Usage	Empowerment, Fairness, Human Welfare, Identity
Defining Disability	Fairness, Human Welfare, Identity
Quality of Life	Choice, Community, Fairness, Human Welfare
Accommodations/Treatments	Empowerment, Fairness
Embarrassment/Self-Loathing	Human Welfare

Whitney, C. (2006). Intersections in identity–identity development among queer women with disabilities. *Sexuality and Disability*, 24(1), 39–52.

This interview study looks at the intersection of disability and queerness and how they influence the development of identity in adult women.

Themes	Values
Assistive Technologies	Community, Identity, Normalcy
AT Adoption/Usage	Access, Identity
Defining Disability	Access, Identity
Pride/Acceptance	Empowerment, Identity, Normalcy
Embarrassment/Self-Loathing	Normalcy
Invisibility/Disclosure	Identity
Stigma	Community, Identity, Normalcy

Williams, P. & Shoultz, B. (1982). *We can speak for ourselves*. Bloomington, IN, USA: Indiana University Press.

A seminal history of the self-advocacy movement in the 1970s by people with cognitive disabilities (generally more severe than the RDs/LDs in my work). Topics of discussion include forming a community, receiving respect, and who makes decisions about care.

Themes	Values
Assistive Technologies	Access, Accountability, Choice, Community, Empowerment, Identity, Normalcy, Respect
AT Adoption/Usage	Empowerment
Defining Disability	Empowerment
Quality of Life	Empowerment
Accommodations/Treatments	Choice, Empowerment
Self-Advocacy	Access, Accountability, Choice, Community, Empowerment, Identity, Normalcy, Respect
Embarrassment/Self-Loathing	Community
General Support Networks	Community, Empowerment, Respect

Williams, W. M. & Ceci, S. J. (1999, August 6). Accommodating learning disabilities can bestow unfair advantages. *Chronicle of Higher Education*.

This opinion article raises concern about providing accommodations to college students with learning disabilities. Criticisms of current policies include the extra responsibility placed on instructors, the use of resources, the legitimacy of benefits of some accommodations, and fairness to other students. A clear distinction is made between other disabilities such as physical disabilities versus learning-disabilities.

Themes	Values
Assistive Technologies	Accountability, Fairness, Respect, Trust
AT Adoption/Usage	Access, Accountability, Fairness, Respect, Trust
Diagnosis	Access, Accountability, Fairness, Respect, Trust
Education	Accountability, Fairness
Laws	Accountability, Fairness, Respect, Trust
Accommodations/Treatments	Access, Accountability, Fairness, Respect, Trust
Support Failure	Trust

Zirkel, P. A. (2000, September 29). Sorting out which students have learning disabilities. *Chronicle of Higher Education*. This opinion article raises concern about the legitimacy of learning disability diagnoses among college students.

Arguments (without citations) are made that an increasing number of false positives are due to wealthier parents gaming the system in order for their children to reap the benefits associated with accommodations. Current legal policies and cases (circa 2000) are mostly criticized for their leniency. The author encourages professors and higher institution to more proactively question and probe LD diagnoses.

Themes	Values
Assistive Technologies	Accountability, Fairness, Respect, Trust
AT Adoption/Usage	Accountability, Fairness, Privacy, Respect, Trust
Diagnosis	Accountability, Fairness, Privacy, Respect, Trust
Education	Accountability, Fairness
Laws	Fairness, Respect, Trust
Accommodations/Treatments	Accountability, Fairness, Respect, Trust

VITA

For the first 10 years of her life, Katherine N. Deibel lived less than two blocks from a public library in Kentucky and, with the encouragement of her parents, was a frequent patron. She eventually moved on to university libraries and graduated summa cum laude from Butler University in 2001 with a Bachelors of Science in computer science and mathematics. At the University of Washington, she first worked with Dr. Henry Kautz on artificial intelligence technologies for increasing independence in people with Alzheimer's disease and dementia and earned her M.S. in Computer Science & Engineering in 2003. From there, she began pursuing research that combined her growing interests in the social aspects of technology and education research. Exploring technologies for supporting reading, she began to focus on the needs of people with reading disabilities which became her doctoral work. In 2011, she earned her Doctor of Philosophy in Computer Science & Engineering from the University of Washington. Driven in part by her passion for reading and disability advocacy, she continues to conduct research on the various intersections of disability, literacy, technology, and higher education.