Consumer Choice in Developmental Disability Services: Assessing the Impact on Quality of Life Indicators

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Abstract

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Intervention approaches with people with developmental disabilities have moved from a care model which emphasized medical treatment and rehabilitation to a support model that emphasizes consumer self-direction and choice (Mary, 1998). Despite this shift in intervention approach, there has been a lack of theoretically-guided quantitative research on the impact of consumer choice. This dissertation study presents three papers which seek to add both to the conceptual literature and the empirical literature about the impact of choice on quality of life outcomes for consumers. It employs data from Washington State's involvement in the 2002 National Core Indicators Project Consumer Survey. A final chapter addresses the practice and policy implications for local agencies.

The first paper presents a conceptual model to explain the mechanism through which choice predicts outcomes for consumers. The proposed conceptual model draws from an integrative review of the independent living perspective, empowerment theory, and social role valorization to explain how choice leads to quality of life outcomes.

The second paper is a study of heterogeneity in the developmental disability population and the access of sub-groups within the population to community-based, consumer-controlled intervention. This study employs latent profile analysis, a mixture modeling technique, to model sub-groups in the population. Two sub-groups are identified: the first fitting a severe intellectual disability profile (n=101) and the second group fitting mild intellectual disability profile (n=220). Differences between the two groups were examined. Results of this study indicate that individuals with mild intellectual disabilities experience greater participation in services that are community-based and consumer-controlled than those with severe intellectual disabilities.

The third paper presents a study of the relationship between choice, living arrangement, and quality of life indicators. Employing data from the 220 participants who fit the mild intellectual disability profile, structural equation modeling was used to assess the influence of type of living arrangement and choice on quality of life. Results of the study indicate that consumers who lived in the community and made more choices had higher scores on the quality of life indicators.

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Chapter 1: Introduction

Several years ago, I was the social worker for Jeff. Jeff was 23 years old, worked at a sheltered workshop, and lived with his mom and dad. When I called to set up an initial meeting, Jeff's mom explained that she was glad I was coming because it was time for Jeff to move out. She wanted to discuss the possibilities for where Jeff could move. I went out to Jeff's home preparing for what I thought would be an inevitable discussion about the lack of money at the state agency and the agency's policy of placement in emergency situations only. However, after meeting Jeff and completing an assessment, I realized he would need only minimal support to live on his own and that there were resources available to assist him with achieving this goal.

A few months later, Jeff, his mother, and I were sitting in a meeting with a provider agency discussing the supports he would need in order to move into his own apartment. Jeff started to confess that he was extremely nervous about this move and that he had been crying himself to sleep every night. I began to think that I had made a terrible mistake in my assessment and that he just wasn't ready to move out. At that point, the staff member from the other agency turned to him and said, "This is going to be your home, and no one is going to tell you what you're going to watch on TV, what you're going to eat for dinner, who you're going have come over to visit, or what time you're going to go to bed." At that moment, Jeff smiled. He said that maybe moving into his own place was going to work out after all.

Jeff, with help from his mother, went on to pick out an apartment and choose a roommate. When I last saw him, he was working on finding a new job that better fit his interests. Jeff became the most critical member of his support team making key decisions about his daily life and his goals for the future.

Jeff had supports that made his transition successful. He had parents and staff who believed that he was capable of making critical life decisions. In addition, formal support services were available to assist him. However, many other adults with developmental disabilities never realize the same opportunities for self-determination. While developmental disability service models espouse the idea that everyone is capable of playing an active role in planning and directing their services, lack of service providers, objections and concerns from family members, and lack of communication systems can create barriers.

The right of individuals with developmental disabilities to self-determination has become increasingly recognized in the last thirty years (Nirje, 1972; Wolfensberger, 1972). Intervention has become increasingly focused on self-determination through giving consumers greater choice and control over their services. For example, interventions like person-centered planning (Holburn & Pfadt, 1998; Kincaid, 1996; O'Brien, O'Brien, & Mount, 1997; Steere, Gregory, Heiny, & Butterworth, 1995) put the person with the disability the in role of decision maker on what types of supports are needed. It is the consumer who decides the goals of intervention and selects both the formal and informal supports that are most relevant to meeting these goals. If the consumer is unable to make all decisions independently, family and friends help.

Even more recent innovations focus on giving the consumer control over how money is spent. One example is self-directed support programs. (Ashbaugh, 2002). In a self-directed support program, the consumer is given a pot of funding and then chooses, with help from family and friends if needed, to spend the money on supports that most appropriately fit his or her needs.

Despite this shift in intervention approach, there has been a lack of theoretical literature that attempts to articulate how consumer choice translates into benefits and to explain what those benefits are. There has also been a lack of empirical literature which attempts to test our assumption that giving consumers more choice is beneficial. In addition, there remain gaps in our knowledge about whether all consumers are able to participate in consumer-directed interventions. We need a better understanding of whether some sub-groups in the developmental disability population are better able to participate in planning and selecting their services than others and whether some sub-groups benefit more from choice than others. This dissertation study presents three papers which seek to add both to the conceptual literature and to the empirical literature about the impact of choice on quality of life outcomes for consumers.

Organization of this dissertation

This dissertation consists of three essays tied together with an introduction and conclusion. It was an agreed upon goal to allow individual chapters to be free-standing papers. Hence, some of the conceptual issues presented in chapter two will be repeated in later chapters, and some of the details of measurement and sampling will be repeated in chapters three and four.

Readers may remember that the original proposal for this dissertation outlined a study of both consumer and family choice. However, it was agreed by the committee that the dissertation would be a report of the consumer study only. The study of family choice will be a separate project to be completed at a later date. The organization of this dissertation is as follows:

Chapter two is a conceptual paper that proposes a model to explain the mechanisms through which choice and decision-making might lead to more positive quality of life outcomes for consumers. I draw from the theoretical literature on self-determination, empowerment, independent living, social role valorization, and stigma theory to describe how choice exists in a context of psychological factors, service-level factors, and contextual factors and how these factors relate to quality of life outcomes. I then discuss how prior research has addressed the relationships outlined in the model.

Chapter three is a study of the heterogeneity in the developmental disability population, its implications for service use, and its implications for outcomes for consumers. This study seeks to examine whether there are unobserved sub-groups among the DD population and whether these subgroups experience differential access to community-based and consumer-driven services. Latent profile analysis is used to model sub-groups within the data set. Two sub-groups are described: the first fitting a severe intellectual disability profile and the second group fitting a mild intellectual disability profile. Differences between the two groups in demographics, in community integration of services, in choice of services and daily activities, and in community inclusion are examined. A multi-group path analysis is used to assess the relationship between choice, living arrangement, and community inclusion for each group.

Chapter four reports on a study which tests a portion of the conceptual model outlined in chapter two. Using data from the 220 participants in the Washington State National Core Indicators study, path analysis and structural equation modeling are used to assess the influence of type of living arrangement and choice on three quality of life indicators: community inclusion, opportunities for relationships, and rights. Confirmatory factor analysis is used to assess whether the three quality of life indicators load on to one common factor. The implications of the findings of this study for practice models that promote consumer choice are discussed.

Chapter five summarizes the findings of the studies in chapters three and four that are of particular relevance to agencies in Washington State. It also highlights some descriptive statistics that may be of interest to local agencies. The policy and practice implications of these findings are discussed and recommendations are made to the Washington State Division of Developmental Disabilities.

Chapter 2: Consumer choice in developmental disability services: A conceptual model

> I used to live at Rainier [School for the Developmentally Disabled]. The problem with living at Rainier is that if you want to go to 7-11 at 1:00 am to get a soda, you just can't (anonymous member of Washington State TASH, 2001).

Chapter Summary

Intervention approaches with people with developmental disabilities have moved from a care model which emphasized medical treatment and rehabilitation towards a support model that emphasizes consumer self-direction and choice (Bambara, 2004; Mary, 1998). Despite this shift in service models, theoretical work has not clearly articulated how increasing choice leads to benefits for consumers. This paper builds on prior theoretical work to refine and present a conceptual model to explain the role of consumer choice in developmental disability services. This conceptual work is based on an integrative review of the independent living perspective, empowerment theory, theories of self-determination and social role valorization. It proposes to explain how choice at a service-system level interacts with individual characteristics, psychological factors, and contextual factors to influence quality of life outcomes for consumers.

Consumer choice is an important practice value in developmental disability services. A conceptual framework to guide the research in this area may ultimately contribute to better provision of services for this population.

Introduction

Making choices is a part of daily life experience that most people take for granted. Most adults view it as their right to make decisions about their own life and their own future. However, this right has not always been recognized as an essential part of the lives of people with developmental disabilities (Halle, 1995). Traditional developmental disability service models emphasized care and treatment over self-determination. Decisions about services and treatment goals were usually made by professionals (Mary, 1998).

Over the last thirty years, service models for people with developmental disabilities have shifted to emphasize the right of people with developmental disabilities to make daily life decisions and be actively involved in planning and selecting services (Bambara, 2004; Mary, 1998). Intentional interventions have developed to increase consumer choice. For example, interventions such as person-centered planning put consumer in the role of central decision-maker as to what supports are needed, who will provide them, and what goals are most critical. The role of the professional is de-emphasized (O'Brien & O'Brien, 2002).

Despite this shift in service models, theoretical work has not clearly articulated how increasing choice leads to benefits for consumers. This paper seeks to build on prior theoretical work to refine our understanding of the role of choice in services to people with developmental disabilities. In particular, this paper seeks to contribute to our understanding of the contextual factors that are relevant to consumer choice. It also seeks to add to our understanding of what benefits might be derived from consumer choice and the mechanisms that might explain why choice would lead to benefits. This paper draws from several areas of theoretical work including: self-determination, the independent living model, empowerment theory, social role valorization, and stigma theory. I will provide an overview of these theories and then explain how they contribute to my conceptual model of consumer choice.

Self-determination

Much of the theoretical work on choice in the developmental disability field has been part of the larger conceptualization of self-determintation. Self-determination was first recognized as a right by Nirje (1972) when he called for the choices, wishes, desires, and aspirations of persons with disabilities to be taken into consideration. He noted that self-determination is particularly difficult to achieve for people with disabilities who are perceived as devalued, but that it is critical to a democratic society that people with severe disabilities participate as full citizens.

Wehmeyer and colleagues have conceptualized self-determination for people with developmental disabilities as having four essential behavioral characteristics: behavioral autonomy, self-regulated behavior, psychological empowerment, and self-realization (Wehmeyer, 1992; 2001; Wehmeyer, Kelchner, & Richards, 1996; Wehmeyer and Schwartz, 1998). Behavioral autonomy involves acting on the individual's preferences and interests free from external influence with respect to self care activities, interactions in the environment, recreational activities, and vocational activities. Self-regulation involves independently managing and monitoring one's own behavior. Psychological empowerment encompasses three areas of perceived control: locus of control, personal efficacy, and motivation. Self-realization encompasses acting on knowledge about oneself and capitalizing on one's strengths.

Wehmeyer (2001) further divides these four essential characteristics into eleven components of self determined behavior: choice-making skills; decision-making skills; problem-solving skills; goal-setting and attainment skills; self-observation, self-evaluation, and self-reinforcement skills; self-instruction skills; self-advocacy and leadership skills; internal locus of control; perceptions of self-efficacy and outcome expectancy; self-awareness; and self-knowledge. Choice-making is a combination of three components: indicating preferences, a part of the decision-making process, and an expression of autonomy and dignity (Guess, Benson, & Siegel-Causey, 1985). Wehmeyer (2001) defines decision-making as a broad set of skills which includes identifying possible actions, the consequences, and the most attractive course of action.

Wehmeyer's (2001) work provides a detailed explanation of how choice is related to psychological factors. Individuals who make more choices would be expected to have an internal locus of control. They are more likely to see outcomes as consequences of their own actions. People who make their own decisions will also have a greater perceived self-efficacy and positive expectations of outcomes. They will possess a greater understanding of their strengths, weaknesses, skills, and limitations. They will believe that they can carry out tasks and that these tasks will lead to more positive outcomes. Choice should also be accompanied by greater knowledge and awareness of oneself. Finally, people who make more of their own decisions will have better skills to advocate for what they need.

Choice, as part of the larger concept of self-determination, is usually defined as an outcome (Shervin & Klein, 2004; Stancliffe, 2001). Personal characteristics, such as intelligence level (Wehmeyer & Garner, 2003), self-knowledge, and self-acceptance

(Field & Hoffman, 1994) have been identified as factors that influence whether people experience self-determination. Choice, as an aspect of self-determined behavior, has been defined as an outcome of the psychological components of self-determination including autonomy, self-regulation, psychological empowerment, self-efficacy, and self-realization (Wehmeyer, Kelchner, & Richards, 1996).

While psychological components play an important role in determining whether people make choices, opportunities for choice are also manipulated through intentional intervention. Professionals can give consumers every opportunity to decide where they will live, where they will work, who their staff will be, and every other life decision. Or, professionals can make decisions or allow family members to make decisions without input from the individual (Guess, et. al., 1985). As an intentional intervention, consumer choice exists among a set of service-level and contextual factors as well as person-level factors. These factors need to be considered in order to gain a better understanding of the role of choice in intervention.

Context of self-determination

There has been a limited amount of research on how self-determination exists within a context which includes family, community, and institutions and how this context either facilitates or limits self-determination (Abery, 1994; Abery & Stancliffe, 1996; Stancliffe, 2001). For example, Abery (1994) points out that family members can be facilitators of self-determination if they become skilled at recognizing and responding to non-verbal cues and if they create opportunities to make choices. At the same time, families have the potential of becoming over-protective and may limit opportunities.

The service system and the community can also play a role in either facilitating or limiting self-determination. Some settings allow for a great range of choices while others do not. For example, residential environments that are community-based and individualized contribute to greater self-determination (Duvdevany, Ben-Zur, & Ambar, 2002; Stancliffe, 2001). This is most likely because smaller community living environments create more opportunities to plan around each resident's interests. Stancliffe (2001) has speculated that community-based employment would also be likely to increase self-determination. He argues that employment in the community allows the person to be more autonomous and allows the individual more options. Also, individuals who work in the community tend to make more money than individuals who work in segregated environments. Access to more money also leads to greater self-determination. Finally, Abery and Stancliffe (1996) argue that more individualized service planning processes should contribute to more self-determination.

Likewise, the community can impact a person's opportunities for self-determination. Some individuals are surrounded by neighbors that have very positive attitudes towards people with developmental disabilities that facilitate participation. On the other hand, other communities may be characterized by negative attitudes and seek to limit participation by people with disabilities in their community. For example, some neighborhoods will try to block the development of community residents for people with developmental disabilities (Abery, 1994).

Choice exists within a context. This context can either allow for a full range of options or severely restrict those options. Brown, Belz, Corsi, and Wenig (1993) point out seven ways that a person can make choice about an activity: choice within an activity, choice between activities, choice to refuse to do an activity, choice to terminate, choice of with whom to do the activity, choice of when, and choice of where. Family, staff, friends, neighbors, and other people in the person's environment play a critical role in determining whether a person has access to all of these choices.

Empowerment

Empowerment is another concept that underlies the conceptualization of consumer choice. Empowerment practice strives to give individuals, families, groups, or communities the ability to gain power (Parsons, Gutierrez, & Cox, 1998). Researchers of disability empowerment stress the importance of choice (Renz-Beaulaurier, 1994; 1998) and self-determination (Weiman, Dosland-Hasenmiller, & O'Melia, 2002) in the empowerment process. They note that people with disabilities have been traditionally deprived of opportunities to make decisions about the direction of their own lives (Weiman, et. al., 2002), and that creating opportunities to make decisions is the key to people with disabilities gaining more power over their lives (Renz-Beaulaurier, 1994; 1998).

Psychological empowerment, the process through with people gain greater control over their lives (Rappaport, 1981), is closely related to the concept of self-determination. For example, self-efficacy and locus of control have been called essential components of both self-determination and empowerment (Dempsey &

Foreman, 1997; Wehmeyer, 1994). In fact, disability activists have used self-determination and empowerment interchangeably (Wehmeyer, 2001).

While self-determination has primarily been defined at the individual level, empowerment can extend beyond the individual level to also group, organization, and community (Dempsey & Foreman, 1997). Gutierrez and Ortega (1991) define three levels of empowerment. The personal level of empowerment consists of how individuals develop feelings of personal power and self efficacy. At the interpersonal level, the focus of empowerment is on the development of specific skills which allow the individual to be more capable of influencing others. Finally, political empowerment is focused on social action and social change. Parsons, Gutierrez, and Cox (1998) stress that practice must focus on all levels to facilitate empowerment of clients.

Fawcett, White, Balcazar, Suarez-Balcazar, Mathews, Paine-Andrews, et. al. (1994) identify specific concerns that arise when applying the concept of empowerment to people with disabilities. First, they note that biological capacity or degree of impairment can impact an individual's ability to participate in empowering interventions. Second, they stress that empowerment for people with disabilities involves confronting environmental, societal, and bureaucratic barriers to full participation in society.

Parsons et. al. (1998) stress that empowerment encompasses individual characteristics and action within a larger social context including: 1) attitudes, beliefs, and values that support one's ability to affect the larger social system; 2) a collective experience that is validating to the individual; 3) knowledge and skills necessary to take action; and 4) action which leads to social change. Greene and Lee (2002) emphasize the elements of the interaction between providers and clients that create empowerment. They explain that empowerment-based interventions include the following components: developing collaborative relationships with clients, engaging in mutual decision-making, working with client-defined goals, supporting clients' self-determination, de-emphasizing the professional's role as the expert, raising client consciousness about oppression, and identifying and building on clients' strengths.

Theories of empowerment provide a framework for understanding how consumer choice as an intervention exists within a context of individual, service system, and environmental levels. Consumer choice, as part of an intentional intervention, is a service system variable. If consumers are given greater choice, this should influence the nature of the relationship that they have with the providers. Individuals who are choosing their own services and making decisions about their daily life activities would be likely to have a more collaborative relationship with their providers. We would also expect that consumers who are making more choices about their services to experience greater psychological empowerment. Finally, consumers who are choosing their own services would be more likely to take an interest in political empowerment and seek to remove physical barriers and change attitudinal barriers that limit their participation in society.

The independent living perspective

Renz-Beaulaurier (1994; 1998) and Brooks (1991) argue that empowerment of people with disabilities can best be achieved through use of the independent living model. The independent living model was first outlined by DeJong (1978; 1983). He argued that people with disabilities, not professionals, should be given the decision-making power in disability interventions. He noted that disability interventions have traditionally been administered from a medical model in which professionals control the intervention and make decisions about what supports are needed. According to DeJong (1978; 1983), it is the consumer with the disability who should be given the power to make decisions about intervention. The consumer is in the best position to know what support is needed and to decide who should provide that support. Thus, involving individuals with disabilities in service planning should lead to a better fit between the services and the individual's needs.

DeJong (1978; 1983) argued that intervention has been wrongly focused on the medical and individual aspects of the disability. Through the medical model of disability, intervention has focused on the treatment or cure of the individual's impairment or the lack of functional skill. According to DeJong, the interventions most relevant to the lives of people with disabilities are focused on removing barriers to participation in society and barriers to independent living. Thus, giving people with disabilities more choice should lead to interventions that focus on the removal of barriers and the creation supports which increase community participation.

The term independent living is not used to imply that people with disabilities will cease to use medical or social services. People live independently if they have control over their own lives and make their own decisions about what supports they need (Potter, 1996) In the context of this model, the term independent living has been used interchangeably with the terms empowerment and self-determination (Renz-Beulaurier, 1998).

The independent living model has received some criticism for its lack of cross-cultural relevance. Authors writing about Asian-Americans and American Indians with developmental disabilities have noted that these cultures value interdependence over independence. They also note that while self-determination is important, this concept needs to be redefined to incorporate the role of the family in making choices (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Langworthy & Wong-Kim, 2003). Thus, revisions to the independent living model have been suggested. The first revision involves recognition that self-determination does not always mean personal autonomy but that self-determination can happen through family and community involvement in making decisions. The second revision involves recognizing that not all cultures value moving out of the family home.

Social role valorization

Both empowerment and the independent living model focus on how to increase the consumer's power in the intervention and in the professional/client relationship. Yet, several critical aspects related to gaining this power remain under-theorized. First, it is unclear how the perceptions and attitudes of family members, staff members, and others impact whether the person gains power. Second, it is not clear how family and staff attitudes and perceptions change when the consumer does gain power in the intervention. Finally, it is unclear how gaining power translates into better outcomes for the consumer. The theory of social role valorization can make an important contribution to understanding these aspects.

Social role valorization builds on the principle of normalization. According the principle of normalization, people with developmental disabilities should be allowed to live a life as close to normal as possible. A normal life means that the person lives in a home-like environment, has a job or does activities typical of adult life, is allowed self-determination, and is allowed the dignity to take risks (Wolfensberger 1972).

Social role valorization means the adding of value to people's social roles and addresses the relationship between the welfare of people with disabilities and the social roles that they occupy. According to Wolfensberger (1983, 2000, 2002), people are devalued when they have a physical or mental impairment. This devaluation has occurred through a series of messages from both media and scientific sources, through segregation, and through a failure to occupy valued social roles (Wolfensberger, 1995). However, Wolfensberger argued that people with disabilities can gain status by obtaining more valued social roles such as employment, relationships with family members, and participating as citizens in society. When people occupy more valued social roles, they are viewed by others in a more positive way. This positive perception can further assist the person in gaining additional socially valued roles.

Wolfensberger's (1983, 1995, 2000) framework can be useful to understanding the mechanisms through which increasing consumer choice can lead to better outcomes for consumers. When a person is actively involved in planning his or her services, staff, family members, and others will perceive that person as competent to make decisions and perceive the consumer's viewpoint as valuable. This perception of the consumer as competent should extend to other areas of the person's life. For example, staff and family will believe that the person is competent to perform other socially-valued roles such as friend, citizen, and employee. Taking on more socially-valued roles should mean that the person experiences more respect for his or her rights, more relationships with friends and family, more inclusion in the community, and greater emotional well-being. In other words, the person should experience a better quality of life.

Social construction/stigma

Intentional interventions that promote choice and decision-making also confront our socially-constructed views about what it means to have a developmental disability. While there are many ways in which people with developmental disabilities are constructed as deviant, choice-making, in particular, confronts the view that people with developmental disabilities are childlike or inhuman. Jordan and Dunlap (2001) note that people with severe cognitive impairment are frequently left out of the traditional rights of passage into adulthood such as voting, marriage, consensual sex, and moving out of the family home. When left out of these adult roles, people with developmental disabilities may be viewed as eternal children instead of as adults with full membership in society.

Stainton (2001) notes that Western societies have traditionally associated human value with human reason. Philosophers have stressed that it is logical thought and reasoning that separates human beings from other animal species. This has led to the view that individuals who do not have typical abilities for logic and reason are less than human. Bogdan and Taylor (1993) note the use of the word "vegetable" when referring to people with severe or profound mental retardation, an indication that they are viewed as less than human. Bogdan and Taylor sought to understand what happens in a relationship between a non-disabled person and a severely cognitively disabled person. In a qualitative study, they found that the non-disabled person attributed human qualities to the other person by: attributing thinking to the other, seeing individuality, viewing the other as reciprocating, and defining a social place for the other.

Choice and decision-making are acts that are equated both with being human and with being an adult. Intentional interventions that give consumers more choice should combat the view that people with developmental disabilities are either eternal children or less than human. Thus, we would expect that an individual with DD who are making more choices would be surrounded by family, friends, staff, and professionals who would view them as adults. This should then lead to the belief that the individual could take on other adult roles.

In addition, people with developmental disabilities are often stigmatized. Goffman (1963) notes that disability stigma consists of strained relationships with non-disabled people and social distance from non-disabled people. Fine and Asch (1993) note that disability stigma is based on some key assumptions including that people with disabilities are "victims" and that having a disability is synonymous with needing help. Intentional interventions that give the consumer more control challenge these assumptions by giving people the opportunity to demonstration that they are active participants instead of helpless victims. Thus, we would expect to see that increasing consumer choice would lead to decreased stigma.

Conceptual model

Considering the theories outlined above, I have conceptualized consumer choice as a service system variable, fitting into a larger model of factors that influence quality of life outcomes for people with developmental disabilities (see figure 2.1 on page 27). This larger model includes four sets of factors: individual characteristics, psychological factors, service system factors, and aspects of the individual's familial and environmental context.

Empowerment and social role valorization contribute to my understanding of the relationships between factors. Empowerment theory stresses that empowerment takes place on multiple levels (Parsons, Gutierrez, & Cox, 1998). Since choice has been described as a key element of disability empowerment (Renz-Beaulaurier, 1994, 1998), choice should have a relationship to empowerment at the person-level and in the larger environmental context. The relationship of choice to these other levels is described below.

Social role valorization contributes to my understanding of the relationship of choice to other services system variables, contextual factors, and to quality of life outcomes. Choosing and planning your own services is a more socially valued role than that of passive recipient of services. Taking on this role should lead those around the individual with the disability such as friends, family members, and providers to see the individual as more competent. This view of the person as competent should lead to other socially-valued roles. These more socially valued roles should lead to better quality of life.

Individual characteristics

Some people with developmental disabilities are limited in their ability to make and express their own choices by the nature and severity of their disability. Fawcett and colleagues (1994) note that biological capacity and degree of impairment can impact an individual's ability to participate in an intervention that promotes choice. People with developmental disabilities may have limitations in their ability to communicate their choices due to physical dimensions of their disability (Taylor, 1997), or they may be limited in their ability to consider several options at a time due to cognitive dimensions of their disability. Both these physical and cognitive dimensions contribute to the individual's adaptive functioning. These aspects of adaptive functioning can impact the person's ability to interact with and communicate with professionals and may contribute to a less collaborative relationship.

Impairment also has a relationship to psychological factors and contextual factors. Impairment can impact a person's ability to acquire knowledge and skills, the person's perception of him or herself, and the individual's ability to understand how he or she is perceived by others. Impairment can also impact the relationship between the person and their social and physical context. Some disabilities can limit a person's ability to communicate which can impede social interaction. Some disabilities are more stigmatized than others. Some require more physical accommodations than others. Any model must take impairment into account.

It is important to note that impairment can impact our ability to assess and accurately measure choice. Difficulty in communication can lead to a failure to recognize the choices of people who are capable of making decisions (Brown, Belz, Corsi, & Wenig, 1993). Some people with developmental disabilities communicate through gestures and other non-verbal means. It is important to find ways to measure non-verbal and other non-traditional means of decision-making (Nozaki & Mochizuki, 1995).

Another variable that affects choice is the person's age cohort. Expectations for involvement in planning services and making daily life choices are not the same across age. Children and young adults are not expected to have the same level of input into planning their services and making life decisions as older adults. However, younger adults have been exposed to a service system that has been more receptive to their involvement. Older adults who were provided services under a professional-driven care model may have a more difficult time adjusting to a service system that demands their participation.

People in different age cohorts may also have different relationships to their communities. For example, Abraham, Gregory, Wolf, and Pemberton (2002) found that age moderated the relationship between self-esteem and community participation. Higher participation was associated with higher self-esteem for older respondents but lower self-esteem for younger respondents.

Psychological factors

The psychological factors that have the most relevance to consumer choice include: self-efficacy and positive outcome expectancies, knowledge and skills, internalized stigma, and locus of control. Based on Wehmeyer's (2001) conceptualization of self-determination, choice-making should have a bi-directional relationship to self-efficacy, positive outcome expectancies, knowledge and skills, and an internalized locus of control. People who have more knowledge and skills should have an easier time making decisions and articulating their choices. Choice should lead to an internal locus of control. At the same time, people who have an internal locus of control are more likely to see ways in which they can control their environment and are more likely to express more choices. People who make more of their own decisions should have a greater sense of self-efficacy and more positive expectations about outcomes.

Choice-making should also correspond with a decrease in the individual's internalized disability stigma. As discussed above, people with disabilities who make their own decisions will be viewed as less deviant and less stigmatized by people around them. This should correspond to people with disabilities viewing themselves as less deviant and stigmatized.

Service system factors

The degree to which consumers make their own decisions about what support they receive falls at the level of the service system. As discussed above, increasing consumer choice can be an intentional intervention in models like person-centered planning (O'Brien & O'Brien, 2002), circles of support (Certo, Lee, Mautz, Markey, Toney, Toney, et. al, 1997), and self-directed support (Ashbaugh, 2002). Service providers can afford people every opportunity to make decisions or can severely limit opportunities. Choice can occur within many areas of a person's life. Stancliffe and

Parmenter (1999) have focused on identifying those areas in which people with developmental disabilities can make choices. They have developed a choice questionnaire that includes items in the following areas: domestic activities, money, health, social activities, personal relationships, and work or day activities.

In addition, choice should be related to the nature of the professional/client relationship. Consumers who make more of their own decisions should tend to have more collaborative relationships with case managers and other professionals. At the same time, having a more collaborative relationship with a case manager or other professional will increase the opportunities that the consumer has to make their own decisions about services.

Family and contextual factors

Choice is also related to certain contextual factors. In particular, factors that have a relationship to choice are barriers in the person's environment and the family and other informal supports. Environmental barriers include not only aspects of the physical environment (e.g., lack of accessible entrances for wheelchair users) but aspects of the social and attitudinal environment as well such as attitudes of people in the community towards people with disabilities.

One can see how choice might have a relationship to environmental barriers by looking at the independent living philosophy. According to the independent living philosophy (DeJong, 1978), interventions that are the most relevant to the lives of people with disabilities address barriers to inclusion and full participation in society. Thus, people who are making their own decisions about the supports they need would attempt to address barriers to inclusion that exist in their lives. For example, this might be a choice to have a personal attendant to be able to swim at a community pool.

Social and attitudinal barriers may also create barriers to services that promote choice. For example, if a community is not very tolerant of people with disabilities, there may be fewer opportunities for community living and community employment. As a result, consumers will have fewer choices as to where they can live and work.

Choice should also have a relationship to a person's family and extended informal support system. Interventions like person-centered planning that promote consumer self-determination draw on supports like friends and family to assist in planning. Abery and Stancliffe (1996) point out that family members can either promote self-determination or become over-protective and hinder it. Thus, whether or not consumers actively participate in choosing their own services can have much to do with whether friends and family actively support them in participating in the process.

The nature of an individual's involvement in consumer-directed services may also have much to do with culture. For example, some people may not equate self-determination with personal autonomy, and it may be more consistent with their culture to involve their family in all their decisions. In addition, some adults may value living with their family of origin over living in their own home. So, continuing to live with family well into adulthood may be an important goal (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Langworthy & Wong-Kim, 2003). Culture may also influence the role that informal support plays in a person's life. For example, past research has noted that African-American families report more informal support through friends and extended family than white families (Flynt & Wood, 1989; Heller & Factor, 1988).

Thus, culture may moderate the relationship between choice and quality of life outcomes.

In addition, interventions to increase consumer choice may impact the quality of relationships that consumers have with friends and family members. Such interventions may promote the strengthening of relationships to friends and family members as consumers may choose to spend more time in these relationships. Finally, choice should lead to other people viewing the person with the disability as possessing more socially valued qualities which should lead to improved relationships.

Quality of life outcomes

Improving and enhancing the person's quality of life has become an overarching principle in human services (Schalock, Bonham, & Merchand, 2000). Schalock (2004) has defined quality of life as having eight core domains for people with developmental disabilities: interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and rights.

Increasing consumer choice could positively impact several of the domains outlined by Shalock (2004). DeJong (1978; 1983) suggests that when people with disabilities direct their own interventions, they will focus these interventions on barriers to inclusion and participation. Thus, we would expect to see increased social inclusion as an outcome of choice. Second, Wolfensberger's theory (1983; 2000) suggests that people with disabilities who make their own decisions will be more valued. Thus, we would expect to see that individual's rights will be more respected and that they will have higher quality interpersonal relationships. Finally, choice has been linked to a decrease in mal-adaptive behavior (Kern, Vorndran, Hilt, Ringdahl, Adelman, & Dunlap, 1998) and to a decrease in learned helplessness (Guess, et. al., 1985). Thus, we would expect to see greater emotional well-being in people who are making more of their own decisions.

Of the factors outlined in this model, service system factors and contextual factors should have the greatest impact on whether people with developmental disabilities experience access to quality of life outcomes. While individual or personal characteristics can impact a person's ability to communicate their hopes and desires, even people with the most severe disabilities can experience inclusion in their community, relationships with friends and family, and well-being provided that they are surrounded by support (Holburn & Vietze, 2002). What is more critical is whether friends, family, and staff that surround the person perceive it as important that the individual experience a good quality of life and facilitate that experience.

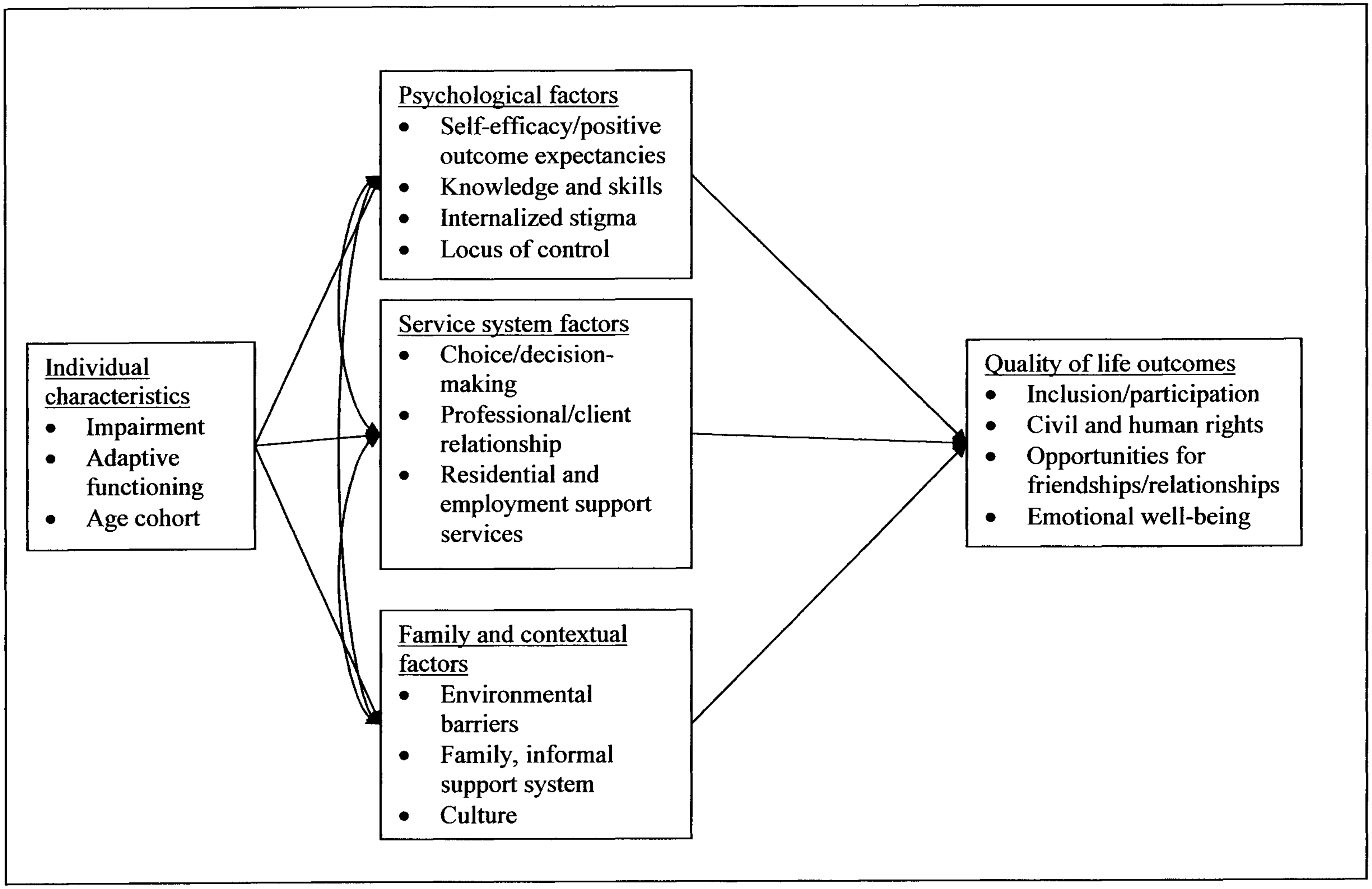

Figure 2.1: Conceptual Model

Support for the model

There is research to support many of the relationships outlined in the above model. Several studies suggest that individual characteristics play a role in predicting self-determination and community integration. First, several authors have noted a positive relationship between IQ and self-determination for people with severe intellectual disabilities (Duvdevany, Ben-Zur, & Ambar, 2002; Wehmeyer & Garner, 2003). In addition, Schalock et. al. (2000) found that higher IQ predicted greater community integration and independence. The relationship between age cohort and self-determination has also been considered. Duvdevany and colleagues (2002) noted that older respondents have higher levels of self-determination.

A few studies have focused on the relationship between stigma and other psychological factors. Abraham, et. al. (2002) studied the relationship between self-esteem and stigma. They found that higher self-esteem was associated with less internalized stigma. Likewise, Dagnan and Waring (2004) found that stigma was associated with a more negative self-evaluation.

Some studies have found that choice and self-determination have a relationship to living arrangement. Wehmeyer and Bolding (1999) found that living arrangement predicted choice but not self-determination or autonomous functioning. They also found greater lifestyle satisfaction for people who worked in the community. Duvdevany et. al. (2002) found that people living with their families had higher levels of self-determination and lifestyle satisfaction than people living in group settings. Size of living unit has also been associated with self-determination and personal control.

Residents of smaller units have been found to exercise more self-determination (Tossebro, 1995) and more personal control (Stancliffe, Abery, & Smith, 2000).

Research also suggests that choice can impact outcomes for people with developmental disabilities. In a review of research on the relationship between choice and behavioral outcomes, Kern et. al. (1998) note that choice is associated with increased engagement in a task, increased social interaction, and decreased behavioral challenges. Wehmeyer and Schwartz (1998) found a positive correlation between self-determination and quality of life.

Areas for further study

Further research is needed to explore other relationships in the proposed model. At the service system level, further research could explore whether consumers who are more involved in choosing and planning their own services have a more collaborative relationship with professionals and other service providers. Future research could also explore whether as DeJong (1978) suggests, interventions that are consumer driven eliminate more of the environmental barriers experienced by the consumer. Research is also need to explore the role of informal support by friends and family in consumer choice. Finally, future research is needed to explore whether as social role valorization would suggest, giving consumers control over their intervention leads to more socially valued roles which might include more relationships and better respect for consumer rights.

Implications

Consumer choice has become an important practice value in working with people with developmental disabilities, yet we still know relatively little about how the use of this practice value translates into outcomes for consumers. A conceptual model, such as the one above, is needed to inform the research agenda in this area. A strong conceptual model may ultimately lead to stronger research which could translate into better practice and ultimately, better outcomes for consumers.

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Chapter 3: Heterogeneity in the developmental disability population: Implications for community-based, consumer-directed services

Chapter summary

"Developmental disability" is a term used to describe a diverse population with many different diagnoses and needs for services. Yet, few research studies have attempted to assess the heterogeneity in this population, to examine its implications for service use, and to assess differential patterns in outcomes among sub-groups in the population. This study employed latent profile analysis, a mixture modeling technique, to assess heterogeneity in a sample of 321 adults with developmental disabilities who participated in Washington State's National Core Indicators Project. Class membership was modeled using two measures of severity of intellectual disability. Examination of the fit indices showed that a two-class model fit the data best with the first class having a severe intellectual disability profile (n=101) and the second class having a mild intellectual disability profile (n=220).

Differences between the two groups were examined. The severe intellectual disability group was more likely to have a guardian or payee, to have co-morbid diagnoses, to have mal-adaptive behavior, to need greater in-home support, and to experience institutionalization. The mild intellectual disability group experienced smaller and more community-based residential and employment services and participated more frequently in choosing their own services than the severe group. A multi-group path analysis was used to assess the impact of size of living unit and consumer decision-making on community inclusion for each group. Results indicated

that smaller living units and choice in services had a stronger relationship to community inclusion for people with severe intellectual disabilities than for people with mild intellectual disabilities.

Consumer direction and community integration are key developmental disability practice values. Results of this study indicate that individuals with mild intellectual disabilities experience participation in services that reflect these practice values more frequently than those with severe intellectual disabilities, yet services had a greater influence on community participation for people in the severe group.

Introduction

In recent years, two key intervention concepts have emerged in the developmental disabilities field. The first is that that services should be provided in integrated, community-based settings (Mary, 1998). The second is that consumers should have as much choice and direction over these services as possible (Kincaid & Fox, 2002). These principles of intervention are widely accepted today in developmental disability services (Everson & Reid, 1997). Yet, we do not know whether some subgroups developmental disability population are better able to access these types of interventions than others. In addition, it is unclear whether community-based, consumer-controlled services lead to more benefits for some subgroups than for others. This study attempts to address these gaps in the literature by examining the relationships between level of disability to type of residential setting, consumer choice, and community inclusion.

Research on consumer choice and community living has suggested that the two concepts are correlated. Wehmeyer and Bolding (1999) found that living arrangement predicted choice and that greater lifestyle satisfaction was correlated with work in the community. In addition, people living with their families have been found to have higher levels of self-determination and lifestyle satisfaction than those living in group settings (Duvdevany, et. al, 2002). Size of living unit has also been associated with self-determination and personal control. Residents of smaller units have been found to exercise more self-determination (Tossebro, 1995) and more personal control (Stancliffe, Abery, & Smith, 2000).

Research also suggests that both choice and living arrangement can have a relationship to the amount of community inclusion that people with developmental disabilities experience. Residents of state institutions have been found to have poorer integration in the community and less contact with families than those living in smaller, community settings (Stancliffe & Lakin, 1998). Consumer direction has been found to predict community integration (Kosciulek & Merz, 2001).

Yet, some authors note that people with severe intellectual disabilities may not experience the same level of involvement in consumer direction as people with milder intellectual disabilities. Reid and Green (2002) note that people with severe and multiple disabilities face barriers to participating in their service planning due to their cognitive impairments, physical impairments, and their ability to communicate. They further explain that this subgroup of the developmental disability population has not realized the same quality-of-life benefits from consumer-driven interventions as people with mild and moderate intellectual disabilities. People with severe disabilities also experience barriers to expressing choices. Other researchers have noted that people with severe and profound disabilities do not express choices in the same way as other people with developmental disabilities. Thus, they point to a need to focus on how various forms of communication including non-verbal gestures can be an expression of choice (Guess, Benson, & Siegel-Causey, 1985; Grove, Bunning, Porter, & Olsson, 1999; Nozaki & Mochizuki, 1995).

Furthermore, studies have noted that adaptive behavior and intelligence quotients have a relationship to self-determination (Wehmeyer & Garner, 2003), quality of life (Felce, Jones, & Lowe, 2002), and type of living arrangement (Lakin, Anderson, Prouty, & Polister, 1999). People with higher IQ scores have been found to experience greater self-determination (Duvdevany, Ben-Zur, & Ambar, 2002; Wehmeyer & Garner, 2003). In addition, Shalock et. al. (2000) found that higher IQ predicted greater community integration and independence. Lakin and colleagues (1999) have noted that the people who remain in MR/DD institutions have more severe impairments while people with mild and moderate disabilities have been moved out.

"Developmental disability" is a term that describes a range of mental and physical impairments and a range of adaptive behavior skills (Cotton & Spirrison, 1991). It encompasses a number of etiologies (Baumeister & Baumeister, 2000). This variation in impairments means that people with developmental disabilities are a heterogeneous population with varying service needs (Smith, 2002). Yet, community-based, consumer-controlled interventions have been developed to serve the entire population (Reid & Green, 2002). This study seeks to further our understanding of whether these interventions techniques are accessed equally by all members of the developmental disability population. This study also seeks to add to our knowledge about whether subgroups in the population are benefit more from community-based, consumer-controlled interventions. Failing to understand this may mean that some individuals are not adequately served.

This study seeks to contribute to the literature by examining differences in subgroups with severe and mild intellectual disabilities. First, this study will identify subgroups in the developmental disability population using indicators of severity of disability. Then, it will examine the differences in subgroups with respect to demographic characteristics, service use patterns, access to needed services, consumer direction in services, and community inclusion. Finally, this study will assess the influence of community integration of respondent's living arrangement, an aspect of community-based intervention, and consumer choice, an aspect of consumer-controlled intervention, on community inclusion in each subgroup.

Data Source

Data from Washington State's involvement in the National Core Indicators Project (NCI) in 2002 were used in this study. This survey is conducted annually with the purpose of developing performance and outcome indicators that state developmental disability authorities can use to evaluate the performance of their service system. NCI collects data through the use of consumer surveys, family and guardian surveys, provider surveys, and administrative data. The domains measured include: community inclusion, choice and decision-making, self-determination, relationships, satisfaction, service coordination, family and individual participation, access, health, and safety. The present study employs only the 2002 consumer surveys (Human Services Research Institute, 2001a, 2001b).

The consumer survey had three sections. The first section, which included questions about demographics, diagnoses, health, residence, services, features of self-determination, and frequency of problem behavior, was mailed to case managers. This section was completed prior to the face-to-face interview. The second section, which included questions about work and daytime activities, home, friends and family, and services of supports, was a face-to-face interview completed with the consumer. Questions in the second section were only asked of the consumer. No proxy respondents were used in this section. Consumers were given the option of responding to the questions verbally or responding with pictures. The third section, which included questions about community inclusion, choice, rights, and access, was also a face-to-face interview with the consumer. If the consumer was unable to answer the questions in this section either verbally or with pictures, the questions were asked of a proxy. Proxy respondents included advocates, family members, home staff, and day staff.

Data used in this study are from the first and third sections of the survey. The majority of the respondents with severe or profound mental retardation were unable to answer questions in the second section of the consumer survey either verbally or with pictures responses. Thus, data from this section is missing for a substantial subset of respondents and cannot be analyzed in the present study.

Sample

Participants were selected by simple random sampling of the population of consumers over the age of eighteen who receive services from the Washington State Division of Developmental Disabilities. The sampling pool consisted of approximately 11,680 adults. An initial sample of 2000 was drawn using a random number generator. Descriptive statistics for the initial sample are reported below. Age, gender, race, and ethnicity were the only descriptive statistics available for the initial sample that could be compared to the final sample that participated in the study.

Out of these 2000 consumers, 1478 had deliverable addresses and did not refuse the initial request to participate to participate in the study. These individuals or their legal guardians were re-contacted by mail for consent to participate in the study. Once the consent form was received, the case manager was contacted by mail and asked to complete the background information section of the survey form. Finally, the consumer was contacted to complete the face-to-face interview.

343 respondents participated in the study. Nine individuals were unwilling to complete the consumer interview, and data from these individuals were removed. In addition, thirteen cases were removed because more than fifty percent of the data was missing. This left a total of 321 cases. Respondents ranged in age from 20 to 84 with an average age of approximately 40 years. As is typical in the DD population, the majority of the respondents were male (53.3%). The majority of the sample (90.6%) was white. Other respondents reported their race or ethnicity as American Indian, Asian-American,

African-American, Latino, and other. The sample did not significantly differ from the sampling pool in terms of age, gender, race, or ethnicity. See table 3.1 below.

Table 3.1: Sample statistics

	Initial sample n=2000	Participating sample n=321	Test statistic
Age – mean (SD)	39.0 (13.2)	39.9 (13.9)	t=1.13
Gender (percent male)	56.2%	53.3%	χ^2=1.12
Race/Ethnicity			χ^2=4.62
American Indian	2.5%	1.3%	
Asian/Pac. Islander	2.6%	2.2%	
African-American	4.0%	2.3%	
White	87.5%	90.6%	
Other	2.5%	3.4%	
Latino	2.7%	2.9%	χ^2=.04

Measures

Severity of intellectual disability

Two measures of severity of intellectual disability were used to assess subgroup membership: level of mental retardation and ability to understand the survey instrument. Level of mental retardation was assessed as part of the questionnaire answered by the case manager and had five possible response categories: 0 = no mental retardation, 1 = mild, 2 = moderate, 3 = severe, and 4 = profound. Level of understanding of the survey was assessed during the consumer interview. Upon completion of the face-to-face interview, the research study interviewers were asked to assess the respondent's ability to answer the questions on the survey instrument. Interviewers were given three possible response categories: 2 = understood most or all of the questions, 1 = unsure whether consumer understood the questions, and 0 = very little understanding or comprehension.

Legal/financial status

Case managers were asked whether the individual was a legally competent adult, had a private guardian, or had a public guardian. Responses to the question were recoded into two categories: legally competent adult or has guardian. A second question asked case managers whether the respondent had a payee. Both variables were coded dichotomously: 0 = no payee/guardian and 1 = has payee/guardian.

Diagnoses

Case managers were asked whether the respondent had a record of any of the following diagnoses: mental illness, autism, cerebral palsy, brain injury, seizure disorder, vision or hearing impairment, physical disability, or communication disorder. Each variable was coded dichotomously (0 = no, 1 =yes).

Maladaptive behavior

Staff or family members were asked about the frequency of three types of mal-adaptive behavior: self-injurious behavior, disruptive behavior, and uncooperative behavior. First, proxy respondents were asked whether each type of behavior occurred. Then, a follow-up question was asked about frequency. The five possible response categories for frequency ranged from less than once a month to one or more times an hour. Data on each type of maladaptive behavior was recoded into one variable with a range of 0 to 2 with a low score indicating no incidences of the particular problem behavior to a high score indicating frequent problem behavior. For example, self-injurious behavior was recoded into: 0 = no self-injury, 1 = less than one time per week, and 2 = one time per week or more.

Living arrangement/support services

Case managers were asked several questions about the respondent's residential setting. The amount of support the person needed at home was measured on a four point scale with possible responses ranging from 0 to 3. A low score indicated as needed visitation and phone contact and a high score indicated that twenty-four hour on-site supervision is required.

Case managers were asked to characterize the person's residence. The seven possible response categories were recoded to create a measure of level of community integration of the residential environment with three categories: 2= institutionalized, 1 = community-based group living, and 0 = own home. Individuals living in specialized MR/DD facilities or nursing homes were considered institutionalized. Group home, agency-operated apartment setting, and foster care/host home were recoded into one category of community-based group living. Foster care was included in the community-based group living category since the model of adult foster care most commonly used in Washington State, the adult family home, more closely resembles a group home environment than an individual's own home. Individuals who lived in their own home or apartment and those who lived with a parent or relative were recoded into one category.

Case managers were asked an open-ended question about how many people with developmental disabilities live in the person's immediate residence. To address problems with skew, responses to this question were recoded into four categories: one person (or, the study participant only), two to three people, four to eight people, and nine or more. Thus, this variable was coded 0 to 3 with a higher score indicating more people with DD living in the residence.

Case managers were asked to characterize who owns the study participant's home. The five possible response categories (family or guardian owned, agency or provider owned, state owned, owned by the study participant, or leased by the study participant) were recoded into two categories: 1 = state- or agency-owned, 0 = individual- or family-owned or leased.

Finally, series of questions asked about whether the respondent received any type of day or employment support services. Categories of services included: supported employment, group employment, facility-based employment, or non-vocational day program. All variables were coded dichotomously: 0 = did not receive service, 1 = did receive service.

Features of self-determination

Case managers were asked whether the person had any one of five features of self-determination: an individually negotiated budget, a person-centered plan, a relationship with a fiscal intermediary, a microboard, or a support broker or personal agent. Responses to these questions were combined to create an index of self-determination which had a range of 0 to 3 with a low score indicating no features of self-determination.

Choice

Nine questions about consumer choice were used in this study: chooses schedule, chooses free time, chooses what to buy, chose home, chose roommates, chose home staff, chose case manager, chose job, and chose job staff. All questions were coded from zero to two with 0 indicating that someone else decides, 1 indicating that the person has help deciding, and 2 indicating that the person decides independently. All items were asked of the consumer. If the consumer was unable to respond, then a proxy respondent answered the question instead. A separate variable indicated whether the consumer or a proxy responded to each question.

Three items were recoded to include respondents with missing data. Participants who responded that they had no home staff were recoded as "yes, chose all staff" because it was decided that not requiring the assistance of home staff and choosing all of your own home staff represent the same level of self-determination. Five participants who indicated that they had no case manager were recoded as having not chosen. These five participants did in fact have a case manager who responded to the first part of the survey. It was assumed that because they were not familiar with their case manager, they had not selected him/her. Study participants who indicated that they did not have a job or day program were recoded as "no" because it was decided that not having a job or day program and having no choice of activity represented the same level of self-determination.

Both individual items and an index were used in the analysis. The index, used in the path analysis, combined the six items for which there was no skip pattern: chooses schedule, chooses free time, chooses what to buy, chose home staff, chose case manager, and chose job. Items were combined to create a measure of choice with a range of 0 to 12.

Community inclusion

Eight questions were asked about the consumer's inclusion in the community. Consumer's were asked whether they: go shopping, go out on errands, go out for entertainment, go out to eat, go out to religious services, go to clubs or community meetings, go out for exercise or sports, and who the respondent goes with. Responses to each question ranged from 0-2 with a low score indicating no inclusion and a high score indicating access to the community. Questions with no middle category were coded as either 0 or 2. Three questions: go out for religious services, go out for sports or exercise, and who the respondent goes with, had a possible middle response category indicating that the person participated in the activity in a less inclusive setting or with less choice in participation. Questions about community inclusion were asked to the consumer. If the consumer was unable to respond, a proxy answered instead. A separate item measured whether the consumer or a proxy had responded to each question.

Community inclusion items were used in the analysis both separately and as part of a community inclusion index. To create the index, responses to these eight questions were combined forming a measure of community inclusion with a range of 0 to 16.

Rights

Two questions on rights were used in this analysis. Consumers were asked whether they could be alone with guests and whether they went to a self-advocacy group. Responses to these questions ranged from 0 to 2 with a low score indicating no access to this right and a high score indicating full access. Respondents who never had quests did not respond to the first questions. These two rights questions were asked either of the study participant or of a proxy. While there were other questions about rights in the National Core Indicators survey, response patterns rendered them unusable in this particular analysis.

Needs met

One question asked respondents whether they received needed services. Responses to this question ranged from 0-2 with a low score indicating that the person did not get needed services and a high score indicating the individual always gets needed services. This question was answered either by the consumer or by a proxy respondent.

Respondent

Proxy respondents were used if the consumer was unable to respond to part or all of the questions in the final section of the survey (questions on choice, community inclusion, access to needed services, and selected questions on rights). Each interview question with a possible proxy respondent had an indicator of whether the consumer answered the question or whether it was answered by a proxy respondent. Both the individual items and an index were used in the analysis. Scores on the index ranged from 0 to 3 with a score of zero indicating that the consumer responded to no questions, a score of one indicating that the consumer answered less than half of the questions, a score of two indicating that the consumer answered more than half, and a score of three indicating that the consumer answered all questions.

Data analysis

Data was analyzed using SPSS 13.0 and MPLUS version 3.0. I used the SPSS 13.0 Missing Value Analysis module to analyze missing data patterns. The data set had a varying range of missing data and twenty-five complete cases. SPSS MVA imputes values for continuous variables through a maximum likelihood method based on Little and Rubin's (1987) work on EM algorithms. Missing data was not imputed for categorical variables or data from questions asked solely to consumers in the second section of the survey. It was assumed that the consumers with missing data failed to respond to these questions for non-random reasons related to their ability to communicate. Thus, imputing data might lead to biased estimates. The Little's MCAR (missing completely at random) test was not significant (χ^2 = 4265.02, DF=4340) suggesting that the data was missing for reasons not related to the variables in the data set (Schafer & Graham, 2002). Cases that had imputed values outside the range of the variable were recoded to either the highest or lowest meaningful value as appropriate.

To identify heterogeneity in developmental disability, I used latent profile analysis. Latent profile analysis, a form of mixture modeling, is a person-centered approach which assesses whether there are unobserved subpopulations within the data. It is well suited to data in which heterogeneity in some aspect of the subjects' characteristics or behavior is believed to be due to membership in unobserved latent classes. It tests whether there is an underlying theoretical typology that fits the data (McCutcheon, 1987).

Two variables were used to assess for heterogeneity: level of mental retardation and level of understanding of the survey instrument. Level of mental retardation was chosen because it is the best indicator of severity of intellectual disability. However, responses to this variable relied on records which had the potential of being several years out of date. Thus, level of MR was used along with a measure of current intellectual functioning: level of understanding of the survey instrument.

The LPA was accomplished using MPLUS version 3.0 (Muthen, & Muthen, 2004). The number of classes was determined iteratively by specifying a number of classes and interpreting the results. Fit of the model was determined by examining the Bayesian Information Criterion (BIC) and entropy. Additionally, a random set of multiple start values were tested to insure a proper solution (Muthen & Muthen, 2004).

Once classes were identified, SPSS 13.0 was used again to further examine class differences. Chi-square tests of independence were applied to the relationship between class and gender, race, legal/financial status, diagnoses, employment supports. Independent samples t-tests were applied to the relationship between class membership and maladaptive behavior, residential support, and features of self-determination. Significance was defined as .05 for all data analyses.

Classes were also compared on their opportunities to participate in daily life choices, inclusion in the community, whether they receive needed services, and rights. The relationships between these variables and class membership could not be directly assessed due to variations in the type of respondent. While some study participants answered all the questions on the survey instrument, other respondents were unable to complete all questions and a proxy respondent answered instead. Prior research has suggested that answers given by consumers and proxies may not be directly comparable (Stancliffe, 1995, 2000). One method of dealing with the influence of proxy is to collect data on whether study participants or proxies responded and to use the information as a control variable (Schalock, Bonham, & Marchand, 2000). This is the method employed in this study. Using the individual proxy respondent items that corresponded to each variable, the influence of respondent on both class and the dependent variable was partialed out and the correlation of the residuals was examined.

Finally, a multiple group path analysis was used to assess the influence of choice and size of living arrangement on community inclusion for each group. MPLUS version 3.0 was used to complete this path analysis. An unconstrained model was run estimating the model parameters for each group separately. Then, a cross-group equality constraint (Kline, 1998) was imposed forcing the same parameters to be estimated for each group.

To assess the goodness of fit, four indexes were used: the Satorra-Bentler rescaled chi-square statistic, the Comparative Fit Index (CFI), the Root Mean Square Error of Approximation (RMSEA), and the Standardized Root Mean Square Residual (SRMR). These indices are recommended by Hu and Bentler (1998) because they are sensitive to model misspecification but less affected by estimation method, non-normal distribution, and small sample size than other indices. The CFI has typical values between 0 and 1 with a value greater than .9 indicating a good fit (Kline, 1998). Scores close to zero on the RMSEA and the SRMR indicate a better fit. Values of less than .10

are desirable for the SRMR. The RMSEA can be interpreted as follows: values less than .05 indicate a close fit, values between .05 and .08 indicate an acceptable fit, values in the range of .08 to .10 indicate a mediocre fit, and values above .10 indicate a poor fit (MacCullum, Browne, & Sugawara, 1996). In addition, the Satorra-Bentler rescaled chi-square statistic was chosen because it reduces bias associated with non-normality. Finally, the Lagrange Multiplier test was used to examine the constrained parameters in the constrained model. This test approximates the amount by which the overall chi-square would decrease if a particular parameter were freely estimated (Kline, 1998).

Findings

The sample included 343 individuals with developmental disabilities. Ninety-one percent of the respondents had a diagnosis of mental retardation with the most frequently reported specifiers being mild (33%) or moderate (25.5%). The most frequently reported other diagnoses were seizure disorder and psychiatric disorder with 32.4% and 20.4% respectively. Other diagnoses reported included autism, brain injury, cerebral palsy, physical disability, communication disorder, and visual or hearing impairment.

Most study participants did not experience maladaptive behavior. Only 15.9% were reported to engage in self-injury, 28.3% had disruptive behavior, and 18.7% had uncooperative behavior. Most respondents (72.3%) needed twenty-four hour on-site support. However, most (62.6%) lived in their own home or with a family member and were the only person with a developmental disability living in their household (44.5%).

The most frequently used type of job or day program was supported employment (40%). See table 3.2 for more descriptive statistics.

Sample heterogeneity

A latent profile analysis was performed to assess heterogeneity in the sample with respect to intellectual disability. Two indicators of class membership were used: level of mental retardation and level of understanding of the survey instrument. The two indicators had a correlation of -.66.

Comparisons between BIC values for a one-class model (BIC = 1915.89), a two-class model (BIC = 1373.08), and a three-class model (BIC = 1391.87) indicated that the two-class model had the lowest BIC value and thus, fit the data best. In addition, the three-class model produced one very small class (n=9) that made it not as interpretable as the two-class model. In the two-class model, the average class probabilities for assignment were .99 for each class indicating that the class memberships were cleanly defined.

Class one, which had 101 members, had an average of severe mental retardation (mean = 3.30). In addition, most respondents in this class were not able to understand or respond to the survey questions (mean = .10). Class two, which had 220 respondents, had an average of mild mental retardation (mean = 1.42) and understood most of the survey questions (mean = 1.91). Results of the latent profile analysis are reported in table 3.2.

Naming the two classes is somewhat problematic. Most of the terminology that is used to describe people with developmental disabilities is stigmatized. New terminology that is put forth inevitably takes on the stigma associated with the old terminology (Danforth, 2002; Smith, 2002). In addition, the measures that were used for estimating class membership, although somewhat crude, assess both the respondent's intellectual ability and current adaptive functioning. Any name given to the classes would need to take both these aspects of ability and functioning into account. With these considerations, I believe that the best way to describe these two classes is to call class one the "severe intellectual disability" group and class two the "mild intellectual disability" group. These are the terms I will use for the remainder of this paper.

Table 3.2: Results of latent profile analysis of severity of intellectual disability

	One-class model		Two-class model			
	(full sample n=321)		Class 1 (n=101)		Class 2 (n=220)	
	Mean	SD	Mean	SD	Mean	SD
Level MR	2.01	1.26	3.30	.86	1.42	.93
Understand	1.34	.89	.10	.30	1.91	.29
BIC	1915.89		1373.08			
Entropy			.95			
Average class probabilities			.99		.99	

Comparison of the mild and severe intellectual disability groups

No differences were found between the mild intellectual disability group and the severe intellectual disability group with respect to age, race, or ethnicity. However, there were differences with respect to gender. The group with severe intellectual disability was more likely to be male. Differences were also found with respect to certain diagnoses. While there were no differences in the two groups in prevalence of psychiatric diagnosis, cerebral palsy, autism, or brain injury, the individuals with severe intellectual disabilities were more likely to have seizure disorders, physical disabilities, communication disabilities, and visual or hearing impairments. There were also differences in maladaptive behavior. Individuals with severe disabilities were more likely to engage in self-injury, disruptive behavior, and uncooperative behavior.

The two classes also differed with respect to the amount and type of support services that they received. The individuals with severe intellectual disabilities needed more staff support, were more likely to be institutionalized and living in larger group arrangements, and were less likely to live in their own home or a family-owned home. Differences were also found in day and employment programs. Individuals with mild intellectual disabilities were more likely to receive supported employment while individuals with severe intellectual disabilities were more likely to receive facility-based employment programs or non-vocational day programs. However, no differences were found between groups in features of self-determination. People with severe disabilities had the same access to service models that promote self-determination (e.g. person-centered planning, an individually negotiated budget, etc.) as people with mild disabilities. See table 3.3 for class comparison.

Table 3.3: Full sample and group characteristics

	Full sample n=321		Severe ID n=101		Mild ID n=220		Test stat. T (χ2)
	M/%	SD	M/%	SD	M/%	SD	
Age	39.9	13.9	41.5	13.6	39.2	14	1.39
Gender (% male)	53.3		62.7		49.1		(4.91)*
Race/ethnicity							(5.81)
American Indian	1.3		0.0		1.9		
Asian/Pac. Islander	2.2		2.0		2.4		
African-American	2.3		1.0		2.9		
White	90.6		95.0		88.5		
Other	3.4		2.0		4.3		
Latino	2.9		2.0		3.3		(.39)
Other diagnoses[1]							
Seizure disorder	32.4		59.4		19.8		(49.33)***
Psychiatric DX	20.4		19.8		20.7		(.04)
Cerebral Palsy	17.9		20.8		16.6		(.83)
Physical disability	17.6		32.7		10.6		(23.15)***
Communication dis.	17.0		37.6		7.4		(44.74)***
Visual/hearing imp.	16.7		27.7		11.5		(13.03)***
Autism	5.0		7.9		3.7		(2.49)
Brain injury	4.7		7.9		3.2		(3.38)
Maladaptive beh.[2]							
Self-injury	.21	.52	.46	.74	.10	.33	4.61***
Disruptive behavior	.40	.68	.71	.82	.25	.55	5.18***
Uncooperative beh.	.24	.53	.37	.66	.18	.45	2.62**
Legal/financial status[1]							
Guardian	62.3		89.1		49.3		(42.99)***
Payee	90.5		99.0		86.0		(12.53)***
Res. Support							
Amount staff support	2.57	.81	2.94	.24	2.40	.91	8.19***
Type of home	.53	.75	1.10	.85	.27	.52	9.03***
# residents with DD	1.99	1.06	2.68	1.10	1.67	.88	8.19***
Own home[1]	64.7		36.8		78.2		(47.95)***
Waiver	47.7		38.1		52.2		(4.58)*
Employ. Services[1]							
Supported employ.	40.0		19.1		50.6		(24.39)***
Voc.-group	11.9		7.0		14.7		(3.09)
Voc.-facility	25.1		37.4		17.9		(11.52)***
Non-voc. Day	22.4		38.9		12.6		(22.45)***
Self-deter.	1.12	.77	1.19	.77	1.09	.77	1.06

* p<.05, **, p<.01, *** p<.001

[1] Missing values were not imputed for categorical variables. Class 1 had 89-101 respondents. Class 2 had 151-217 respondents.

[2] 0 = no maladaptive behavior, 1 = less than once a week, 2 = once a week or more

After controlling for the effect of proxy respondent, differences were found between groups in their expression of choices. Individuals with mild intellectual disabilities were more likely to choose their daily schedule, to choose what they would do in their free time, to choose what they buy, to have chosen their home, their roommates, their job, and their job staff than individuals with severe intellectual disabilities. The only non-significant finding was in home staff. Both zero-order and partial correlations are reported in table 3.4.

Fewer significant differences existed between the two groups with respect to opportunities for community inclusion, rights, and whether they felt they received needed services. Controlling for proxy respondent, people with severe intellectual disabilities were as likely to be allowed to be alone with guests, to receive needed services, and to experience most aspects of community inclusion. Significant differences were found for go to a self-advocacy meetings, go to clubs or community events, and who the person goes with into the community. People with severe intellectual disabilities were less like to go to self-advocacy meetings and more likely to go into the community in large groups. Interestingly, people with severe intellectual disabilities were more likely to participate in clubs or community events. However, this difference was not significant in the zero-order correlation and appeared only after the influence of proxy respondent was controlled for. Results of these analyses can also be found in table 3.4.

Table 3.4: Choice, community inclusion, and needed services with respondent partialed out

	Full sample Mean(SD)	Severe ID Mean(SD)	Mild ID Mean(SD)	Zero-order correlation	Partial correlation
Choose schedule N=315	1.31 (.77)	.69 (.72)	1.60 (.61)	.56***	.29***
Choose free time N=315	1.57 (.64)	1.14 (.74)	1.77 (.47)	.46***	.21***
Choose buy N=312	1.39 (.71)	.83 (.74)	1.65 (.52)	.54***	.24***
Chose home[1] N=227	.64 (.70)	.17 (.47)	.90 (.67)	.51***	.20**
Chose roommates[1] N=208	.81 (.89)	.24 (.51)	1.18 (.89)	.51***	.14*
Chose home staff N=266	.79 (.83)	.48 (.64)	.97 (.87)	.28***	.07
Chose job N=269	1.62 (.71)	1.28 (.54)	1.79 (.72)	.34***	.16*
Chose job staff[2] N=203	.62 (.69)	.45 (.58)	.71 (.71)	.21**	.14*
Get services N=310	1.57 (.70)	1.60 (.65)	1.56 (.72)	-.02	-.07
Alone with guests[3] N=229	1.68 (.60)	1.44 (.74)	1.77 (.51)	.25***	.09
Self-advocacy N=282	.69 (.92)	.43 (.81)	.79 (.94)	.19**	.14*
Go shopping N=315	1.79 (.61)	1.58 (.82)	1.89 (.46)	.24***	.11
Entertainment N=313	1.71 (.70)	1.78 (.64)	1.69 (.73)	-.06	-.06
Eat out N=314	1.70 (.72)	1.52 (.86)	1.79 (.62)	.18**	.03
Go out sports N=310	.99 (.86)	.79 (.82)	1.08 (.87)	.16**	.07
Go out clubs N=311	.80 (.98)	.82 (.99)	.79 (.98)	-.01	-.12*
Religious services N=306	1.00 (.99)	.78 (.98)	1.09 (.99)	.14*	.07
Who goes with N=306	.99 (.79)	.60 (.84)	1.17 (.71)	.34***	.21***

*p<.05, **p<.01, **p<.001

[1] Respondents who live with their family have missing values.
[2] Respondents who did not have a job or job staff have missing values.
[3] Respondents who never had guests have missing values.

Assessing influence of choice and living arrangement on community inclusion

A multiple group path analysis was used to assess the influence of choice and living arrangement on community inclusion (see figure 3.1 below). Multiple group path analysis was chosen because it provided a means to assess whether group membership moderates the relationship between variables in the model. Choice was assessed using an index of six items as described in the measures above. Living arrangement was assessed using the one variable that measured the number of people with developmental disabilities living in the respondent's household. Community inclusion was assessed using the index of the eight community inclusion items. Proxy respondent was assessed using an index of respondent items.

The unconstrained path model had good fit indices as follows: chi-square = .001 (1), CFI = 1.00, RMSEA = .00, and SRMR = .001. This model was compared to a path model with the parameters constrained to be equal across groups. The constrained model had a poorer fit than the unconstrained model with fit indices as follows: chi-square = 12.99 (6), CFI = .93, RMSEA = .085, and SRMR = .08. It was thus determined that the unconstrained model fit the data better. Modification indexes were examined in the constrained model to test the group differences on each of the five constrained paths. Significant modification indexes were found for the paths from choice to community inclusion and the path from living arrangement to community inclusion. Results are reported in table 3.6.

Correlations between variables used in the path analysis are reported in table 3.5. Correlations are reported first in the full sample and then within groups. Results of the multiple group path analysis are reported in table 3.6. Both unstandardized and standardized path coefficients are reported. The unstandardized path coefficients are provided for cross-group comparison as the groups differ in their variances (Kline, 1998).

Paths from living arrangement to community inclusion and from choice to community inclusion were significant for the severe intellectual disability group, yet not significant for the mild intellectual disability group. In addition, the unconstrained model explained 25% (R^2=.25) of the variance in community inclusion for the severe group but only 8% of the variance in the same variable for the mild group (R^2=.08). Thus, while both choice and living arrangement appear to have a strong influence on whether people with severe intellectual disabilities have access to the community, the same variables do not appear to influence access to the community for people with mild intellectual disabilities.

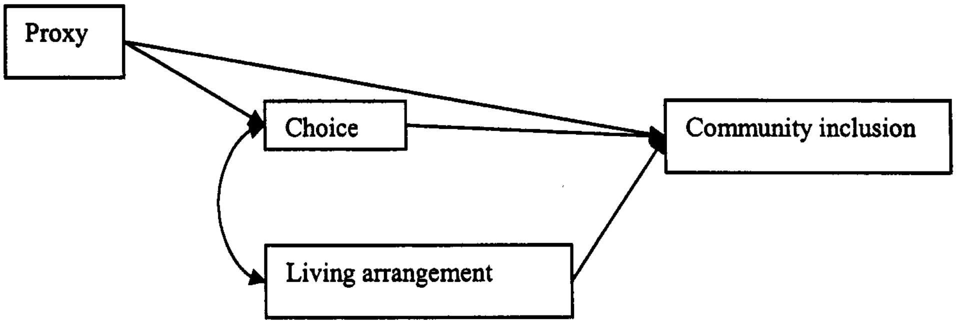

Figure 3.1: Multiple group path analysis of relationships between predictors and community inclusion

Table 3.5: Correlations: full sample and within group

	Choice[1]	Living arr.[1]	Community inc.[1]
Living arr.	$-.42^{***}\ (-.29^{**}/-.18^{**})$		
Community inc.	$.38^{***}\ (.40^{***}/.22^{**})$	$-.34^{***}\ (-.40^{***}/-.14^{*})$	
Proxy	$.64^{***}\ (.21^{*}/.42^{***})$	$-.32^{***}\ (.07/.02)$	$.31^{***}\ (.09/.21^{**})$

$^{*}p<.05$, $^{**}p<.01$, $^{***}p<.001$

[1] Correlations are listed as follows: full sample, n=321 (severe group, n=101/mild group, n=220).

Table 3.6: Multiple group path analysis

Modification indexes for equality-constrained direct effects		Path coefficients for the unconstrained model	
Direct effects	Modification indexes (χ^2)	Severe ID group[1] (n=101)	Mild ID group[1] (n=220)
Proxy → Choice	1.63	2.14* (.21)	.89*** (.42)
Proxy → Com. Inc.	.30	.76 (.05)	.39* (.16)
Choice → Com. Inc.	5.99*	.45*** (.30)	.16 (.14)
Liv. arrang. → Com. Inc.	5.56*	-.95*** (-.32)	-.34 (-.12)
Choice ↔ Liv. Arrang.	2.34	-.73** (-.31)	-.34** (-.18)

*p<.05, **p<.01, ***p<.001

[1] The first value listed is the unstandardized path coefficient. Values in parentheses are standardized coefficients.

Explained variance (severe group/mild group):

Choice	.04/.18
Community inclusion	.25/.08

Discussion

This paper suggests that people with severe and profound intellectual disabilities have some characteristics that separate them from those individuals with milder intellectual disabilities. First, more of the individuals in the severe group were male. This was an interesting finding since prior research has suggested that sex ratios are more equal in people with severe impairments (Thompson, Caruso, & Ellerbeck, 2003). Another difference was that people in the severe group had more co-morbid diagnoses and maladaptive behavior than those in the mild group. This finding is consistent with the findings of prior research that people with more severe intellectual disabilities have underlying etiologies that impact more bodily systems and are associated with more maladaptive behavior (Baumeister & Baumeister, 2000).

Respondents with more severe disabilities were less likely to experience choice even when controlling for the influence of proxy respondent. This is not a surprising finding as it is likely that people in the severe group had a much more difficult time with verbal expression than people in the mild group. Thus, people in the severe group would have had a more difficult time expressing their choices which might have led to them being rated by proxies as experiencing less choice. These significant findings were present even when controlling for proxy, yet is still difficult to discern whether the difference was related to verbal expression or related to the choice construct. Further exploration of choice measures which take into account non-verbal expressions of choice is needed.

Respondents in both the severe and mild groups had access to the community. However, people with severe disabilities were more likely to go out in large groups.

This aspect of community inclusion may be related to living arrangement. People in the severe group tend to live in larger group settings and may go into the community with their living group frequently.

Results of the multiple group path analysis indicated choice and living arrangement impacted whether people in the severe group experienced community inclusion, but had no influence over whether people in the mild group experienced inclusion. For people with mild intellectual disabilities, access to the community did not depend on their living arrangement or their opportunities to make choices about their daily lives or services. They were able to gain access to their community regardless of these two factors. However, for people with severe disabilities, large group living arrangements and a lack of choice are negatively associated with access to the community.

It is important to note that this paper presents one way of understanding the heterogeneity in the developmental disability population. While results suggest that there are sub-groups within the sample with respect to severity in intellectual disability, caution should be taken in interpreting these findings. It should not be assumed that these groups represent an underlying essence of intellectual disability (Gelb, 1997). It should also not be assumed that these two groups explain all the heterogeneity in developmental disability. In fact, many aspects of the heterogeneity in this population such as those related to sensory and physical disabilities cannot be captured by this analysis, and there is much variation within groups.

In addition, definitions of developmental disability that are used to qualify people for services vary from state to state. Thus, we cannot assume that this sample of people with developmental disabilities from Washington State is representative of the U.S. developmental disability population. In comparison to the other fifteen states that participated in the National Core Indicators Consumer Survey in 2002, Washington had fewer participants with a diagnosis of mental retardation, only 91% in Washington compared to 96.3% of participants from all participating states. Washington had higher prevalence rates of seizure disorder (32.4% in comparison to 20.5% for all participating states), cerebral palsy (17.9% in comparison to 13.8 for all participating states), and communication disorders (17% in comparison to 12.4% for all participating states) (Human Services Research Institute, 2003). Rates of institutionalization also vary from state to state. In a survey of deinstitutionalization completed in fiscal year 2002, Washington ranked 32nd indicating that 31 states have a lower percentage of average daily residents (Rizzolo, Hemp, Braddock, & Pomeranz-Essley, 2004).

It is also noteworthy that only a limited amount of information about the rights of the two groups could be compared and that no information about the consumer's opportunities for relationships that could be compared across groups. Since some questions on the Core Indicators survey were asked only to the study participant, limited information was gathered about the rights and relationships of people who were unable to respond. While there may be concerns about the validity of information provided by proxy respondents (Reid & Green, 2002), a subset of this study had no data about key constructs in the data set.

Implications

This study indicates that attention needs to be given to decreasing the size of living arrangements and to increasing opportunities for choice for people with severe intellectual disabilities. Not only did people in the severe group experience less choice and live in larger and more segregated environments, but these aspects of their service provision contributed to experiencing less community inclusion. Prior research suggests that increasing choice and smaller living arrangements may lead to improved community inclusion as well as improvements in quality of life (Stancliffe & Lakin, 1998; Wehmeyer & Schwartz, 1998). This issue of size of living unit is very closely tied to the larger issue of deinstitutionalization as the larger group living arrangements in this study were either MR/DD state institutions or nursing homes. Thus, this study emphasizes the need to continue deinstitutionalization.

In addition, the findings of this study indicate that survey instruments that rely on responses from the consumer will lead to inadequate information about a key subgroup of the developmental disability population. The individuals with the most severe intellectual disabilities were missing key information about their access to rights and relationships. It is recommended that National Core Indicators consider adding the proxy response option to all items in their survey to allow more information about the subgroup with severe disabilities to be collected.

Finally, this study indicates that respondents in both the mild and severe groups had equal access to key features of service provision and quality of life. Most of the respondents were gaining access to their community and people with severe intellectual disabilities were as likely to experience access as people with mild intellectual disabilities. In addition, severity of disability was not related to whether the respondents gained access to features of self-determination. The two groups had equal access to these features.

Notes to chapter 3

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Chapter 4: Assessing influence of choice on three quality of life indicators: community inclusion, rights, and opportunities for relationships

Chapter summary

Consumer choice is a key concept in developmental disability intervention, but relatively little quantitative research has focused on the relationship between choice and quality of life outcomes. This study employs data from Washington State's Division of Developmental Disabilities 2002 National Core Indicators project to study the relationship between choice and three indicators of quality of life: community inclusion, rights, and opportunities for relationships. 220 consumers participated in this study. Structural equation modeling was used to assess the influence of type of living arrangement and choice on quality of life. Consumers who lived in the community and made more choices had higher scores on the quality of life indicators. The findings of this study support prior research that has suggested positive relationships between community-based living, choice, and quality of life. This study suggests benefits to practice models that give consumers more choice.

Introduction

Consumer choice has been called the key to empowerment for people with disabilities (Renz-Beaulaurier, 1994, 1998). Yet, it has not always been recognized as an essential part of the lives of people with disabilities (Halle, 1995). Historically, people with developmental disabilities have been denied choice through institutionalization and the provision of services that emphasized care and treatment over self-determination (Mary, 1998).

Over the last thirty years, service models for people with developmental disabilities have shifted to emphasize the right to make daily life decisions and be actively involved in planning and selecting services and in planning all aspects of their daily life (Bambara, 2004; Mary, 1998). Interventions like person-centered planning put the consumer in the role of decision-maker about what supports are needed and who will provide them (O'Brien & O'Brien, 2002). Yet, there is a lack of theoretically-based quantitative work that examines the benefits of increased consumer choice. This study will examine whether consumer choice along with type of residential services has quality of life benefits for consumers.

Quality of life has been defined as having eight core domains for people with developmental disabilities: interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and rights (Schalock, 2004). Prior theoretical work suggests that consumer choice can impact many of these domains. Abery and Stancliffe (1996) argue that more individualized planning of services should contribute to greater self-determination. DeJong (1978, 1983) has argued that if consumers are given greater control over their services, they will select the services that best meet their needs, that remove barriers to participation in society, and that facilitate independent living. Thus, it might follow that consumers that are choosing their services will experience greater access to rights and greater community inclusion. Finally, consumer choice may have an impact on the relationships with friends and families. Consumers may choose to spend more time with friends and families and choose supports that help facilitate those relationships.

Prior research has suggested that consumer choice and self-determination are correlated with community living. Wehmeyer and Bolding (1999) found that living arrangement predicted choice. Duvdevany et. al. (2002) found that people living with their families had higher levels of self-determination and lifestyle satisfaction than people living in group settings. Size of living unit has also been associated with self-determination and personal control. Residents of smaller units have been found to exercise more self-determination (Tossebro, 1995) and more personal control (Stancliffe, Abery, & Smith, 2000).

One prior research study has examined the relationship between living arrangement and community integration. Stancliffe and Lakin (1998) found that residents of state institutions had poorer integration in the community and less contact with families than those living in smaller, community settings. Another research study has examined the relationship between consumer-directed services and quality of life. Kosciulek and Merz (2001) found that consumer direction predicted community integration and that consumer direction had a positive relationship to quality of life when mediated by empowerment. Yet, I have been unable to identify any studies that examined the relationship of both community-based living and consumer choice and to quality of life indicators in the same study.

This study seeks to add to the literature by examining the influence of choice and living arrangement on quality of life. It also seeks to add to our understanding of quality of life by examining whether this construct can be modeled as a single latent variable. Three indicators of quality of life will be examined: community inclusion, access to rights, and access to relationships. First, I will test and confirm measurement models for the three latent constructs used in the study: choice, type of living arrangement, and quality of life. Then, this study will assess the influence of choice, and type of living situation on three measured quality of life indicators: community inclusion, rights, and opportunities for relationships. Finally, it will assess the influence of choice and living arrangement on a latent quality of life construct.

Data Source

Data from Washington State's involvement in the National Core Indicators Project (NCI) in 2002 were used in this study. The National Core Indicators Project is conducted annually with the purpose of developing performance and outcome indicators that state developmental disability authorities can use to evaluate the performance of their service system. NCI collects data through the use of consumer surveys, family and guardian surveys, provider surveys, and administrative data. The domains measured include: community inclusion, choice and decision-making, self-determination, relationships, satisfaction, service coordination, family and individual participation, access, health, and safety (Human Services Research Institute, 2001a, 2001b). The present study employs only the 2002 consumer surveys.

The consumer survey had three sections. The first section, which included questions about demographics, diagnoses, health, residence, services, features of self-determination, and frequency of problem behavior, was mailed to case managers. The second section, which included questions about work and daytime activities, home, friends and family, and services of supports, was a face-to-face interview completed with the consumer. Questions in the second section were only asked of the consumer, and consumers responded either verbally or with pictures. The third section, which included questions about community inclusion, choice, rights, and access, was also a face-to-face interview. If the consumer was unable to answer the questions in this section, the questions were asked of a proxy. Proxy respondents included advocates, family members, home staff, and day staff.

Sample

Participants were selected in a two stage process. First, random sampling of the population of consumers who receive services from the Washington State Division of Developmental Disabilities was completed. Respondents or their legal guardians were initially contacted by mail for consent to participate in the study. Once the consent form was received, the case manager was contacted and asked to complete the background information section of the survey form. Finally, the consumer was contacted to complete the face-to-face interview. 343 respondents participated in the study. Nine individuals were unwilling to complete the consumer interview, and data from these individuals was removed. In addition, thirteen cases were removed because more than fifty percent of the data on these individuals was missing. This left a total of 321 cases.

The second stage of sample selection process involved identifying the subset of participants who were able to participate in the present study. Due to survey design, individuals in the sample with the most severe disabilities had missing data on questions about their rights and opportunities for relationships. Data was missing because the study participant was unable to respond and a proxy was not asked to complete the survey. It was decided that missing data for this group could not be imputed without introducing bias. Thus, only the subgroup of respondents who were able to understand and answer the survey questions was used in this analysis. This subgroup was identified through a latent profile analysis using two indicators: level of mental retardation and level of understanding of the survey instrument. The resulting sample had 220 respondents.

Measures

Level of mental retardation

Level of mental retardation was assessed as part of the questionnaire answered by the case manager and had five possible response categories: 0 = no mental retardation, 1 = mild MR, 2 = moderate MR, 3 = severe MR, and 4 = profound MR. This variable, along with level of understanding of the survey, was used in the latent profile analysis to select the group for this study.

Understanding of the survey

Level of understanding of the survey was assessed during the consumer interview. Upon completion of the face-to-face interview, the research study interviewers were asked to assess the respondent's ability to answer the questions asked. There were three possible response categories: 0 = understood most or all of the questions, 1 = not sure whether respondent understood, and 2 = very little understanding or comprehension.

Living arrangement

Case managers were asked to characterize the person's residence. Possible response categories included: specialized MR/DD facility, group home, agency-operated apartment, independent home, parent/relative's home, foster care or host home, and nursing facility. Responses to this question were recoded to create a measure of level of community integration of the residential environment with three categories: institutionalized, community-based group living, and own home. Individuals living in specialized MR/DD facilities or nursing homes were considered institutionalized. Group home, agency-operated apartment setting, and foster care or host home were recoded into one category of community-based group living. Foster care was included in the community-based group living category since the model of adult foster care most commonly used in Washington State, the adult family home, more closely resembles a group home environment than an individual's own home. Individuals who lived in their own home or apartment and those who lived with a parent or relative were recoded into one category. Scores ranged from 0 to 2 with a high score indicating a more institutionalized setting.

Case managers were asked an open-ended question about how many people with developmental disabilities live in the person's immediate residence. Responses to this question were recoded into four categories: 1 = one person (or, the study participant only), 2 = two to three people, 3 = four to eight, and 4 = nine or more.

Case managers were asked to characterize who owns the study participant's home. The five possible response categories (family or guardian owned, agency or provider owned, state owned, owned by the study participant, or leased by the study participant) were recoded into two categories: 1 = state- or agency-owned versus individual- and 0 = family-owned.

Choice

Six indicators of consumer choice were used in this study: chooses schedule, chooses what to do during free time, chooses what to buy, chose job, chose home staff, and chose case manager. All questions were coded 0-2 with 0 indicating that someone else decides, a score of 1 indicating that the person has help deciding, and 2 indicating that the person decides independently.

Participants who responded that they had no home staff were recoded as “yes” because it was decided that not requiring the assistance of home staff and choosing your own staff represent the same level of self-determination. Study participants who had no job or day program were recoded as “no” because it was decided that having no job or activity during the day and having no choice over activity represent the same level of self-determination. Participants who responded that they had no case manager were recoded as not having chosen their case manager. In fact, these participants did have a case manager who had responded to the first section of the survey, and it was assumed that their response indicated that they did not know and had not chosen their case manager. Due to a lack of variability in the chose case manager item, chose home staff and chose case manager were combined to create one measure of whether the person had choice in staff with a range of 0 to 4. The other four choice variables had a range of 0 to 2. These five variables were used as indicators of the latent choice construct.

Community inclusion

Eight questions were asked about the consumer's inclusion in the community. Consumer's were asked whether they: go shopping, go out on errands, go out for entertainment, go out to eat, go out to religious services, go to clubs or community meetings, go out for exercise or sports, and who the respondent goes with. Responses to each question were coded either 0 or 2 with a low score indicating no inclusion and a high score indicating access to the community. Three questions: go out for religious services, go out for sports or exercise, and who the respondent goes with, had a possible middle response category indicating that the person participated in the activity in a less inclusive setting or with less choice in participation. Responses to these eight questions were combined to form an index of community inclusion with a range of 0 to 16.

Rights

Six variables were used to create a scale of rights. Consumers were asked if their mail is ever opened without permission, if they can use the phone without restrictions, if staff always ask permission when entering their home, if staff always ask permission when entering their bedroom, if they can be alone when they choose, and if they go to a self-advocacy group. Responses were coded from 0 to 2 with 0 indicating that rights are never respected, 1 indicating that rights are sometimes respected, and 2 indicating that rights are always respected. A score of 1 on self-advocacy indicated that the person had been given the option to go to a group but had chosen not to attend. Respondents who indicated that they did not receive mail were given a score of 0 as this suggested that staff or family opened all correspondence related them. Data from these six rights questions were combined to create an index with a range of 0 to 12.

Opportunities for relationships

Five questions were used to create an index of opportunities for and access to relationships. Respondents were asked whether they have friends, have a best friend, see friends when they want, see family when they want, and whether they ever feel lonely. Responses were coded from 0 to 2 with 0 indicating no, 1 indicating sometimes, and 2 indicating yes. Responses to "ever feel lonely" were reverse coded. The five questions were combined to create an index with a range of 0 to 10.

Respondent

Proxy respondents were used if the consumer was unable to respond to part or all of the questions in the final section of the survey (questions on choice, community inclusion, access to needed services, and selected questions on rights). Each interview question with a possible proxy respondent had an indicator of whether the consumer answered the question or whether it was answered by a proxy respondent. Data from these indicators were combined to create an index of the consumer's participation in the survey. Scores on the index ranged from 0 to 3 with a score of zero indicating that the consumer responded to no questions, a score of one indicating that the consumer answered at least one but less than half, a score of two indicating that the consumer answered more than half but not all, and a score of three indicating that the consumer answered all questions.

Prior research has suggested that answers given by consumers and proxies may not be directly comparable (Stancliffe, 1995, 2000). One method of dealing with the influence of proxy is to collect data on whether study participants or proxies responded and to use the information as a control variable (Shalock, Bonham, & Marchand, 2000). The proxy index was used as a control variable in this study.

Data analysis

Data were analyzed using SPSS 13.0 and MPLUS version 3.0. Analysis of the descriptive statistics was completed using SPSS 13.0. The SPSS Missing Value Analysis module was used to examine missing data patterns and impute missing values in a two stage process. SPSS MVA imputes values for continuous variables through a maximum likelihood method based on Little and Rubin's (1987) work on EM algorithms. In stage one, missing data was imputed on the full 2002 Washington State consumer sample. The stage one data set had a varying range of missing data and twenty-five complete cases. In this stage, data from the second section of the survey answered solely by the consumer were not imputed. It was assumed that most of the consumers with missing data failed to respond to these questions for non-random reasons related to their ability to communicate. Thus, imputing data might lead to biased estimates (Schafer & Graham, 2002). Missing data was not imputed for categorical variables. Cases that had imputed values outside the range of the variable were recoded to either the highest or lowest meaningful value as appropriate.

The subgroup of the consumer sample used in this study was then chosen through a latent profile analysis in MPLUS version 3.0. Two variables used to assess class membership: level of mental retardation and level of understanding of the survey instrument (see chapter 3). A two-class model was chosen as BIC values indicated that the two-class model (BIC = 1373.08) fit the data better than the one-class model (BIC = 1915.89) or the three-class model (BIC = 1391.87). The smaller class of 101 respondents who were not able to understand and respond to the survey questions was removed from the data set. SPSS Missing Value Analysis was then used to impute any remaining missing values from the rights or opportunities for relationships indexes for the remaining class of 220 respondents.

The hypothetical models shown in figures 4.1 and 4.2 were developed and structural equation modeling techniques were used to assess the model fit. Two structural models were tested in this study. The first model assesses the relationship of two latent variables, choice and living arrangement to each of three measured quality of life indicators: community inclusion, rights, and opportunities for relationships. The second model assesses the relationship of the two latent variables (choice and living arrangement) to a latent quality of life construct. The analysis for each model was completed in a two-step process. A confirmatory factor analysis was conducted to determine the adequacy of the measurement model. Once a satisfactory measurement model was obtained, the theoretically-specified structural model was tested. Both confirmatory factor analysis and structural equation modeling techniques were conducted using MPLUS version 3.0 (Muthen & Muthen, 2004) with maximum likelihood estimation.

To assess the overall goodness of fit of both the measurement model and the structural model, four indexes were used: the Satorra-Bentler rescaled chi-square statistic, the Comparative Fit Index (CFI), the Root Mean Square Error of Approximation (RMSEA), and the Standardized Root Mean Square Residual (SRMR). These indices are recommended by Hu and Bentler (1998) because they are sensitive to model misspecification but less affected by estimation method, non-normal distribution, and small sample size than other indices. The CFI has typical values between 0 and 1 with a value greater than .9 indicating a good fit (Kline, 1998). Scores close to zero on the RMSEA and the SRMR indicate a better fit. Values of less than .10 are desirable for the SRMR. The RMSEA can be interpreted as follows: values less than .05 indicate a close fit, values between .05 and .08 indicate an acceptable fit, values in the range of .08 to .10 indicate a mediocre fit, and values above .10 indicate a poor fit (MacCullum, Browne, & Sugawara, 1996). In addition, the Satorra-Bentler rescaled chi-square statistic was chosen because it reduces bias associated with non-normality. Finally, the Lagrange Multiplier test was used to examine the parameters fixed to zero. This test approximates the amount by which the overall chi-square would decrease if a particular parameter were freely estimated (Kline, 1998).

Findings

The sample included 220 individuals with developmental disabilities. Respondents ranged in age from 20 to 84 with an average age of approximately 39 years. About half of the respondents were male (49.1%). The majority of the sample (88.5%) was white. Other respondents reported their race or ethnicity as American Indian, Asian-American, African-American, Latino, and other.

Eighty-seven percent of the respondents had a diagnosis of mental retardation. Most had either mild (46.4%) or moderate (30.9%) mental retardation. The most frequently reported other diagnoses were psychiatric disorder and seizure disorder with 20.4% and 19.8% respectively. Other diagnoses reported included autism, brain injury, cerebral palsy, physical disability, communication disorder, and visual or hearing impairment.

Most lived in their own home or with a family member (76.8%) and were the only person with a developmental disability living in their household (56.4%). The most frequently used type of job or day program was supported employment (50.6%).

All participants experienced some degree of community inclusion, rights, and opportunities for relationships as no one received the lowest possible score on any index. Scores on the community inclusion composite variable ranged from two to sixteen. Scores on the rights and opportunities for relationships variables ranged from four to twelve and three to ten respectively. See table 4.1 for more descriptive statistics.

In addition, the correlations of all observed variables used in the structural models were examined. These are displayed in table 4.2

Table 4.1: Sample characteristics

	N=220	
	Mean/%	SD
Age	39.2	14.0
Gender (% male)	49.1	
Race/ethnicity		
American Indian	1.9	
Asian/Pac. Islander	2.4	
African-American	2.9	
White	88.5	
Latino	3.3	
Other	4.3	
Legal/financial status[1]		
Guardian	49.3	
Payee	86.0	
Level of mental retardation	1.42	.93
Other diagnoses[1]		
Seizure disorder	19.8	
Psychiatric DX	20.7	
Cerebral Palsy	16.6	
Physical disability	10.6	
Communication disorder	7.4	
Visual or hearing imp.	11.5	
Autism	3.7	
Brain injury	3.2	
Understanding of survey	1.91	.29
Respondent	2.08	1.01
Resident. Support		
Type of home[2]	.27	.52
# residents with DD	1.67	.88
Own home	78.2	
Choice[3]		
Choose schedule	1.60	.61
Choose free time	1.77	.47
Choose what to buy	1.65	.52
Chose job	1.67	.71
Chose staff	1.38	1.08
Community inclusion	11.34	2.52
Rights	9.92	1.51
Opp. For relationships	7.93	1.53

[1] Missing values were not imputed for categorical variables. Class 1 had 89-101respondents. Class 2 had 151-217 respondents.

[2] Variable was coded as follows: 0=own home or family home, 1=community-based group living, 2=institution.

[3] Variables were coded as follows: 0=no choice, 1=had some input, 2=consumer made choice.

Table 4.2: Correlation matrix, observed variables

	Schedule	Free time	Choose buy	Chose job	Chose staff	Respondent
Free time	.56***	-	-	-	-	-
Choose buy	.46***	.39***	-	-	-	-
Chose job	.19**	.29***	.21**	-	-	-
Chose staff	.16*	.15*	.21**	.15*	-	-
Respondent	.43***	.43***	.40***	.17*	.10	-
Type home	-.10	-.01	-.11	.10	-.18**	-.13
Own home	-.10	-.04	-.10	.06	-.22**	-.04
With DD	-.07	.03	-.13	.10	-.33***	.02
Comm. Inc.	.06	.20**	.10	.18**	.16*	.21**
Rights	.14*	.17*	.08	.21**	.22**	.12
Relation.	.01	.02	.10	.07	.15*	.05

	Type home	Own home	With DD	Comm. Inclusion	Rights
Own home	.79***	-	-	-	-
With DD	.66***	.62***	-	-	-
Comm. Inc.	-.21**	-.10	-.14*	-	-
Rights	-.30***	-.33***	-.30***	.28***	-
Relation.	-.15*	-.22**	-.21**	.19**	.25***

*p<.05, **p<.01, ***p<.001

Influence of choice and living arrangement on community inclusion, rights, and relationships

The structural model depicted in figure 4.1 consists of a test of the influence of choice and living arrangement on three quality of life indicators: community inclusion, rights, and opportunities for relationships. Community inclusion, rights, and opportunities for relationships were each modeled as manifested variables. Prior to testing this model, the measurement model for type of living arrangement and choice was tested. The measurement model had a good fit with fit indices as follows: X^2 = 27.00 (18), CFI = .98, RMSEA = .048, and SRMR = .060. The error on v5, change staff, and v6, number of people with DD, were allowed to co-vary as the Lagrange Multiplier Test indicated that adding this parameter would improve model fit, X^2 = 16.02. The two factors had a correlation of -.11. Standardized factor loadings are reported in table 4.3.

The structural model depicted in figure 4.1 had a good fit with fit indices as follows: X^2 = 78.92 (45), CFI = .95, RMSEA = .059, and SRMR = .060. Again, the error on v5, change staff, and v6, number of people with DD, were allowed to co-vary as the Lagrange Multiplier Test indicated that adding this parameter would improve model fit, X^2 = 15.73. The correlation between choice and living arrangement was non-significant and failed to improve the model fit. Thus, it was removed from the model.

Significant paths were found from choice to rights and from living arrangement to community inclusion, rights, and opportunities for relationships. The path from respondent to choice was also significant. Paths from choice to community inclusion and opportunities for relationships were not significant. Yet, they improved the model fit so they were retained in the model. The path from respondent to community inclusion was not significant but was retained in the model as it improved the overall fit. The model explained 8% of the variance in community inclusion, 4% of the variance in opportunities for relationships, and 16% of the variance in rights.

Table 4.3: Confirmatory factor analysis: Two factor model

Latent construct and observed indicator	Standardized factor loading
Choice (f1)	
Choose schedule (v1)	.76*
Choose free time activities (v2)	.72*
Choose what to buy (v3)	.58*
Chose job or day program (v4)	.33*
Chose home staff and case manager (v5)	.25*
Type of residential setting (f2)	
How many people with DD (v6)	.69*
Type of home: institution, comm. Group, or own home (v7)	.92*
Who owns or rents consumer's home (v8)	.85*
Covariance (v5, v6)	-.21*

*p<.001

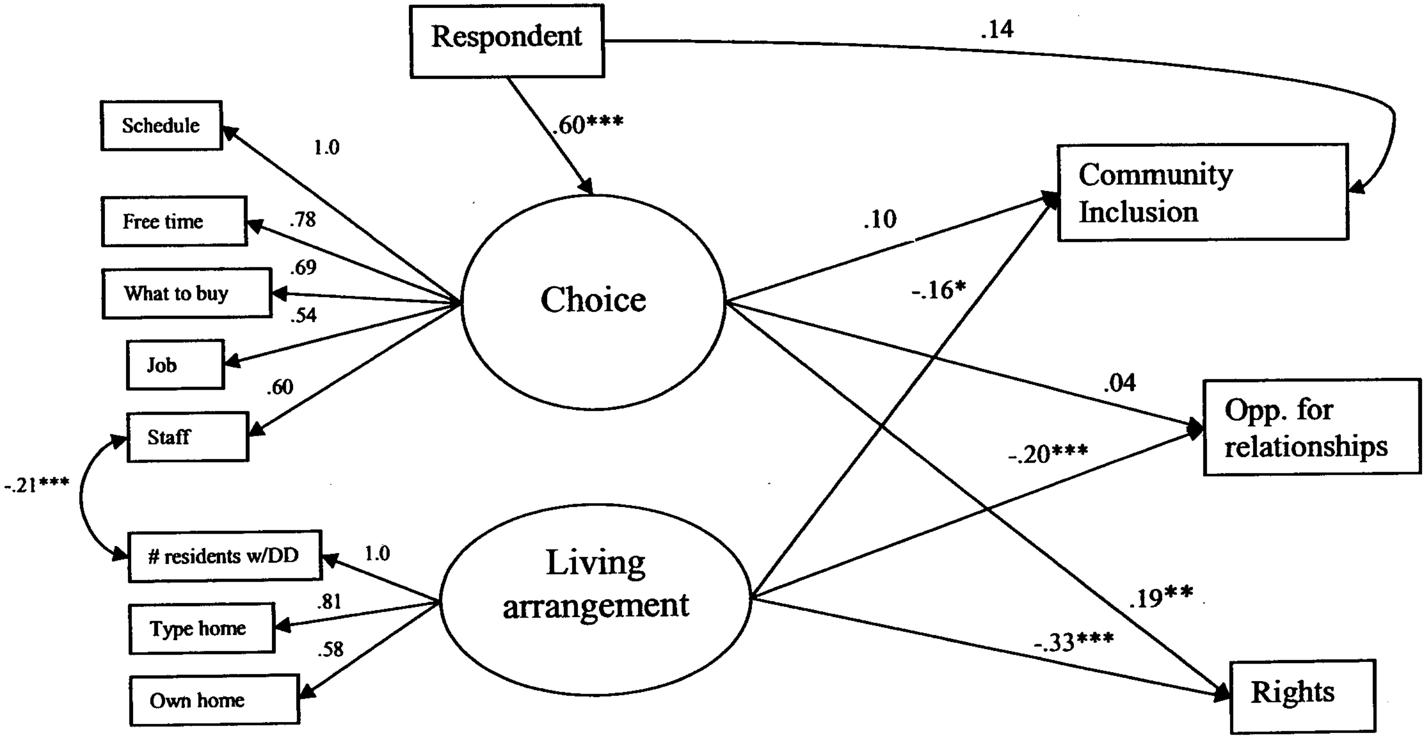

Figure 4.1: Influence of choice and living arrangement on community inclusion, opportunities for relationships, and rights

*p<.05, **p<.01, ***p<.001

Explained variance
Choice ....$R^2 = .35$
Community inclusion.........................$R^2 = .08$
Rights..$R^2 = .15$
Opportunities for relationships ....$R^2 = .04$

Influence of choice and living arrangement on quality of life

Another confirmatory factor analysis model was estimated using all variables except respondent. All factor loadings were free to vary while all factor variances were fixed at 1.0 in order to give the latent variable a measurement scale (Kline, 1998). Tables 4.4 and 4.5 present the factor loadings and the intercorrelations among factors respectively. All factor loadings were significant. The measurement model yielded an adequate fit: X^2 = 70.24 (40), CFI = .95, RMSEA = .059, and SRMR = .063. The error on v5, change staff, and v6, number of people with DD, were allowed to co-vary as the Lagrange Multiplier Test indicated that adding this parameter would improve model fit, X^2 = 15.17.

The structural model depicted in figure 4.2 consists of a test of the influence of choice and type of living arrangement on a latent quality of life factor. The indicators with the strongest factor loadings were fixed to 1.0 to scale the factor. The structural model had a good fit, with fit indices as follows: X^2 = 80.36 (49), CFI = .95, RMSEA = .054, and SRMR = .060. Again, the error on v5, change staff, and v6, number of people with DD, were allowed to co-vary as the Lagrange Multiplier Test indicated that adding this parameter would improve model fit (X^2 = 15.80). The correlation between f1, choice, and f2, living arrangement was tested but was not retained as it did not improve the model fit and was thus, removed. The model explained 30% of the variance in quality of life (R^2 = .30). As was expected, less institutionalized, more community-based living arrangements and greater exercise of choice were associated with greater quality of life. In addition, the presence of a proxy respondent had a significant influence on both the choice construct and the measured community inclusion variable.

Table 4.4: Confirmatory factor analysis: Three factor model

Latent construct and observed indicator	Standardized factor loadings
Choice (f1)	
Choose schedule (v1)	.74*
Choose free time activities (v2)	.74*
Choose what to buy (v3)	.58*
Chose job or day program (v4)	.35*
Chose home staff and case manager (v5)	.26*
Type of residential setting (f2)	
How many people with DD (v6)	.70*
Type of home: institution, comm. Group, or own home (v7)	.92*
Who owns or rents consumer's home (v8)	.86*
Quality of life indicators (f3)	
Community inclusion (v9)	.43*
Rights (v10)	.68*
Opportunities for relationships (v11)	.37*
Covariance – v5, v6	-.20*

*p < .001

Table 4.5: Factor correlations

	Choice	Type of home
Type of home	-.11	--
Quality of life	.34*	-.51**

*p<.01, **p<.001

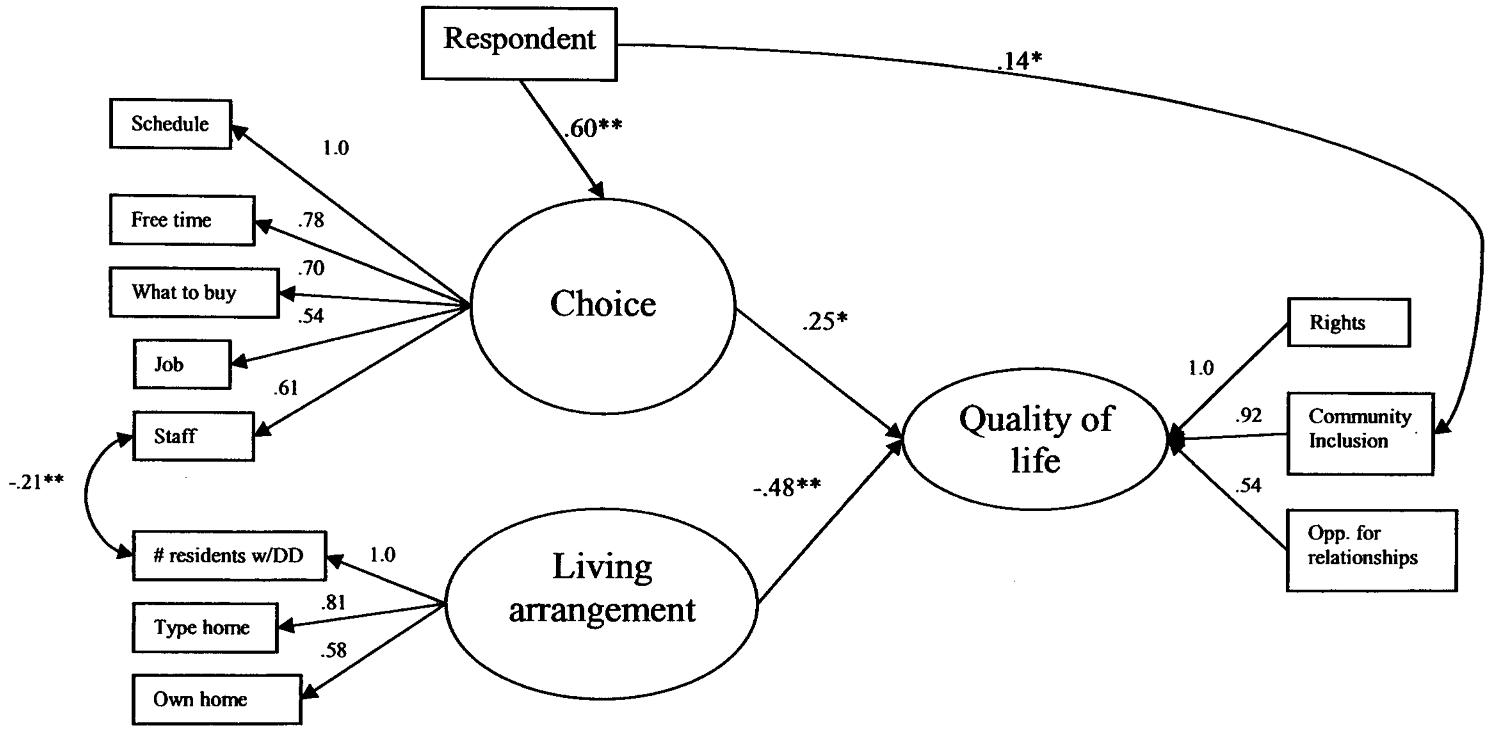

Figure 4.2: Influence of choice and living arrangement on quality of life
*p<.05, **p<.001
Explained Variance
Choice ....$R^2 = .35$
Quality of life.........................$R^2 = .30$

Discussion

This study supports the findings of other research which suggest that large group living arrangements have a negative effect on the quality of life of individuals with developmental disabilities (Stancliffe & Lakin, 1998). In the first structural model, type of living relationship correlated to every quality of life indicator. The only significant path from choice was to rights. In the second model, living arrangement had an even stronger relationship to quality of life than the relationship between choice and quality of life.

Directional arrows in the structural models used in this study are theoretical. They cannot be confirmed because this is cross-sectional data. However, there are strong reasons related to theory and measurement that suggest the model is accurate. First, questions about choice and quality of life were asked in such a way as to suggest a predictive ordering. For example, two items in the choice construct measured whether the study participant chose his or her home and home staff. Items in the quality of life construct asked whether staff allowed access to rights, to relationships, and to the community. Second, there are theoretical reasons to believe that residential services could influence quality of life. Residential services have a very strong influence in the lives of people with developmental disabilities. Many individuals in the study required 24 hour support. Thus, for these individuals, residential staff and other aspects of their services are a constant presence in their lives that either facilitate or hinder quality of life.

It is likely that the correlation in error on the chose staff variable and number of people with DD living in the unit variable were related to method effects. People who live in larger group arrangements usually share residential staff with their fellow residents. These shared staffing arrangements make it unusual for residents to have any say in choosing new staff. However, it is interesting that there was no correlation between the latent construct "choice" and the latent construct "type of living arrangement". This finding is inconsistent with the findings of prior research which has indicated that these two contructs are correlated (Duvdevany, et. al, 2002; Stancliffe, et. al., 2000; Tossebro, 1995; Wehmeyer & Bolding, 1999).

It is noteworthy that the three indicators of quality of life loaded on to one factor. This supports the findings of prior research which has indicated that there is an underlying latent quality of life construct. However, prior research also suggests that the latent construct quality of life may include other indicators such as physical and emotional well-being and personal development (Schalock, 2004). Only three indicators of the latent quality of life construct were available to be used in this study: community inclusion, access to rights, and access to relationships. Further research is needed to determine whether these findings would be supported if a more comprehensive measure of quality of life were used.

While community-based living and choice explained a fair amount of the variance in the three quality of life indicators, there might be other variables that would have contributed to the model if they had been measured. For example, the level of community integration of a person's work situation or day program might have an influence on quality of life. Also, the individual's relationship with the case manager and other support staff could also have an influence. Case managers that work more collaboratively with consumers might contribute to greater quality of life. Further research is needed to determine whether these variables would also have an influence.

Implications

This study has two important implications for practice with people with developmental disabilities and for developmental disability policy. First and most importantly, it emphasizes the need to continue deinstitutionalization and to expand the use of small group or individual living arrangements. The larger group living arrangements, which were most typically MR/DD state institutions and nursing homes, were associated with poorer quality of life across all three aspects of the construct that were measured.

Second, this study emphasizes the need to continue to increase the choice that consumers experience over their daily lives and their services. While choice did not prove to be as important a variable as living arrangement, it was associated with experiencing more rights.

This study has an additional implication for developmental disability research design. Only a subset of the individuals that participated in the National Core Indicators Project could participate in the present study. Since the survey instrument used in this study relied on responses from the consumer, the individuals with the most severe intellectual disabilities who were unable to respond to the survey questions were missing key information about their access to rights and relationships. This meant that a critical segment of the population was unable to participate in this study. It is recommended that future studies use the proxy response option across all items to allow more information about the subgroup with severe disabilities to be collected.

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Chapter 5: Conclusions and Implications for agencies in the State of Washington

This dissertation has presented three papers which attempt to contribute to our understanding of how consumer choice and community-based living impact the quality of life of people with developmental disabilities. It has examined these constructs both conceptually and using data collected on consumers in the State of Washington. This dissertation has also examined how people with severe intellectual disabilities experience these constructs differently from people with mild intellectual disabilities.

There are findings of this dissertation study that I believe will be of particular interest to agencies that serve people in Washington State. These include both the findings reported in the two preceding empirical papers as well as some additional descriptive statistics. This chapter will highlight findings in the areas of features of self-determination, community-based residential and employment services, consumer choice, community inclusion, and quality of life. It will also report some study design issues that may be of particular interest to the Division of Developmental Disabilities. I will discuss how the findings lead to a set of recommendations to DDD and conclude with a discussion of the national implications of this study.

Features of self-determination

Many study participants experienced few features of self-determination. Case managers were asked five questions about whether the respondent's features of self-determination. These features included: an individually negotiated budget, a person-centered plan, a fiscal intermediary, a microboard, or a support broker. Nearly twenty-two percent of the study participants experienced none of these features of self-determination. The most common answers were one or two features of self-determination, with 46.4% and 29.6% respectively. Only 2.2% of study participants experienced three features of self-determination, and not one case manager indicated that the study participant had four or all five features. Participants in the study might benefit from increased self-determination. The Division of Developmental Disabilities could explore ways to improve access to features of self-determination for their clients.

It is particularly noteworthy that case managers reported that only 64% of the study participants had a person-centered plan. It is possible that this relatively low number is due to measurement error. In the state of Washington, 'person-centered plan' is not a term commonly used for describing the planning process. It might be that a question asking about 'individual service plans' or 'plans of care' would have produced a higher percentage of positive responses. However, it is important to note that person-centered planning is a particular philosophy of care planning which begins with assessing the individual's preferences, goals, and aspirations (O'Brien & O'Brien, 2002). Not all individualized planning processes reflect the person-centered planning philosophy. The Division of Developmental Disabilities might benefit from exploring whether the low number of positive responses to this question reflects measurement error due to terminology used or a lack of case manager training in the person-centered planning philosophy.

Despite the finding that a substantial number of service recipients experience limited access to features of self-determination, it is noteworthy that people with severe intellectual disabilities had as much access to these models of service delivery as people with mild disabilities. The study findings suggest that the Division of Developmental Disabilities is reaching this segment of their population with the most severe disabilities with these services as successfully as it's reaching the rest of the population.

Community-based residential and employment services

The findings of this dissertation study indicate that there is a need to continue to deinstitutionalize consumers in Washington State and to provide more community based services. Nearly sixteen percent of the study participants lived in either a nursing home or a state MR/DD facility. In particular, people with more severe intellectual disabilities experienced higher levels of institutionalization and less access to community-based residential settings than people with mild intellectual disabilities. The type of residential environment is an important consideration as results of this study indicate that living environment impacts other aspects of the person's life. As will be discussed later in this chapter, results of this study indicate that people living in institutions and large community group living arrangement experienced poorer quality of life.

This study also indicated that consumers with severe intellectual disabilities were more likely to work in segregated employment settings such as sheltered workshops or to be in non-vocational programs while people with mild intellectual disabilities were more likely to be in a more integrated employment setting such as supported employment. The Division could work to get people with the most severe disabilities in their population into more integrated employment settings.

Consumer choice

All participants in this study experienced some level of involvement in choosing their services or their daily schedule. People with mild intellectual disabilities were more likely to experience choice than people with severe intellectual disabilities. Statistically significant differences in level of choice between the mild and severe groups remained even when controlling for the influence of proxy respondent in every comparison except one: choice in home staff.

It is possible that these findings could be the result of barriers in communication experienced by people with severe intellectual disabilities. Most of the people with severe intellectual disabilities were not able to directly respond to the questions asked in the survey. It is likely that this inability to respond is representative of an inability to verbally express choices to friends, family, and staff. Further research is needed to discern whether this difference indicates a failure to measure non-verbal communication or a difference in the level of decision-making people with developmental disabilities experience.

The study described in this dissertation also sought to test assumptions about whether choice contributes to the quality of life for people with developmental disabilities. The findings indicated a relationship between choice and community inclusion for people with severe intellectual disabilities and a relationship between choice and rights for people with mild intellectual disabilities. Other relationships between choice and quality of life indicators tested in this study were not significant.

Community inclusion

Most of the study participants experienced a high degree of community inclusion. Most of the respondents went out shopping (89.6%), went out on errands (96.2%), went out for entertainment (85.7%), or went out to eat (85%). Fewer respondents experienced going out for religious services (50.9%), to clubs or community meetings (39.9%), or for sports or exercise (62.4%). All respondents experienced some form of community participation as no one received a score of zero across all of the inclusion items. It is also noteworthy that when controlling for the influence of proxy respondent, there were very few statistically significant differences between the community inclusion of people with mild disabilities and people with severe disabilities suggesting that people with severe disabilities are experiencing equal levels of community inclusion.

While both groups experienced community inclusion, this study also indicated that institutionalized living arrangements and a lack of choice in services was detrimental to the community inclusion of people with severe intellectual disabilities. People with mild disabilities were able to access their community regardless of their living situation and their involvement in choosing their services. However, for those in the severe group, large group living arrangements and a lack of choice was associated with less community inclusion.

Quality of life

This study examined three quality of life indicators for people with mild intellectual disabilities: community inclusion (described above), rights, and opportunities for relationships. Study design issues made it impossible to examine most of the quality of life indicators for people with severe disabilities. All participants in the mild group experienced some degree of access to rights and to relationships. No study participant had a score of zero on either of these scales.

The three quality of life indicators that were studied loaded on to one factor. In other words, community inclusion, opportunities for relationships, and rights as measured in this study had an underlying relationship to one another that could be described through statistical analysis. This finding supported prior research which indicates that there is one underlying concept of quality of life for people with intellectual disabilities which can be described as a combination of multiple facets (Schalock, 2004).

Limitations due to study design

The design of the National Core Indicators survey instrument left gaps in information about key constructs including choice and the quality of life indicators. First, some aspects of quality of life were not measured for people with the most severe intellectual disabilities. Certain questions on the survey were only asked of the consumer. This meant that only consumers who were able to respond verbally or with pictures had data from these questions. Thus, people with the most severe disabilities which impacted communication were missing information about two quality of life indicators: access to rights and relationships.

Second, some questions on the survey, primarily those about choice and community inclusion, were asked of a proxy respondent only if the consumer could not respond to the question. As prior research indicates that responses by proxies and consumers may not be directly comparable (Stancliffe, 2000), data on these questions could not be directly assessed without first partialing out the influence of the proxy.

In addition, some issues of terminology used on the survey left gaps in the information gained. For example, the questions about type of living arrangement did not include a category for an adult-family home arrangement. While not every state offers adult-family homes to their consumers, Washington does and it is uniquely different from other arrangements listed on the survey. In addition, the term person-centered planning is not frequently used in the state of Washington. The use of this term in the self-determination section might have lowered the response rate on this question.

Finally, this study was completed through secondary data analysis. In other words, the data employed for this project was not originally collected for the purpose of this project. The method of data collection created some gaps in the measures. For example, some items that measured rights and choice had skip patterns that rendered them unusable in the indexes. In addition, a limited number of domains of quality of life were measured. If more complete measures could have been utilized, measurement error might have been reduced.

Recommendations to the Washington State Division of Developmental Disabilities

Based on the above findings, the following recommendations are made to the Division of Developmental Disabilities. First, and perhaps most important, it is recommended that DDD continue its efforts towards deinstitutionalization and continue to avoid large group community living environments for the consumers that it serves.

The findings of this study indicate that institutional and large group living environments are associated with lower quality of life influencing all three quality of life indicators that were measured: community inclusion, access to rights, and access to relationships.

Second, it is recommended that DDD look at strategies for creating more integrated work environments for people with severe disabilities. This study indicated that individuals with mild disabilities have better access to integrated employment settings while people with severe disabilities are more likely to work in sheltered workshops or to be involved in non-vocational day programs. DDD might consider whether it can expand opportunities for supported employment to people with more severe intellectual disabilities.

Third, there is a need to explore how people with developmental disabilities can have greater involvement in service planning and choosing their daily schedules. In particular, there is a need to further explore whether people with severe disabilities are being left out of interventions that promote consumer choice or whether measurement error has contributed to the appearance that they are left out. Intervention methods to give more choice to individuals with severe disabilities as well as evaluation methods need to include recognition of how consumers can express choice through non-verbal forms of communication.

In addition, the Division of Developmental Disabilities needs to focus on increasing access to features of self-determination for all of its consumers. In particular, the Division could consider whether case managers are adequately being trained in person-centered planning philosophy or another similar philosophy. If not, the Division might consider whether consumers would benefit from this type of planning philosophy and whether they could invest resources in training case managers in this philosophy.

Finally, DDD might consider using survey instruments that better assess responses from their consumers with the most severe disabilities and as well as instruments that lead to responses that are more easily compared across subgroups within the population. One solution might be to ask all questions on the survey to a proxy respondent whether or not they were responded to by the consumer. The use of the proxy respondent across the survey would insure both full participation from all respondents and would allow responses to be comparable across all sub-groups of consumers. Another option would be to collect data separately on consumers who can and cannot respond to the survey instrument.

National implications

While this chapter has focused primarily on results that will be of interest to local agencies, the results of this dissertation study could have national implications as well. In particular, there are four findings that may be of national importance. First, there is the finding that larger group living arrangements were associated with poorer quality of life. Developmental disability services nationwide have being moving towards the use of smaller group living arrangements, and this finding confirms other findings that smaller settings are beneficial (Stancliffe & Lakin, 1998). Second, there is the finding that choice is positively associated with some indicators of quality of life. Again, consumer choice is part of a national trend in developmental disability services

(O'Brien & O'Brien, 2002). Third, there is the finding that consumers with severe intellectual disabilities do not have the same access to consumer choice as those with mild intellectual disabilities. While the Washington State developmental disability population may be slightly different than that of other states, the national population is heterogeneous and includes both people with mild and severe disabilities. Finally, the finding that the quality of life indicators loaded onto one factor mirrors research that is occurring both nationally and internationally that attempts to explain one underlying construct for quality of life (Schalock, 2004).

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Appendix A: Consent forms

University of Washington
Center for Disability Policy and Research

Consent Form (Subject)

The person to call about this study is:

Mary Richardson
Center for Disability Policy and Research
University of Washington
146 North Canal Street, Suite 313
Seattle, WA 98103-8652
(206) 616-7488

The Division of Developmental Disabilities (DDD) has asked the University of Washington to help it learn whether people with developmental disabilities are happy with their services. DDD also wants to know where services could be better.

We are talking with people with disabilities and their families and friends. If you want to talk with us, we will ask you questions about your services. It will take about an hour to ask all the questions. We would like to know how you feel about things.

You do not have to answer any questions that you don't want to. There are no right or wrong answers to these questions. If you don't know how to answer a question, we will explain what it means. If some of the questions make you unhappy, you don't have to answer them. You will not be paid to answer questions.

Only research staff in DDD and in CDPR will see your information. Persons in DDD who deliver services or decide how much service you receive will not know how you answered our questions. The researchers will destroy all information that personally identifies you by June 30, 2005, three years after completion of the study.

We will only use this information to evaluate DDD services and supports. But if we learn that anyone may have been abused, we must tell the state about it.

You will not lose any services or benefits because you answered questions or because you didn't answer questions.

If you have any questions you may call Dr. Mary Richardson at 1-877-395-5466. This call will not cost any money.

Signature of Investigator Date

"I understand what this study is about. I agree to answer questions, but I know I don't have to answer any questions I don't want to. I know that I will not lose any services or benefits because I answered questions or because I didn't answer questions. The people who are doing this study have told me that I may ask questions about it."

Signature of Subject Date

Signature of Parent/Guardian Date

FinalVersion

University of Washington
Center for Disability Policy and Research

Consent Form (Primary Contact)

The Core Indicators Project

Principal Investigator: Mary Richardson, Ph.D.
Associate Professor
Department of Health Services
Center for Disability Policy and Research
University of Washington
146 North Canal Street, Suite 313
Seattle, WA 98103-8652
(206) 616-7488

Investigator's Statement:

Purpose and Benefits

The purpose of this study is to collect information for the Core Indicators Project, which is a national project to study if states do a good job of providing services to people with developmental disabilities. By collecting this information, Washington State's Division of Developmental Disabilities (DDD) and other agencies will be able to do a better job providing services.

Procedures

We are interviewing people with disabilities and their parents/guardians/advocate/staff in many states to try to learn how best to help people with disabilities. If you agree to take part in this interview, you will be asked a series of questions about the services your friend, family member, or client receives from DDD. The interview should take about an hour.

You will be asked questions about community inclusion, choices, rights, and access as well as questions related to your friend, family member, or client's health, residence, other supports and services, and frequency of problem behavior. Some of the questions may be personal or sensitive in nature. A few examples include, "Has this person ever participated in a self-advocacy group meeting, conference or event?", "Did this person choose the place where s/he lives?", "Can this person have privacy to be alone with guests when s/he wants to, or does someone else have to be present? Can s/he have overnight guests?", or "Are there services or supports that this person needed that s/he couldn't get in the past year?". You do not have to answer any questions that you don't want to. There are no right or wrong answers to these questions. If you don't understand a question, let the interviewer know, and the interviewer will try to explain it. It's okay if you don't know how to answer. We would like to know how you feel about things. Please tell us how you honestly feel.

Risks, Stress And Discomfort

There are minimal physical or economic risks to you. You will not be paid to answer questions. You may experience some discomfort or stress because some of the questions may be about personal matters. You do not have to answer any questions that cause you discomfort or stress.

Other Information

Participation in this study is entirely voluntary. If you don't want to participate, it will not affect any services or benefits you are currently receiving. You may stop participating at any time, and you don't have to answer any questions that make you feel uncomfortable. You do not have to complete the interview unless you want to.

Once information has been collected from the interviews, that information will be coded. The key to the code that links identification of a particular person to the code will be kept separate from the data. Only research staff in DDD and CDPR will see your information. Persons in DDD who deliver services or decide how much service you receive will not know how you answered our questions. The researchers will destroy all information that personally identifies you by June 30, 2005, three years after completion of the study. From that point on it will not be possible for anyone to identify the people who have participated in the interviews.

State law requires that we report anything we learn about abuse of children or dependent adults to DSHS.

If you have any questions you may call Dr. Mary Richardson, toll free, at 1-877-395-5466.

Signature of Investigator   Date

Subject's Statement:

"The study described above has been explained to me. I voluntarily consent to participate in this activity. I know I can refuse to answer any question or withdraw from the study at any time without penalty. I have had an opportunity to ask questions. I know that future questions I may have about the research or about my rights will be answered by the investigator above."

Signature of Primary Contact   Date

Copies to: Primary Contact
Investigator's file

Appendix B: 2002 Washington State Consumer Survey

CORE INDICATORS PROJECT

CONSUMER SURVEY

JUNE 2001

Description of Project:

This survey was developed in conjunction with the **Core Indicators Project**, co-sponsored by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the project is to identify and measure **core indicators** of performance of state developmental disabilities service systems. The project is currently in its fourth year, with a total of twenty states participating. This survey is intended to measure a subset of the performance indicators identified by the project Steering Committee, made up of representatives from the participating states.

Organization of Survey:

The survey consists of five sections.

- The **Pre-Survey Form** requests information that may be used by the interviewer to schedule and conduct the interviews.
- The **Background Information** section requests information that will be analyzed in conjunction with the interview responses. This information must be collected for all individuals surveyed. Your state will specify which elements must be obtained directly by the interviewer.
- **Section I** contains questions that may only be answered by face-to-face interviews with the person receiving services and supports. These are subjective, "satisfaction" related questions that may not be answered by anyone else.
- **Section II** contains questions that may be answered by someone who knows the person well, such as a family member, friend, staff person, guardian or advocate. Interviews with other respondents may be conducted either in person or over the phone.
- The **Interviewer Feedback Sheet** is the last page of the survey. Please fill out one sheet for each interview you complete.

Pre-Survey Form

This pre-survey form should be completed by the state or surveying organization using appropriate information sources, such as state data systems, case managers/service coordinators, or providers. The interviewer will then use this information to schedule and conduct the interview.

Name of person completing this form: ______________________________

Date: ________________

Consumer's Name: ________________________

Phone: _____ - ___________

Home address: ____
Street

________________ __________ _________
City State Zip

If applicable, please answer the following:

Is the signature of a legal guardian required for this consumer to consent to participation in this study? ___ Yes ___ No

Name of Guardian: ________________________

Phone: _____ - ___________

Home address: ____
Street

________________ __________ _________
City State Zip

E-mail address: ________________________

PS-1. **Contact**... Who should the interviewer call to arrange an interview with this person?

Name: ________________________ Relationship: __________________

Daytime Phone: _________________ Evening Phone : _______________

Pager: _________________________ Cellular Phone: ________________

E-mail address: _________________

Note... We would like to talk with persons alone, when appropriate. Some persons may feel uncomfortable with strangers, may have community protection issues, or may have medical or behavioral issues that require them to be under constant supervision by a trained caregiver.

Do you recommend that a caregiver be present while this person is interviewed?

___ Yes ___ No

PS-2. **Communication needs**... Does this person have any special communication needs? (Example: primary language other than English, sign language, communication board.) Please explain what arrangements are needed for the interview.

____

____

PS-3. **Case manager/service coordinator**... What is the name and phone number of this person's case manager/service coordinator?

Name: ____________________________ Phone: _______/___________

Pager: _________________________ Cellular Phone: ________________

E-mail address: _________________

PS-3a. Approximately how many times during the past year has the case manager/service coordinator had contact (in person or by telephone) with this client or his/her guardian/family members? _______ times

PS-4. **Advocate**… If this person has someone who helps represent him/her at planning meetings and in making important decisions, please provide this person's name, phone number, and relationship. (Note: this may include staff, family, friends, or guardians who are involved in the person's life.)

Name: ________________________ Relationship: ________________

PS-5. **Other Interviewees…** If this person is unable or unwilling to complete Section II of the survey, please indicate the name(s) and number(s) of others who could respond on his/her behalf.

Name: ________________________ Relationship: ________________

Daytime Phone: ________________ Evening Phone : ______________

Cellular Phone: ________________ E-mail address: ________________

Name: ________________________ Relationship: ________________

Daytime Phone: ________________ Evening Phone : ______________

Cellular Phone: ________________ E-mail address: ________________

PS-6. **Living Arrangement**… Please indicate who this person lives with.

___ lives alone

___ lives with parent/relatives

___ lives in large residential care facility

___ lives in shared house or apartment

If applicable, provide first names of roommates or housemates:

____

PS-7. **Support Staff in the Home and During the Day**… If there are any people who are paid to provide supports in this person's home, please indicate their first names. If there are several workers, please list the primary staff who spend the most time with this person. Also indicate the first names of any day and/or job support staff.

Home Support Staff: ______________________________________

Day Support Staff/Job Support Staff/Coach: _________________________

PS-7a. Does this person receive Attendant Care, Medicaid, Personal Care, Chore, or other in-home support services?

_____ Yes _____ No

PS-8. **Job/Day Activities**... If applicable, please indicate what this person calls his/her job, school or day activity program.

Place of work: ____________________

School:____________ Day program:____________

PS-9. **Self-Advocacy Organization**... What self-advocacy groups are active and well-known in the person's area? (Examples: People First, Self-Advocates Becoming Empowered, Speaking for Ourselves.)

____

____

BACKGROUND INFORMATION

BI-1. Survey Code: __ __ __ __ __ __ __ __ __ __
(unique ID number)

Note: This code should be provided by the state project coordinator and is for data analysis purposes only. A unique code number should be assigned to each person.

BI-2. Region or County: {if applicable}________________________

The questions in this section are best answered by reference to agency records or computer system reference (dependent upon availability by state). It is suggested that this section be completed along with the pre-survey form by the appropriate agency staff member, such as a case manager/service coordinator.

Please indicate who provided this information: (check all that apply)
__1 Person receiving services
__2 Advocate, Parent, Guardian, Personal Representative, Relative
__3 Staff who provides supports where person lives
__4 Staff who provides supports at a day or other service location
__5 Case Manager, service coordinator, social worker
__6 Other person
__7 State data system

PERSONAL

BI-3. Date of birth: (mm/dd/yy) ___/___/___

BI-4. Age: ______

BI-5. Gender:
__ 1 male
__ 2 female

BI-6. What is this person's race? (check ONE)
__ 1 American Indian or Alaska Native
__ 2 Asian
__ 3 Black or African American
__ 4 Native Hawaiian or Other Pacific Islander
__ 5 White
__ 6 Other race not listed

__7 Two or more races
__8 Don't know

BI-7. Is this person Hispanic or Latino?

__1 Yes
__2 No
__3 Don't know

BI-8. Legal status: (check one)

__1 Legally competent adult
__2 Has private guardian or conservator (including parent/relative or non-relative)
__3 Has state or county guardian or conservator
__4 Don't know, or has never been evaluated

BI-9. Does this person have a payee or someone else who manages his/her money?

__1 No
__2 Yes
__3 Don't know

BI-10. Marital status: (check one)

__1 Single, never married
__2 Married
__3 Single, married in past
__4 Don't know

BI-11. How is this person diagnosed in his/her records? (check one)

__0 Does not have MR label
__1 Mild MR
__2 Moderate MR
__3 Severe MR
__4 Profound MR
__5 Don't know or unspecified in records

BI-12. What disabilities other than MR are noted in this person's records? (check all that apply)

__ 1 Mental illness/psychiatric diagnosis (e.g. depression)
__ 2 Autism
__ 3 Cerebral Palsy
__ 4 Brain injury
__ 5 Seizure disorder/neurological problem
__ 6 Chemical dependency
__ 7 Vision or hearing impairment
__ 8 Physical disability
__ 9 Communication disorder
__ 10 Alzheimer's disease
__ 11 Other disabilities not listed
__ 12 No disabilities other than MR
__ 13 Don't know or unspecified in records

BI-13. What is this person's <u>primary</u> means of expression? (check one)

__ 1 Speaks English
__ 2 Speaks other primary language
__ 3 Uses gestures
__ 4 Uses sign language or finger spelling
__ 5 Uses communication device
__ 6 Other
__ 7 Don't know

BI-13a. What is this person's preferred language? (check one)

☐ English
☐ Spanish
☐ Vietnamese
☐ Cambodian
☐ Korean
☐ Laotian
☐ Russian
☐ Taiwanese
☐ Mandarin Chinese
☐ German
☐ Luganda
☐ Swahili
☐ Tunisian
☐ Cantonese
☐ Tagalong
☐ Farsi
☐ ASL
☐ Finger spelling
☐ Other: ____________
☐ Non-Verbal

BI-14. How would you describe this person's mobility? (check one)

__ 1 Walks (with or without aids)
__ 2 Non-ambulatory
__ 3 Don't know

BI-15. How would you describe this person's vision? (check one)

__ 1 Sees well, with or without corrective lenses
__ 2 Vision problems limit activities, such as reading or travel
__ 3 Limited or no vision (legally blind)
__ 4 Don't know

HEALTH

BI-16. How many days in the past month (4 weeks) has this person's normal routine been interrupted because s/he was sick? (i.e., person did not go to work, school, day program or other scheduled activity outside the home due to being sick)

___ ___ Number of days

BI-17. Does this person currently take medications for...

(check one column for each):

no	yes	don't know	
__ 1	__ 2	__ 3	Mood disorders (e.g. depression)?
__ 1	__ 2	__ 3	Anxiety?
__ 1	__ 2	__ 3	Behavior problems?

BI-18. If this person has seizures, how often do they occur? (check one)

__ 0 NOT APPLICABLE -- does not have seizures
__ 1 Less than once/month
__ 2 Once/month
__ 3 Once/week
__ 4 More than once/week
__ 5 Don't know or not available in records

BI-19. How often does this person require care by a nurse or physician? (check one)

__ 1 Less than once/month
__ 2 Once/month
__ 3 Once/week
__ 4 Once/day
__ 5 Requires 24-hour immediate access
__ 6 Don't know or not available in records

BI-20. When was his/her last physical exam? (check one)

__ 1 Within the past year
__ 2 Over one year ago
__ 3 Don't know or not available in records

BI-21. If female, when was her last OB/GYN exam? (check one)

__ 0 NOT APPLICABLE -- male
__ 1 Within the past year
__ 2 Over one year ago
__ 3 Has never had an OB/GYN exam
__ 4 Don't know or not available in records

BI-22. When was his/her last dentist visit? (check one)

__ 1 Within the last six months
__ 2 Over six months ago
__ 3 Don't know or not available in records

RESIDENCE

BI-23. How many different places has this person lived within the past year? (Present home counts as one. Do not include moves within the same facility.)

___ ___ Number of places

BI-24. How would you characterize the place where this person lives? (check one)

__ 1 Specialized institutional facility for persons with MR/DD (includes ICFs/MR)
__ 2 Group home
__ 3 Agency-operated apartment type setting (**agency** owns or leases the apartment)
__ 4 Independent home or apartment (agency may provide support, but **person** owns or leases the home)
__ 5 Parent/relative's home
__ 6 Foster care or host home (person lives in home of unrelated, paid caregiver)
__ 7 Nursing facility
__ 8 Other (specify) ______________________
__ 9 Don't know

BI-25. Who owns or leases the place where this person lives? (check one)

__ 1 Family, guardian, or friend
__ 2 Private agency or home provider/foster family
__ 3 State or County agency
__ 4 Person rents home (name is on the lease)
__ 5 Person owns home (name is on the title)
__ 6 Don't know
__ 7 Other

BI-26. How many people live in the person's immediate residence? (If person lives on the grounds of an institutional facility, in a smaller unit or house, use the smaller number.)

___ ___ number of people with developmental disabilities (including person receiving services)
___ ___ number of people without developmental disabilities (include family)
___ ___ number of paid caregivers who live in residence

BI-27. What amount of support does this person receive at home? (check one)

__ 1 24-hour on-site support or supervision (people living with or being available in his/her home during any hours that s/he is home)
__ 2 Daily on-site support (for a limited number of hours/day, not round-the-clock)
__ 3 Less frequent than on-site support
__ 4 As needed visitation and phone contact
__ 5 None of the above
__ 6 Don't know

OTHER SUPPORTS AND SERVICES

BI-28. What other services and supports does this person currently receive? (check one column for each)**:**

no	yes	don't know	
__ 1	__ 2	__ 3	Service Coordination/Case Management
__ 1	__ 2	__ 3	Vocational - supported employment
__ 1	__ 2	__ 3	Vocational - group employment (enclave, mobile crews)
__ 1	__ 2	__ 3	Vocational - facility based (sheltered workshops, work activity centers)
__ 1	__ 2	__ 3	Non-vocational day service - facility based (day habilitation, day treatment, seniors programs)
__ 1	__ 2	__ 3	Community participation/accessibility connections (supports used to get people into the community)
__ 1	__ 2	__ 3	Assistive technology (supports to facilitate the use of adaptive equipment)
__ 1	__ 2	__ 3	Clinical Services (therapies, behavior management, psychological services, etc.)
__ 1	__ 2	__ 3	Transportation
__ 1	__ 2	__ 3	Respite
__ 1	__ 2	__ 3	Other

BI-29. Does this person receive Home and Community Based Waiver Services? (check one)

__ 1 No
__ 2 Yes
__ 3 Don't know

FEATURES OF SELF-DETERMINATION

BI-30. Does this person currently have...? (check one column for each):

no	yes	don't know	
__1	__2	__3	**an individually negotiated budget** -- the individual and his/her circle of support have control over and knowledge of how much is spent on that person's behalf and what it is being spent on
__1	__2	__3	**a person-centered plan** -- a service plan developed by the individual and his/her circle of support, often with help from a facilitator
__1	__2	__3	**a relationship with a fiscal intermediary or intermediary service organization** -- organizations that act as "employers of record" or "co-employers" for an individual who hires his/her own staff
__1	__2	__3	**a "microboard" that manages his/her funds** -- a group of families responsible for administering a block of funds for several individuals
__1	__2	__3	**a support broker or personal agent** -- an independent agent who is hired to negotiate services or supports for an individual

FREQUENCY OF PROBLEM BEHAVIOR

A family member or staff person on site may be asked to fill out the questions on the following page at some point during the interview.

Introduction:

Analyses of project data show that the frequency of problem behavior is significantly related to many of the questions on the survey. Since we are trying to compare states, we need a way to factor out these kinds of "consumer characteristics" so that we can draw conclusions about what the different states are doing. We understand that these questions might be objectionable, and we assure you that they will not be used to evaluate or to label this individual. The information we are asking you to provide will allow us to "adjust" the data so that we can compare state performance.

Instructions:

Please indicate who provided this information:

__1 Advocate, parent, guardian, personal representative, relative
__2 Staff who provides supports where person lives
__3 Staff who provides supports at a day or other service location
__4 Case manager, service coordinator, social worker
__5 Other

If not filled out, please explain:

__1 Person on site refused
__2 No one available on site
__3 Other
__4 Information obtained through ICAP assessment or other database

IMPORTANT: DO NOT ASK THE CONSUMER THESE QUESTIONS.

For each of the types of behavior described, please indicate whether or not this person exhibits this behavior, and if so, about how often.

BI-31. Self-Injury: Does this person ever cause injury to him/herself, for example, by hitting self, biting, banging head, scratching or puncturing skin?

__1 **No**
__2 **Yes**
__3 **Don't Know**

If yes, about how often does the behavior occur? (check one)

__1 less than once/month
__2 1-3 times/month
__3 1-6 times/week
__4 1-10 times/day
__5 one or more times/hour

BI-32. Disruptive Behavior: Does this person ever interfere with the activities of others, for example, by starting fights, laughing or crying without reason, yelling or screaming?

__1 **No**
__2 **Yes**
__3 **Don't Know**

If yes, about how often does the behavior occur? (check one)

__1 less than once/month
__2 1-3 times/month
__3 1-6 times/week
__4 1-10 times/day
__5 one or more times/hour

BI-33. Uncooperative Behavior: Does this person ever engage in "uncooperative" behavior, for example, breaking rules or laws, cheating, acting defiant, or stealing?

__1 **No**
__2 **Yes**
__3 **Don't Know**

If yes, about how often does the behavior occur? (check one)

__1 less than once/month
__2 1-3 times/month
__3 1-6 times/week
__4 1-10 times/day
__5 one or more times/hour

SECTION I: Direct Interview with Person Receiving Services and Supports

General Instructions:

- This section may only be completed by **directly interviewing the person receiving services and supports**.
- Do not use responses from any other person to complete this section.
- Consumers may skip any question. If the person receiving services does not respond to a question or gives an unclear response, code the question as "9."
- Do not leave any questions blank.
- Be sure to read all instructions carefully.
- If possible, the interview should be conducted in private. Parents or guardians may be present if they insist. Others may be present if the consumer requests it, or if another person is needed for interpretation purposes. If staff believe that a private interview may pose risks to interviewers, then staff should be present. If others are providing assistance, interviewers should emphasize that we are trying to find out the consumer's perspective.
- Help the person with any words that are not understood. You may repeat or rephrase questions to improve understanding. Some questions have suggested rephrasing in parentheses - you do not need to limit yourself to these suggestions.
- Prior to the interview, interviewers should use the pre-survey form to fill in the blanks throughout the survey. Using familiar names and terms during the interview will help ensure that the person understands the questions. Questions that refer to pre-survey information are indicated with a bell symbol: 🔔
- If you have questions concerning the intent of a survey question, refer to the list of Core Indicators in your training packet.
- A wide margin is provided for recording notes as necessary. Please be sure to fill out the **Interviewer Feedback Sheet** after each interview.

Take a few minutes to introduce yourself and make the person feel comfortable. Read or paraphrase the following introduction. Pause after each statement, making sure the respondent understands.

"Hi, my name is ____. I'm from _____, and I'm here to ask you some questions about where you live, where you work, your friends and family, and the people who help you. By answering these questions, you are helping us figure out how people in _____ (state) are doing, and how to make supports and services better."

"This is <u>not</u> a test, and there are no right or wrong answers to these questions. If you don't understand a question, let me know and I'll try to explain it. It's okay if you don't know how to answer."

"You don't have to answer any questions that you don't want to. Just tell me if you don't want to answer."

"I'd like to know your opinions, how you feel about things. Whatever you tell me will be kept private, so you can be honest."

(If applicable): Ask respondent to sign consent form before proceeding with interview.

WORK / DAYTIME ACTIVITIES

For Questions 1-4, include all types of work and daytime activities - paid, unpaid, community-based jobs, supported employment, facility-based jobs, day programs, volunteer work, non-vocational programs, training facilities, etc. If respondent has more than one job/day activity, ask how s/he feels in general or "most of the time."

1. I'd like to start by asking you about what you do during the day – if you have a job or other place that you go to.

PS-8 🔔

Do you work at (go to) ______________________?
Do you like working (going) there?

__8 NOT APPLICABLE – no job or day activity
__2 Yes
__1 In-between
__0 No
__9 Don't know, no response, unclear response

2. Do you have staff who help you there?

PS-7 🔔

Does ____________________ help you there?

If the person does not have staff at the job or day activity, code Questions 3 and 4 as "NOT APPLICABLE."

Is s/he nice and polite to you?

__8 **NOT APPLICABLE** - no job or day activity staff
__2 Yes, most staff are nice
__1 Some staff are nice
__0 No, most staff are not nice
__9 Don't know, no response, unclear response

If No or Some, tell the person, *"Would you like me to let your case manager know that you feel that your staff are not nice? I won't tell your case manager how you answered my other questions.*

3. Are you feeling happy or sad today?

This is a consistency check question – do not rephrase.

__2 Happy
__1 In-between
__0 Sad
__9 Don't know, no response, unclear response

HOME

Now I'm going to ask you about where you live.

4. Do you like your home or where you live? *(Do you like living here?)*

__2 Yes
__1 In-between
__0 No
__9 Don't know, no response, unclear response

5. **Can you be alone if you want to?** *(Can you have privacy?)*

Here we are looking at privacy (e.g. going in a room and closing the door), not the person's need for supervision (e.g. staying home alone).

__8 **NOT APPLICABLE** - lives alone
__2 Yes, has enough time alone
__0 No, would like more time alone
__9 Don't know, no response, unclear response

6. **Are you ever afraid or scared when you are at home?**

__2 Yes, most of the time
__1 Sometimes
__0 No, rarely
__9 Don't know, no response, unclear response

If **Yes** or **Sometimes**, tell the person, *"Why do you feel afraid or scared?"* ______________________________

If respondent indicates possible abuse or neglect, contact APS. Otherwise, tell the person, *"Would you like me to let your case manager know that you feel afraid or scared when you are at home? I won't tell your case manager how you answered my other questions."*

7. Are you ever afraid or scared when you are out in your neighborhood?

__2 Yes, most of the time
__1 Sometimes
__0 No, rarely
__9 Don't know, no response, unclear response

If **Yes** or **Sometimes**, tell the person, *"Why do you feel afraid or scared?"* ______________________________

If respondent indicates possible abuse or neglect, contact APS. Otherwise, tell the person, *"Would you like me to let your case manager know that you feel afraid or scared when you are out in your neighborhood? I won't tell your case manager how you answered my other questions."*

8. Do you have staff who help you where you live?

PS-7

Does ________________ help you at home?
Is s/he nice and polite to you?

__8 NOT APPLICABLE – no home support staff
__2 Yes
__1 Sometimes
__0 No
__9 Don't know, no response, unclear response

If **No** or **Sometimes**, tell the person, *"Would you like me to let your case manager know that you feel that your staff are not nice? I won't tell your case manager how you answered my other questions."*

PS-6&7a Ask questions 8 a – e if the person has an in-home provider (see PS-7a) and DOES NOT live with a parent/relative (see PS-6). Otherwise, skip to question .9

8a. How long did it take to find your current provider? _____ weeks

8b. How many providers have you had in the past year? _____

8c. Is your provider related to you?

__2 Yes
__0 No
__9 Don't know, no response, unclear response

8d. Is this provider available when you need him/her?

__2 Yes
__1 Sometimes
__0 No
__9 Don't know, no response, unclear response

8e. Does this provider do a good job?

__2 Yes
__1 Sometimes
__0 No
__9 Don't know, no response, unclear response

9. Do people (including staff) let you know before they come into your home? *(Do they ring the doorbell or knock first and wait for an answer?)*

__8 **NOT APPLICABLE** – no home support staff
__2 Yes
__1 Sometimes, or only some staff
__0 No
__9 Don't know, no response, unclear response

10. Do people (including staff) ask permission before coming into your bedroom?

- __8 NOT APPLICABLE – no home support staff
- __2 Yes, unless it's an emergency
- __1 Sometimes
- __0 No
- __9 Don't know, no response, unclear response

11. Let me check - are you feeling <u>sad</u> or <u>happy</u> today?

This is a consistency check question – do not rephrase.

- __2 Happy
- __1 In-between
- __0 Sad
- __9 Don't now, no response, unclear response

FRIENDS AND FAMILY

12. Now I'm going to ask you about friends.

Do you have friends you like to talk to or do things with?

If s/he answers "yes," ask who the friends are and try to determine if they are family, staff, roommates, co-workers, etc. You can use prompts such as: *Can you tell me their names? Are these friends staff or your family?*

- __2 Yes, has friends who are <u>not</u> staff or family
- __1 Yes, all friends are staff or family, or cannot determine
- __0 No, does not have friends
- __9 Don't know, no response, unclear response

If the person responds "NO" TO QUESTION 14, code Questions 15-16 as "NOT APPLICABLE."

13. **Do you have a best friend, or someone you are really close to?** *(Is there someone you can talk to about personal things?)*

It doesn't matter if they are family or staff here.

__8 NOT APPLICABLE - does not have friends
__2 Yes
__0 No
__9 Don't know, no response, unclear response

14. **Can you see your friends when you want to see them?** *(Can you make plans with your friends when you want to?)*

We are trying to determine if person gets <u>support</u> to see friends. Try to factor out situations where friends are not available – this is not the issue.

__8 NOT APPLICABLE – does not have any friends
__2 Yes, can see friends whenever s/he wants to
__1 Sometimes can't see friends (e.g. not enough staff or transportation)
__0 No, often unable to see friends
__9 Don't know, no response, unclear response

15. **Do you ever feel lonely?**

If s/he responds "yes," probe to determine how often s/he feels lonely.

__2 [No] – not often
__1 Sometimes
__0 [Yes] – often feels lonely
__9 Don't know, no response, unclear response

16. Do you have family that you see?

If the person lives with family, ask about other family members that do not live in the home.

Can you see your family when you want to? *(Can you pick the times you see them? Does someone help you make plans to see them?)*

If family is not available or does not wish to have contact, code as "NOT APPLICABLE." If the person has family but does not want to see them, code as "2."

__8	**NOT APPLICABLE** – family not available or family does not wish to have contact
__2	Yes, sees family whenever s/he wants to, or chooses not to see family
__1	Sometimes
__0	No
__9	Don't know, no response, unclear response

SERVICES/SUPPORTS COORDINATION

ASK QUESTIONS 19-20 ONLY IF PERSON HAS A CASE MANAGER/SERVICE COORDINATOR. If person does not have a case manager/service coordinator, code these questions as "NOT APPLICABLE". If the person has a case manager/service coordinator but says they do not or do not know him/her, code questions 19-20 as "0."

17. Do you know your case manager/service coordinator?

PS-3

Do you know ________________ ?

__8 NOT APPLICABLE – person <u>does not have</u> case manager/service coordinator

__2 Yes, person knows case manager/service coordinator

__1 Maybe, not sure

__0 No, person <u>does not know</u> case manager/service coordinator

__9 Don't know, no response, unclear response

Ask questions 17 a & b if the person answered Yes to Question 17. Otherwise, skip to question 18.

17a. About how many times during the past year have you had contact (in person or by telephone) with your case manager?

_____

17b. When you leave a telephone message for your case manager, is your call returned promptly?

__2 Yes

__1 Sometimes

__0 No

__9 Don't know, no response, unclear response

18. If you ask for something, does s/he help you get what you need?

__8 NOT APPLICABLE – person <u>does not have</u> case manager/service coordinator, or person does not ask for help

__2 Yes, does help

__1 Sometimes helps

__0 No, does not help or person <u>does not know</u> case manager/ service coordinator

__9 Don't know, no response, unclear response

19. Does s/he ask you what you want?

__8 NOT APPLICABLE – person does not have case manager/service coordinator, or person does not talk to case manager
__2 Yes
__1 Sometimes
__0 No, does not ask or person does not know case manager/ service coordinator
__9 Don't know, no response, unclear response

20. Do you know who your advocate or guardian is?

PS-4

Is ________________ your advocate or guardian?

__8 NOT APPLICABLE – has no advocate or is own guardian
__2 Yes
__1 Maybe, not sure
__0 No
__9 Don't know, no response, unclear response

21. Do people help you do new things you want to do?

__2 Yes, people always help
__1 People sometimes help
__0 No, people never help
__9 Don't know, no response, unclear response

22. When you want to go somewhere, do you always have a way to get there? *(Can you get a ride when you need one?)*

__2 Yes, almost always
__1 Sometimes
__0 No, almost never
__9 Don't know, no response, unclear response

23. Interviewer: Could Section I be completed?

__1 Yes, person answered independently or with some assistance
__2 Yes, person answered using alternative/picture response format
__3 No, person could not communicate sufficiently to complete this section
__4 No, person was unwilling to participate
__5 No, other reason

24. Interviewer: In your opinion, did the individual understand most of the questions or not?

__8 NOT APPLICABLE – did not complete
__2 Yes, understood most questions (even if prompted) and could give an opinion
__1 Not sure
__0 No, very little understanding or no comprehension

25. **Interviewer:** In your opinion, did the individual answer the questions in a consistent manner? (Do you feel his/her responses were valid?)

__8 **NOT APPLICABLE** – did not complete
__2 Yes, gave consistent and valid responses
__1 Not sure
__0 No, did not give consistent and valid responses

If you answered "yes" to questions 24-26, then determine now if s/he is willing to answer more questions. If the consumer is not willing to continue, or if you believe comprehension or consistency was a problem, then say:
"Thank you for your help. It's been very nice talking to you. You've been very helpful."

Otherwise, continue to the next section.

SECTION II: Interview with the Person Receiving Services or with Other Respondents

Interview the person receiving services if possible. If you are unable to interview the person, other respondents may be interviewed (family, advocate, staff) if they are knowledgeable in the areas below. If the person receiving services has completed Section I, but has become tired or does not wish to continue with this section, you may interview other persons. Use alternative wording when questioning other respondents. Also, check the appropriate box to indicate who is responding.

Ask the person if s/he wishes to continue with the questions, or if s/he would like to take a short break.

COMMUNITY INCLUSION

In this section, we are trying to find out if the person participates in integrated activities. Try to rule out non-integrated activities, for example, Special Olympics. If the person answers "yes," you may ask for an example to verify that the person understood the question.

26. Do you (does this person) go shopping? *(What do you go shopping for? Examples: groceries, clothing, house-wares, tapes/CDs.)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__0 No
__9 No response, unclear, don't know

27. Do you (does this person) go out on errands or appointments? *(Where do you go? Examples: doctor, dentist, bank, post office, hair dressers/barber.)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__0 No
__9 No response, unclear, don't know

28. Do you (does this person) go out for entertainment? *(Where do you go? Examples: movies, library, plays, concerts, museums, art galleries.)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__0 No
__9 No response, unclear, don't know

29. Do you (does this person) always eat at home, or do you sometimes go out to eat? *(What restaurants do you go to?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Sometimes goes out to eat
__0 Always eats at home
__9 No response, unclear, don't know

30. Do you (does this person) go to religious services? *(Where do you go? Examples: church, synagogue, or other place of worship.)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes, attend religious services of their choice
__1 Yes, but would prefer not to go, or would prefer to go elsewhere
__0 No
__9 No response, unclear, don't know

If No,

30a. Would you like to go to religious services?

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__0 No
__9 No response, unclear, don't know

31. Do you (does this person) go to clubs or other community meetings? *(Where do you go? Examples: non-religious clubs, social groups or community organizations.)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__0 No
__9 No response, unclear, don't know

32. Most of the time, when you go out in the community, who do you go with (who does this person go out in the community with)? *(Do you go by yourself? With friends or family? With the people you live with?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Person goes alone or with staff
__1 Person goes with friends and or family
__0 Person goes with staff and other people s/he lives with
__9 No response, unclear, don't know

33. Do you (does this person) exercise or play sports? *(Where kind of exercise? Examples: jogging, swimming, riding bike, etc.)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes, in a community setting
__1 Yes, gets exercise but in a non-integrated setting
__0 No
__9 No response, unclear, don't know

CHOICES

The intent of these questions is to determine if persons receiving services are involved in decision-making.

- In this section, code "2" only if you can convince yourself that this person made a real choice. Code "1" if you think the person had some input in making the decision.
- Choices made with spouses/partners should be coded as "without help."
- Do not overuse the "NOT APPLICABLE" code here. It is not appropriate to use "8" to indicate NOT ALLOWED or NOT CAPABLE of making decisions in this area. There is a code for indicating that someone else made the decision.

Read one of the following introductions to the respondent(s):

For Consumers:

I'm going to ask you questions about some decisions you may have made or helped make. For each question, I'd like you to tell me if you made the choice by yourself, if you had some say about it, or if someone else decided for you.

For Other Respondents:

I'm going to ask some questions now about decisions this person may have made. For each question, please indicate if s/he made the decision independently, if s/he had some input in making the decision, or if someone else made the decision for him/her.

If the person lives with his/her family, code questions 34-36 as "NOT APPLICABLE."

34. Who chose (or picked) the place where you live? *(Did you choose by yourself or with help?)*

*(**Other respondent:** Who chose the place where s/he lives? Did s/he have any input in making the decision?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** – lives with family
__2 Person chose without help
__1 Person had some input
__0 Someone else chose
__9 Don't know, no response, unclear response

35. How many places did you visit before moving here?

*(**Other respondent** – How many places did s/he look at before moving in?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** – lives with family
__2 Looked at more than one place
__1 Visited one place only
__0 Did not visit before moving in
__9 Don't know, no response, unclear response, can't remember – too long ago

36. Did you choose (or pick) the people you live with (or did you choose to live by yourself)? *(Did anyone ask you who you'd like to live with? Were you given choices, did you get to interview people?)*

PS-6 🔔

Did you choose to live with __________ ?

*(**Other respondent** – Did this person choose any of the people s/he lives with? Or: Did this person choose to live alone?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** – lives with family
__2 Yes, chose people s/he lives with, or chose to live alone
__1 Chose some people or had some input
__0 No, someone else chose
__9 Don't know, no response, unclear response

37. Do you choose (or pick) who helps you at home? *(Do you get to interview them? Did you get to meet different people or was someone assigned to you? If you wanted to change, could you ask for someone different?)*

PS-7 🔔

Did you choose ___________ to work with you?

*(**Other respondent** – Does this person choose his/her residential staff?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** - no staff in the home
__2 Yes, person chooses staff
__1 Staff are assigned but s/he can request a change if not satisfied
__0 No, someone else chooses
__9 Don't know, no response, unclear response

If not yet clear from response,

37a. If you wanted someone else to help you at home, can you ask for someone different?

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__0 No
__9 No response, unclear, don't know

38. Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?

(Other respondent – Who decides this person's daily schedule, like when to get up, when to eat, when to go to sleep?)

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Person decides
__1 Person has help deciding
__0 Someone else decides
__9 Don't know, no response, unclear response

39. Who decides how you spend your free time (when you are not working, in school, or at the day program)?

*(**Other respondent** – Who decides how this person spends his/her free time?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2	Person decides
__1	Person has help deciding
__0	Someone else decides
__9	Don't know, no response, unclear response

40. Who chose (or picked) the place where you work (or go during the day)? *(Did you choose by yourself or with help?)*

PS-8

Did you choose to work at (go to)________ ?

*(**Other respondent:** Who chose the place where s/he works or goes during the day? Did s/he have any input in making the decision?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8	**NOT APPLICABLE** – no work or day activity
__2	Person chose without help
__1	Person had some input
__0	Someone else chose
__9	Don't know, no response, unclear response

41. How many places did you visit before working (going) there?

(Other respondent – How many places did s/he look at before working/going there?)

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** – no work or day activity
__2 Looked at more than one place
__1 Visited one place only
__0 Did not visit beforehand
__9 Don't know, no response, unclear response, can't remember – too long ago

42. Do you choose (or pick) who helps you at work? *(Do you get to interview them? Was someone assigned to you? Could you request someone different?)*

PS-7 🔔

Did you choose ________________ to help you at work?

(Other respondent – Does this person choose his/her work/day activity staff?)

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** - no job or day activity staff
__2 Yes
__1 Some staff, or staff are assigned but s/he can request someone different
__0 No
__9 Don't know, no response, unclear response

If not yet clear from response,

42a. If you wanted someone else to help you at work, can you ask for someone different?

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__0 No
__9 No response, unclear, don't know

43. Do you choose what you buy with your spending money? *(Do not include things like rent or groceries.)*

*(**Other respondent** – Does this person choose how to spend this his/her money?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Person chooses
__1 Person has help choosing what to buy, or has set limits (such as can buy small items, but not big items)
__0 Someone else chooses
__9 Don't know, no response, unclear response

44. Did you choose or pick your case manager/service coordinator?

PS-3 🔔

Did you choose ______________ to work with you?

*(**Other respondent** – Did this person choose his/her case manager/service coordinator?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

- __8 **NOT APPLICABLE** - no case manager/service coordinator
- __2 Yes, chose case manager/service coordinator
- __1 Case manager/service coordinator was assigned but s/he can request a change if not satisfied
- __0 No, someone else chose case manager/service coordinator
- __9 Don't know, no response, unclear response

RIGHTS

45. Do people read your mail without your permission?

*(**Other respondent** – Does anyone read this person's mail without permission?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

- __8 **NOT APPLICABLE** - does not get mail
- __2 [No] – person reads own mail or others read with permission
- __1 Some mail is read without permission
- __0 [Yes] – mail is always read without permission
- __9 Don't know, no response, unclear response

46. **Do you ever have friends come over to visit?**

If no, code as "NOT APPLICABLE." If yes, ask:

Can you be alone with them, or does someone have to be with you? *(Are there rules or restrictions about having guests over?)*

*(**Other respondent** – can this person have privacy to be alone with guests when s/he wants to, or does someone else have to be present?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** – no friends or friends do not visit
__2 Can be alone with guests
__1 There are some restrictions (e.g only in common areas, or not overnight)
__0 Someone else always has to be present
__9 Don't know, no response, unclear response

47. **Are you allowed to use the phone when you want to?**

*(**Other respondent** – is this person allowed to use the phone when s/he wants to?)*

If person is unable to use the phone or doesn't have access to a phone/TTY, code as "NOT APPLICABLE."

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** - doesn't have phone/TTY or unable to use phone
__2 Yes, can use anytime, either independently or with assistance, has own phone, or uses email
__1 There are some rules/restrictions on use of phone
__0 No, person is not allowed to use phone at will
__9 Don't know, no response, unclear response

48. **Have you ever participated in a self-advocacy group meeting, conference, or event?** *(A self advocacy group is where people with disabilities meet together to talk about things in their lives that are important to them.)*

PS-9 ⏰

(Have you ever gone to a ______________________ meeting or event?)

*(**Other respondent** – Has this person ever attended a self-advocacy group meeting or event?)*

Indicate respondent: ( ) 1-consumer ( ) 2-other

__8 **NOT APPLICABLE** – there is no self-advocacy group in the area
__2 Yes
__1 Had the opportunity but chose not to participate
__0 No
__9 Don't know, no response, unclear response

If No,

48a. **Would you like to go to a self-advocacy group meeting, conference, or event?**

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__0 No
__9 No response, unclear, don't know

ACCESS

49. Do you get the services you need?

We are only looking for services and supports here, such as transportation, job coaching, taking a class, getting medical care, etc.

(Other respondent – Does this person get the services and supports s/he needs?)

Indicate respondent: ( ) 1-consumer ( ) 2-other

__2 Yes
__1 Sometimes, or doesn't get enough of the services needed
__0 No
__9 Don't know, no response, unclear response

If no, what services are needed?

____

50. Interviewer: Please indicate who completed this section (check all that apply):

__1 Person receiving services
__2 Advocate, Parent, Guardian, Personal Representative, Relative
__3 Staff who provides supports where person lives
__4 Staff who provides supports at a day or other service location
__5 Other

INTERVIEWER FEEDBACK SHEET

Instructions to Interviewers:

Please take a few minutes to complete a feedback sheet after each interview you complete.

Interviewer's Initials or Code (optional):_______________

1. How long did it take to complete the direct interview(s) (Sections I and II only)?

   __ __ **Hours** __ __ **Minutes**

2. How long did it take to complete the entire form, including phone-calls, collecting background information, arranging and conducting the interviews, travel time, etc.?

   __ __ **Hours** __ __ **Minutes**

3. Were there any questions that were problematic?

   ___ **Yes** ___ **No**

If yes, indicate the question number(s) below and describe the problem and any suggestions you have for improvement.

Question:	**Problem/Suggestions:**
____	____
	____
	____
____	____
	____
	____
____	____
	____
	____

Other Comments:

____

____

____

Vita

Susan L. Neely-Barnes was born in Chapel Hill, North Carolina. She completed her Bachelor of Arts in cultural anthropology and religion at Duke University in Durham, North Carolina in 1996. She completed her Master of Social Work at Washington University in St. Louis, Missouri in 1999. After completing her degree, she worked at the St. Louis Regional Center for Mental Retardation and Developmental Disabilities. She entered the doctoral program in Social Welfare at the University of Washington in 2000. Susan completed a Leadership Excellence in Neurodevelopmental Disabilities traineeship and became a Licensed Independent Clinical Social Worker in 2004. She currently resides in Memphis, Tennessee.