Exploring the role of comics in addressing challenges of Japanese immigrant parents of children with disabilities in special education advocacy

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Abstract

Exploring the role of comics in addressing challenges of Japanese immigrant parents of children with disabilities in special education advocacy

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The purpose of this qualitative comparative case study was to examine the experiences of eight Japanese immigrant parents of children with disabilities learning about special education law and parent advocacy in two different formats and styles of presentation. Two tools (*manga* and text) were developed based on data from a previous pilot study on Japanese parent advocacy (Omori, 2016), as well as information about the Individuals with Disabilities Education Act (IDEA) and procedural safeguards. Grounded in Dewey's (1934) perspective on art as experience and Clark's (2018) framework of understanding culture and cultural capital in the context of IDEA in the United States, this study highlights the affordances of using multimodal mediums such as *manga* to convey and deliver information in culturally responsive ways to Japanese immigrant families of children with disabilities. Findings revealed that parents made meaningful emotional and intellectual connections to both tools when learning about special education advocacy. However,

most parents stated their stronger preference for the aesthetic-based format over the text format, as they emphasized the importance of presenting information in culturally sensitive ways.

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Dedication

For Japanese (immigrant) families of children with disabilities in the U.S. ☺

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Exploring the role of comics in addressing challenges of Japanese immigrant parents of children with disabilities in special education advocacy

Parent advocacy in special education has steadily gained more attention over the last few decades. Given that the Individuals with Disabilities Education Act or IDEA (20 U.S.C. §1400) in the United States (hereafter, U.S.) was founded upon the activism of parent advocates, what it means to engage in these advocacy practices have been explored across different contexts. Research on parent advocacy in special education has continued to grow, in terms of identifying different styles of parent advocacy (Trainor, 2010; Rehm et.al, 2013), types of cultural and economic capital required for effective parent advocacy (Trainor, 2008, 2010; Ong-Dean, 2009; Harry & Klingner, 2014; Clark, 2018), the types of barriers parent advocates have continued to face when navigating special education (Hess, Molina & Kozleski, 2006), and how parents understand their rights and protections under IDEA (Leiter & Wyngaarden, 2004; Fitzgerald & Watkins, 2006) among other issues. Although research studies have continued to gain deeper understanding into what effective parent advocacy looks like, these experiences have generally reflected white, monolingual, educated, higher socioeconomic status parents, whereas advocacy for culturally and linguistically diverse (CLD) families is still not fully understood (Kalyanpur, Harry & Skrtic, 2000; Harry, 2008; Harry & Klingner, 2014).

The reality for most CLD immigrant families was that they did not always have access to the type of cultural capital needed to advocate effectively (Lareau & Horvat, 1999; Kalyanpur, Harry & Skrtic, 2000; Kalyanpur & Harry, 2012; Clark, 2018). In fact, the cultural expectation of parent advocacy has remained less accessible to CLD immigrant parents, who shared different worldviews, values, and practices from white American middle class families. Kalyanpur, Harry & Skrtic (2000) emphasized how the principles and ideologies behind the legal mandate for parent participation in IDEA presumed that all families believed in American cultural constructions of individual rights and freedom of choice.

To add further to the complexities of CLD parent advocacy, information and resources have not always been available or accessible to immigrant families who were not proficient in English. Although translating materials can be one approach to bridging the gap for CLD parents whose primary language is not English, it is also important to consider that many resources were reportedly inaccurate or confusing (Cho & Ganotti, 2005; Cheatham, 2011). Different studies focusing on supporting CLD families and their children have suggested using different formats when communicating with CLD parents (Fiedler & Swanger, 2000; Miller & Nguyen, 2014). Thus, this dissertation explored one of many possibilities in addressing some of the cultural disconnects between the law and CLD parent advocacy, by drawing upon the use of a different type of medium—comics.

When understanding complex information, comics have proven to be useful across different research studies. Using a combination of images and words through comics have been shown to make complicated topics more accessible to the lay audience, as they offer different ways to convey information to engage their audiences (Kukkonen, 2011; Wartenberg, 2012). This approach has been particularly useful in studies where the subject matter at hand is more complex. In addition, comics and sequential art have also been utilized across diverse cultural contexts, such as Japan, where the use of *manga* or Japanese-style comics has become a highly prevalent source of education, learning, and mass media. Given that *manga* as an educational medium may be more culturally accessible to Japanese families due not only to its widespread use in Japan but also its effectiveness as a learning tool (Murakami & Bryce, 2009), this current study focused more specifically on Japanese immigrant parents and explored a different approach to gaining their cultural insight on the issues around CLD parent advocacy.

This dissertation also builds upon the findings and analyses of a previous qualitative research project on the cultural barriers and challenges to parent advocacy in special education for Japanese immigrant families in the U.S. (Omori, 2016). The purpose of this study was to explore how Japanese immigrant parents of children with disabilities respond to and reflect on their real-life advocacy experiences navigating special education services using two different mediums—*manga* and written text. This was based on the notion that arts-based research can capture and evoke meanings that measurement alone cannot, where its design enables its viewers to see aspects of the social world that they might have otherwise overlooked (Dewey, 1934; Eisner, 1985; Barone & Eisner, 2012). Moreover, arts-based research has the ability to push its audience to “rethink” certain aspects of this social world by “re-experiencing” them, thereby contributing to more awareness and deeper human understanding (Dewey, 1934).

Chapter 2

Literature review

This chapter begins with a general overview of parent advocacy, in terms of how parent rights have been defined in special education law (Individuals with Disabilities Education Act, 2004) in the United States (U.S.), as well as how parent advocacy has generally been conceptualized and understood in research. Following this overview, there is some discussion on issues around parent advocacy in culturally and linguistically diverse (CLD) communities and understanding the role and importance of cultural capital for families to become effective advocates. This is followed by some discussions around addressing cultural factors around parent advocacy. The final section of this literature review discusses how non-traditional, arts-focused methods can provide individuals with rich learning experiences through Dewey's (1934) theories on art as experience and Eisner's (1985) perspectives on aesthetic modes of knowing. This section also explores how comics have been utilized as useful learning tools for educational purposes; where there will be a focus on exploring the benefits of using *manga* (i.e. Japanese comics) to address cultural issues around parent advocacy in American special education for immigrant Japanese families.

Parent rights and advocacy, as reflected in IDEA

Since the 1970s, parent experiences of advocacy for their children with disabilities have been shaped by changes in social attitudes, different mandates and policies including the Education for All Handicapped Children Act (EAHCA, 1975), later renamed the Individuals with Disabilities Education Act (IDEA 1990, 1997, 2004), as well as the civil rights legislation under Section 504 of the Rehabilitation Act (1973) and the Americans with Disabilities Act (ADA, 1990). Since these laws were implemented, these contextual shifts have both reflected and shaped the ways in which professionals and parents have continued to work together for the benefit of the child receiving special education services under IDEA. The purpose of these laws was primarily to prohibit discrimination on the basis of disability across different social and community settings, including schools, public services, accommodations, as well as public and private programs and activities that receive federal financial assistance. Before the EAHCA in 1975, there had been very little systemic accountability regarding how children with disabilities were educated. Since then, specific rights and protections have been outlined more clearly for parents, as well as for their children with disabilities. IDEA (2004) has essentially set a precedent in terms of how children with disabilities receive services and support for their learning needs, as well as how parents were expected to be involved in this process.

A basic principle of IDEA (2004) is that children with disabilities and their parents/caregivers are entitled to specific rights and procedural safeguards or protections under this law, where parents are expected to be involved as equal partners in their child's special education planning and decision-making (IDEA, 2004). The fact that parents are considered to be equal partners of their child's IEP teams means that they should be informed and aware of the types of support that are being considered for their child's education.

According to the IDEA (2004), parents have a say in whether or not they give permission to their child being both evaluated and reevaluated. Providing consent as a parent is thus crucial, not only for evaluation purposes but any time decisions have to be made by the IEP team (IDEA, 2004). Examples may include consenting to the types of services outlined in a student's IEP or where a student will be receiving these services (i.e. placement). In addition, parents also have the right to disagree with evaluation results that were completed by schools and parents have the right to request an independent educational evaluation (IDEA, 2004). Other rights include: i) parent's right to *mediation*, where a neutral third-party mediator helps parents and schools to communicate more effectively and reach some type of consensus over the disagreement; ii) parent's right to a resolution meeting, as well as iii) their right to file a *written state complaint* (IDEA, 2004).

Considering the types of rights and protections afforded to families of children with disabilities under IDEA, it is important to delve deeper into what that might look like in reality—the world of parent advocacy and how parents become involved in their children's special education services.

General overview of parent advocacy research

Research on the history and evolution of parent advocacy efforts have focused primarily on the experiences of white American middle and upper class parents of children with disabilities, where the concept of "advocacy" was essentially being a "good" parent of a child with disability who knew how to be strong, effective, articulate and was able to get her child what he or she needed (Mlawer, 1993). Early disability rights literature described advocacy as the act of speaking and acting on behalf of another person or group of people to help address their preferences, strengths and needs (Wolfensberg, 1977 as cited in Trainor, 2010). This body of research, in addition to a vast amount of written publications on parent advocacy have explored and addressed different nuanced issues around this topic such as: parent beliefs and knowledge about special education and IDEA (Nutting et.al., 2004); the readability of procedural safeguards, i.e. parent rights (Fitzgerald & Watkins, 2006); barriers in obtaining services (Leiter & Krauss, 2004); how parents become effective advocates through specialized trainings (Burke, 2013); as well as how parents become knowledgeable about exercising their rights as advocates (Nespor & Hicks, 2010). Through such research studies, we gain more insight into supporting parents on different aspects of parent advocacy and special education as research continues to evolve. However, because these studies focused mainly on the narratives of white, monolingual, middle to upper class families who generally faced different barriers from CLD families, what we have come to know from these studies was not representative of the larger picture of parent advocacy.

Brief overview of CLD parent advocacy research

Parent advocacy research over the last few decades have included more insights into the advocacy experiences of CLD families in the U.S., including African American, Latino and Asian families (Kalyanpur & Harry, 2012; Turnbull, 2011; Bowes & Sim, 2006; Blanchett, Klingner & Harry, 2009; Lo & Hiatt-Michael, 2014; Gonzales & Gabel, 2017). Across these studies and others, advocacy itself has continued to be defined and described in similar yet different ways that have resulted in identifying numerous parent advocacy styles across different communities. For example, Nespor & Hicks (2010) described parents as taking an *adversarial vs mediating* approach to advocacy or a *participatory vs professionalizing* constructions of advocacy. Trainor (2008) also described diverse approaches to parent advocacy including the *intuitive advocate*, *disability expert*, *strategists*, and *agents for systemic change*. Rehm et.al (2013) identified different parent advocacy styles by building off of Trainor (2010), such as *high profile, strategic*, *grateful-gratifier* and *unsuccessful negotiations* that included parents from racially diverse backgrounds.

Stanley (2015) described how African American mothers of children with disabilities defined advocacy on their terms, whether it was on an individual or collective level with other families from their community. Advocacy also included locating and utilizing community resources, as well as communicating with teachers and school administrators and above all, making their advocacy visible by being “present” in their children’s schools. In Burke et.al., (2017), the efforts of white and CLD parents advocating for their children's social communication supports were examined, where both parents and professionals reported that advocacy for parents was about learning parent rights, bringing in external people and communicating with schools. However, many parents also reported that advocacy was stressful and that that in some cases did not result in what was asked for, despite professionals stating that they believed that advocacy always yielded positive outcomes. In Hess, Molina, and Kozleski (2006), the primary goal was to clarify the issues as voiced by parents of CLD families in relation to their children's special education. The study found that parents advocated in different ways for their children, where some did so in quiet and indirect ways, while others shared their knowledge, ideas and experiences on how to access services and ask for what they need. In a study focusing on Latino families, Angell & Solomon (2017) found that despite the families' efforts to advocate, they also faced resistance even while assuming the role of a "good autism parent." This left many parents questioning how such negative responses from schools could be the result of racial discrimination.

The reality for CLD immigrant families of children with disabilities was that in order for them to advocate more effectively, it was critical for special educators to understand how to engage families from very different cultural and language backgrounds. These families were not only facing structural inequities due to the lack of appropriate information and resources, but also a cultural disconnect with the expectation of advocacy being more culturally accessible for "privileged parents" with more social, cultural and economic capital (Ong-Dean, 2009).

Although these studies have undoubtedly provided invaluable insight into the ways that families, especially from CLD communities, have continued to make sense of advocacy for their children, it is also critical to explore how factors such as race, class, culture and their unique intersections have contributed to and have informed how these CLD families developed such styles of advocacy and negotiated their own expectations and roles with their children’s schools. Kozleski et.al (2008) noted the need for more research that foregrounded culture across diverse families in special education, as they explored how families of two distinctly different cultural backgrounds accessed services and support for their children with disabilities. Thus, how we approach research around CLD families of children with disabilities may also depend on how much we take cultural factors into consideration when designing these studies.

Parent advocacy and cultural capital

What has complicated much of the understanding around parent advocacy and the expectations set forth by IDEA was that the language around what it meant to be an effective parent advocate had not been explicitly stated in the law, where the term “advocate” or “advocacy” were also clearly absent (Trainor, 2008). Instead, details around “parent participation” implied that parents would be advocating by default through participating to secure appropriate resources. In this sense, the idea of a “good” parent advocate as expected by IDEA was a parent who understood and accepted their role after receiving resources including parent right handbooks and other documents; where, on top of attending IEP meetings consistently, the parent would also communicate in a way that demonstrated her ability and willingness to collaborate (Trainor, 2008). Thus, this “ideal” parent advocate would possess the social, cultural and economic capital needed to be seen as successful. Ong-Dean (2009) similarly discussed how parents were equipped in different ways, where their ability to advocate successfully depended highly on the resources they had and whether these resources affected their involvement in identifying and accommodating their children’s disabilities. “Privileged parents,” as described by Ong-Dean (2009) were those who tended to be more successful in their advocacy efforts, as they possessed more knowledge (i.e. cultural capital) and the means (i.e. economic and social capital) to make disability claims for their children and to negotiate accommodations for special education services.

Having access to different forms of capital are clearly important as a parent advocate in special education. By drawing upon Bourdieu’s (1986) theories around cultural capital, he argued that different people were socialized differently, depending on where they were socially located. As a result, this socialization would come to define what was considered natural or normal for that individual (i.e. habitus). These background experiences would go on to shape the type of resources the individual would have access to, as they navigated different institutions in the social world (i.e. field). Thus, cultural capital refers to the knowledge and skills that people develop that can be translated into different forms of value, as they move through various institutions in their lifetime. Lareau & Weininger (2003) also discussed how cultural capital would be better understood not only as the appreciation of “high” cultural forms, but more generally as widely shared, high status cultural signals (i.e. attitudes, values, behaviors, formal knowledge, etc) used for social and cultural exclusion. In addition to Bourdieu’s (1986) concept of cultural capital is economic capital, which reflects an individual’s socioeconomic status and their access to gain resources through financial means. Social capital is comprised of relationships and social networks among people, where having social ties with people who have access to highly valued resources is also important (Lareau, 2015). These capital resources function together resulting in social reproduction (Bourdieu, 1986), where “privileged parents” would then have the means to access additional resources, in contrast to CLD parents with cultural capital that was not necessarily valued when navigating different American institutions and systems.

Clark (2018) also described how white middle-class parents were also more likely to exhibit the skills that were seen to align with the IDEA process of “ardent advocacy,” i.e. behaving in ways that signaled equal expertise. Parents with a strong knowledge of special education and behavioral strategies were seen as having the cultural capital needed to navigate the process. This was in addition to knowing how to communicate in specific ways with schools and having the “right” disposition as a parent. Clark (2018) delved deeper by arguing that white parents were in a better position to secure special education resources, as they had privileged access to the wealth and social capital valued in schools, thus generating more cultural capital to secure resources for their child. Even in cases where middle class African American families were able to communicate more effectively with schools than similar families from a lower socioeconomic background, these families still faced an institutional setting that implicitly privileged white families. Moreover, white middle-class parents were more disposed to communicate with schools in ways that signaled their belonging in a social space (Clark, 2018), where certain “socioemotional” styles that reflected trust in schools were seen as desirable and acceptable (Lareau & Horvat, 1999).

Clark (2018) further discussed how special education resources were disproportionately allocated by race and class, where she claimed that although scholars and policy makers were understandably concerned about bias and discrimination, the law has paid relatively little attention to the ways that elites can reproduce privilege through using their cultural capital. In fact, Clark (2018) argued that although parental capital is shaped by hierarchical race and class positioning, cultural capital hides those influences within the confines of IDEA’s cultural assumptions about parent ardent advocacy. As a result of the systematic ways in which cultural capital is stratified by race and class, some parents are simply seen as better advocates than others.

Thus, in order to address the culture in law, it would be critical for scholars and policymakers to understand "culture" from a different perspective than in the past. According to Clark (2018), policymakers have attempted to level the playing field by "correcting" value differences between the privileged and the disadvantaged through a "cultures as value" approach. However, instead of taking this approach, legal scholars need to be aware that the law requires specific knowledge and strategic behaviors that are stratified by race and class in order to benefit from it. Clark (2018) argues that culture can be understood as "context specific behaviors and knowledge informed by structural and cultural constraints" (p.433). Having a *knowledge and behavior strategy* approach to culture would benefit families, especially CLD families in their advocacy efforts, as they would have a way to push back on racist and discriminatory tropes around "blaming the victim." By questioning the system, parents would be in a better position to gain access to cultural capital in the form of knowledge and behavior strategies and feel more successful in their advocacy efforts.

The cultural factor in parent advocacy for Asian families

It is important to point out that the very concept of advocacy as generally defined in the earlier sections is culturally specific to the U.S. Thus, families who immigrate to the U.S. might not share the same understanding of what it takes to acquire services, especially in special education. Existing research focusing on the advocacy efforts of other CLD families have consistently reported that understanding the special education system, as well as their rights and protections are confusing and challenging to understand (Cho & Ganotti, 2005; Cheatham, 2011). However, it is also worth noting the underrepresentation of research focusing on parent advocacy for Asian families of children with disabilities, especially in the context of CLD families in the U.S.

Given the vast diversity of Asian values, languages, and cultures, it is important to understand how cultural factors as a whole may influence the ways parents advocate for their child or not. Although there may be some common values across different Asian cultures, there are also distinct characteristics that are specific to each culture. In a study linking policy documents to the experiences of Chinese immigrant parents of children with disabilities, Lai and Vadeboncoeur (2013) examined the apparent contradictions that parents faced. On one hand, parents were told that their involvement was an important part of the partnership with schools and that it was legally required. However, parents were also expected not to do or ask for too much. In addition, parents were told by schools that their knowledge and input were valuable yet, they would experience schools responding aggressively when they provided input. Thus, these mixed messages left these Chinese immigrant parents feeling that they could not fully participate as intended by the law, as they did not have enough social or cultural capital to successfully advocate for themselves and their children.

The small but existing literature on Asian American families of children with disabilities reported that they scored significantly lower on levels of assertiveness, communication and other self-advocacy skills, compared to non-Asian American families including European Americans (Huang et.al., 2004; Rubin, Chang & Huang, 1998). Most Asian immigrant families arrive from cultures where speaking up for themselves, challenging the authority of professionals and educators, and taking individualistic actions are stigmatized and highly discouraged (Rubin, Chang & Huang, 1998). The factors that contribute to the level of self-advocacy skills are different for Asian immigrant families in the U.S. compared to non-Asian immigrant families.

However, Huang et.al (2004) found that Asian American parents who were more acculturated to the U.S. were more likely to assert themselves and show more self-confidence in social settings. The age of the parent was also an important factor, where older parents were more likely to speak up on behalf of their children with disabilities. Abe & Zane (1990) also noted that Asian American individuals, who were second generation and beyond, did not differ significantly from white Americans in terms of assertiveness. The cultural and intergenerational differences between Asian diasporic families, as well as stereotypes impacting Asians in the U.S. add more complex layers when considering how to effectively support diverse Asian families to acquire strong advocacy skills for their children with disabilities.

As the result of a mismatch of cultural styles of communication and expectations, as well as unfamiliarity with American special education and IDEA, most Asian immigrant families, especially those with limited English proficiency levels had difficulty navigating the system to fully advocate for their children. In addition, even where language interpretation was provided, the parent's opportunity to fully participate in the IEP team could be compromised if the interpreter did not have knowledge of special education terminologies, as well as an extensive knowledge of both languages (Cheatham, 2011). In this way, interpreter quality could play a critical role in determining what services are provided to the family.

Some advocacy efforts have been discussed in studies on Asian families including Japanese, Korean, and Taiwanese families in their respective countries and in the U.S. (Kayama et.al., 2017), comparisons between East Asian (immigrant) and East Asian American parents (Yan, 2017), as well as South Asian Indian families in the U.S. (Kalyanpur & Gowramma, 2007), and Pakistani/Bangladeshi families in England (Fazil et.al, 2004). For example, the study by Kalyanpur & Gowramma (2007) revealed the significance of cultural barriers for South Indian families to access services and educational goals for their children with disabilities. Examples of these barriers included factors such as negative familial attitudes or the (cultural) perception that the stigma of the disability reflected on the entire family, where feelings of shame and embarrassment often resulted in lack of support by extended family members. In addition, cultural factors such as the caste system had to be taken into consideration as parents insisted that their children with disabilities pursued employment options that reflected the appropriate caste of their family. Lack of information was also a primary concern for many parents in this study, as well as dealing with negative and discriminatory attitudes from professionals (Kalyanpur & Gowramma, 2007).

Across these studies on Asian families, the cultural stigmas behind their children's disabilities became barriers for many of them. Factors such as how educators approached these parents in culturally sensitive ways or what the parents knew about disability in general and whether parents found supportive social networks while talking about their child's disability impacted how they advocated for their children or not. Kayama (2010) found that Japanese and (white) American mothers identified similar themes and expectations of their children's special education teachers such as the importance of trust and being treated as an equal. However, Japanese mothers understood these terms within a Japanese cultural context and American mothers also had their own culturally specific interpretations. Thus, mothers from both groups had different (cultural) interpretations of the same terms and concepts. In order to avoid these potential cultural miscommunications, many research studies have discussed how it is essential to have positive rapport and focus on relationship-building to ensure that parents feel comfortable in communicating more openly with their children's teachers. Without a strong interpersonal dynamic where the professional's demeanor and communication is consistent with what they state, some Japanese immigrant parents may feel discouraged when getting involved with their child’s school.

In order for Japanese parents to become more effective advocates and be actively involved as envisioned in IDEA, it is essential for them to understand the cultural differences and norms in the expectations of teachers and the education system in the U.S., as well as their role as parents. This is especially important as some Japanese immigrant parents might interpret the cultural nuances of a term or concept such as ‘advocacy’ slightly differently from what was intended in the law. Thus, although it is critical to address different structural barriers in supporting immigrant parents and their children with disabilities, one should also be attuned to the cultural aspects of parent advocacy, in terms of what these parents know and still need to gain in their knowledge and skills. In this way, they can begin to understand that although a concept like ‘advocacy’ may be rooted in American ideals and values, with the right information and support, they can have a better understanding of what it means to advocate effectively in special education. Because translated resources have not always shown to be effective or useful for families, there is a need to delve deeper into what might constitute a more meaningful learning experience for immigrant parents.

Tapping into experiential learning benefits of arts-based methods through comics

This section begins by exploring how learning through ‘art as experience’ has been defined by Dewey (1934). This is followed by some background on comics and their experiential benefits. Lastly, there is some discussion on how *manga* or Japanese comics are well-suited to address Japanese (cultural) issues through its widespread use as an educational medium and cultural artifact, as well as its ability to provide an experience for the reader through its art-based form.

Dewey and art as experience

In order to begin exploring what constitutes a positive learning experience for individuals, it is important to define what it means to have an 'experience.' For Dewey (1934), having an experience was not simply a psychological phenomenon or about what was felt exclusively within the individual. Although he acknowledged that it was up to the individual to make sense of what they were experiencing (thus making it personal on some level), it is also imperative to understand that all experiences are grounded in their social contexts. A key component of what it meant to have an experience, according to Dewey relied heavily on how individuals made sense of the emotional components of their experiences in the context of whatever situation they were facing.

Dewey (1934) emphasized the importance of emotions as being the "cement" of a complete experience, where we were more likely to perceive our world positively if we felt positive emotions, as well as the reverse. Thus, in situations that were emotionally significant, certain features of what would otherwise be an ordinary experience would likely be perceived and experienced differently, depending on the emotion that was present. Emotions functioned much like a filter through which one's perceptions were screened, allowing some features of the environment to stand out and others to fade away (Jackson, 1998). Thus, having an experience was seen as the product of continuous and cumulative interactions with different ordinary objects and events, where our daily mundane perceptions of them shaped how we related to the world around us.

Emotions were likely to change and transform throughout this process in what Dewey called a trajectory that constituted the emotional history of the experience (Jackson 1994, 1998). Although emotions could fluctuate depending on what was being experienced in that immediate environment, they also served to unify the experience as *complete* and *unique*. Through having these fulfilling experiences of ‘doing’ and ‘undergoing,’ Dewey believed that individuals could *experience* a significant change of some kind, forcing them to modify their old ways of looking at the world around them, where new and old perspectives would become more integrated and new patterns and worldviews could emerge. By being attuned to the emotional dimensions of experience while reflecting on how we feel about the situation, Dewey argued that we effectively contribute to our own transformation. This change in perspective, unified by our emotions was what it meant to have an aesthetic experience, according to Dewey. Dewey believed that all complete experiences had an aesthetic quality and resembled satisfying experiences in general, even those within ordinary or mundane contexts.

Dewey believed that the arts, through its ability to “refine, concentrate and intensify” certain emotions, forced us to focus on the immediacy of the objects and events around us, in terms of what originally struck us about its presence (Jackson 1998). What the arts offered in fact, were refinements of qualities to be found in ordinary experiences. The arts in this sense did not constitute what one might refer to as “fine art.” Although Dewey did not explicitly discuss in detail what would be included as “the arts” in “art as experience,” one can assume that the arts could include a broad and diverse range of creative expressions of individuals or groups e.g. through artistic forms such as poetry, dance, music, drawing, among many others.

When undergoing art as experience, Dewey also emphasized how it was critical for one to perceive the relationships between ‘doing and undergoing,’ and whether we made sense of them from more aesthetic or intellectual perspectives could also lead to tensions and problems for both the artist and the audience. Dewey discussed that in order for one to have *an* experience, there had to be an expectation that there would be a degree of complexity in the experience. In addition, Dewey also emphasized that it would not be possible to have a complete experience without considering both emotions and cognition; that one could not exist without the other. The audience could encounter challenges with the work that the artist did not foresee or account for. In contrast, the opposite could be true as well, where positive emotions could arise from receiving feedback that was beyond one's own expectations. Thus, these tensions and problems between differences in expectation and anticipation could also lead to a myriad of emotions that can shape the overall experience for the audience.

Eisner (1985) discussed similar themes when he discussed "aesthetic modes of knowing" and what it meant to have an experience. Eisner (1985) discussed that in order for one to have a true experience with something, it was also critical for the viewer to have some level of competence in order to perceive the qualities of form in that specific object or item. In this sense, Eisner (1985) believed that one's internal life was shaped by the forms that s/he was able to experience (p.25). This was based on the notion that arts-based research could capture and evoke meaning that measurement alone could not, where its design could push its audience to "rethink" certain aspects of the social world by re-experiencing them, thereby contributing to more awareness and deeper human understanding.

Benefits of comics in conveying complex information

Eisner (1985) stated that having an aesthetic mode of knowing provided the experiential rewards of taking the journey itself. One such example of an aesthetic or arts-based medium that was explored for this dissertation was comics. Given how comics can vary in terms of style, format, length, among other factors, it is important to acknowledge how comics have functioned across these different disciplines to convey complicated information, as well as diverse experiences.

What exactly counts as a comic and how can they provide an experience for the reader? Comics are broadly defined as the co-presence and interplay of image and written text (Hatfield, 2009). Kukkonen (2011) described two important aspects of comics as being a type of medium and a vehicle for storytelling. According to Kukkonen, comics are a multimodal medium that generally have recognizable panel sequences, speech bubbles and speed lines, all of which are designed to tell a story to their readers. Moreover, these different modes within comics which include images, words and sequences also impact how a story is narrated and conveyed. These unique aspects using multimodal expressions increase the accessibility of the graphic narrative. This means that comics as a medium has storytelling capabilities that are much more complex and dynamic than generally understood (Cohn, 2011). An important point to consider is that in order to understand the messages behind individual comic panels, it is crucial to weave together both graphic and textual elements to build a larger context for the reader. Having multiple modes of information arranged together in a sequence of panels thus contributing an added richness in the messages conveyed and also the overall experience.

Over the past half century, comics have continued to gain more credibility within the discourse of education and research. Currently, comics have becoming increasingly popular within research across diverse disciplines including health and medicine (Green & Myers, 2010; Williams, 2012; Leavitt, 2014; McNicol, 2014; Glazer, 2015; McMullin, 2016), education (Galman, 2009; Short & Reeve, 2009; Scherr, 2013), disability studies (Birge, 2010) and among many other disciplines. For example, health professionals in the medical field have tapped into the experiential benefits of comics by providing patients with information that was not just limited to factual details about the illness and its symptoms, but also similar experiences of other patients in a graphic format. Having a multimodal comic format helped patients to not only anticipate and understand complicated medical procedures in advance, but also provided a relatable context where they could experience the successful recovery process of another patient in similar circumstances.

A study comparing the use of comics and text booklets to deliver complex information about science found that comics increased the knowledge of and attitudes towards science and nanotechnology, where the results implied that science comics had the potential to develop a layperson's knowledge on the topics and increase their overall interest in learning (advanced) science (Lin et.al, 2015). It is interesting to note that regardless of how complex the information was, comics provided different ways to delve deeper into the experience, which inevitably led to higher engagement overall for these students.

Moreover, comics and autobiographical graphic novels on disability and illness narratives, such as *Epileptic* (Beauchard, 2005), *Cancer made me a shallower person* (Engelberg, 2006), *Spiral Cage* (Davison, 2003), and *With the Light* "*Hikari to tomo ni" manga* series (Tobe, 2007) among many others have also brought to light the power of multimodal narratives and their ability to capture and convey powerful experiences and the socio-political realities surrounding disability narratives. This is important given that representations of disability tend to be hyper represented in negative ways, especially in the media (Couser, 2005; Irwin & Moeller, 2010; Farrell, 2014). However, comics and graphic novels have continued to resist these negative stereotypes by addressing these stigmas in different ways. For example, Davison (2003) challenged different disability tropes about what it meant to be a man with spina bifida, who was perceived in a certain light by society due to his lack of ability and thus, his access to masculinity. However, he also challenged the status quo of the nondisabled by allowing the viewer to experience his life through a combination of images, words and forms that spoke to how disabled lives need not be pitied by virtue of having a disability (Davison, 2003).

Similarly, *Hikari to tomo ni* (Tobe, 2007) also challenged the status quo of how disability, more specifically, autism was perceived and accepted in Japan. It began as a series of *manga* portraying a Japanese family, whose son was diagnosed with autism when he was a toddler. Through the mother's perspective, the reader was able to experience the challenges that this particular family went through as her son grew from a baby into a teenager, thus highlighting many (social) difficulties that families in Japan face when navigating Japanese social norms and cultural stigmas around disability. As a result of this *manga*'s ability to provide a powerful experience around how children with disabilities and their families were being treated in Japan, it eventually became a popular televised series in Japan, where it also eventually won many prestigious awards (Bryce, Matthews & Takeyama, 2014). Providing the experience of the *manga* through television increased awareness to disability issues in Japan, thus creating a more public platform to highlight the social challenges that Japanese families of children with disabilities faced in Japan.

Manga as a (cultural) learning tool for Japanese families of children with disabilities

Much like western-style comics and graphic novels, Japanese *manga* employs similar techniques to provide more visual and interactive experiences for the reader. In addition, *manga* also includes cultural and language specific features as well, such as the use of onomatopoeia and playing off the Japanese language itself through the intentional choice of specific Japanese script (Murakami & Bryce, 2009). Having these added features in *manga* helps the reader to experience more emotional connections, as the visual cues convey an additional layer of meaning for an interactive experience. Moreover, these experiences connect back to what Dewey (1934) and Eisner (1985) described as art as experience and aesthetic modes of knowing respectively, through *manga* and its ability to convey information in an arts-based form.

It should be noted that although *manga* is similar in many ways to western-style comics, there are also features and characteristics of *manga* that are specific to Japanese culture (Ito, 2005; Murakami & Bryce, 2009, Cohn, 2011). Like any other form of visual art, *manga* does not exist in a vacuum but is immersed and positioned in a particular sociocultural environment that includes specific values around cultural norms, history, language, politics, family, religion, gender, disability etc. *Manga* also reflects the reality of Japanese society in terms of different norms, beliefs, traditions, and social phenomena, including social order and hierarchy, sexism, racism, ableism, ageism, classism, and so on (Ito, 2005, Cohn, 2011). Thus, *manga* is not merely a comic narrative that happened to be in the Japanese language but is a cultural artifact in its own right, which reflects the norms and values of Japanese culture.

By drawing upon the research behind the benefits of using a multimodal medium such as *manga* and its ability to convey complex information in culturally accessible ways, this study sought to examine the (cultural) disconnect between what was intended in the IDEA and the advocacy experiences of Japanese immigrant families by developing information in Japanese using both *manga* and text formats. Clark (2018) described the need to support CLD parents in their advocacy efforts by helping them to access the knowledge and behavior skills (i.e. cultural capital) needed to be successful. Thus, exploring the use of different mediums provided an exciting opportunity to explore issues related to parent advocacy and IDEA for Japanese immigrant parents.

The research questions that guided this study were: 1) How do immigrant Japanese parents of children with disabilities respond to and make meaning of graphic versus written information on IDEA and the narratives of other Japanese families' experiences with American special education advocacy? and 2) What kinds of affordances might there be in using *manga* (over a standard text format) for Japanese families to feel more prepared when advocating for their children?

Chapter 3

Methods

Research on culturally and linguistically diverse (CLD) parent advocacy has described how parents from diverse cultural and language backgrounds have continued to face difficulties with understanding the implicit cultural expectations of parent advocacy embedded within the Individuals with Disabilities Education Act (IDEA) (Kalyanpur, Harry & Skrtic, 2000; Clark, 2018). Within this small body of research, the barriers and challenges specific to Asian families, especially those from immigrant backgrounds have not been well understood. To begin addressing this gap in parent advocacy research, this dissertation focused on gaining insight into the advocacy experiences of eight immigrant Japanese parents of children with disabilities through a comparative case study design using two different tools—text and *manga*. This section begins by describing the research design of this comparative case study and the process of creating and developing the tools used. This is followed by discussions around researcher positionality, participant recruitment, interview protocols and data analysis.

Research design

For the purpose of this research study, I developed a comparative case study design utilizing a comic narrative and a written text narrative to examine the advocacy experiences of two groups of Japanese immigrant parents of children with disabilities. I explored how each instrument provided ways for Japanese immigrant parents to make sense of culturally specific understandings about advocacy and parent rights in U.S. special education.

Case studies generally involve an approach that is used to “generate an in-depth multifaceted understanding of a complex issue in its real-life context” (Crowe et.al, 2011). All research methodologies have their affordances and limitations that involve making decisions about the study design. Some of the affordances of case study methodologies are that they are particularly well-suited when the research questions at hand are looking to understand “how” and “why” certain phenomena exist (Gerring, 2004; Yin, 2009; Yin & Campbell, 2018). In addition, case studies are particularly helpful when these phenomena occur in their natural environment, where the researcher has little control over the events and the boundaries between phenomenon and context are not clearly evident (Yin, 2009). For this reason, this type of research is considered “naturalistic” design, in which studies can be used to “explain, describe or explore” events in which they occur (Crowe et.al., 2011). According to Stake (1995), a case study is both the process of learning about the case and the product of the learning. In addition, case studies can offer more insights into the different types of gaps that exist in its delivery or the reasons a particular implementation strategy might be chosen over the other. This can be especially beneficial to develop or refine theory (Crowe, 2011). Thus, in order to understand the circumstances of these occurrences, it is important to consider a variety of methods that renders more insight into the topic of interest. For example, it is not uncommon for many case studies to triangulate evidence collected from interviews, observations, key artifacts, surveys, and researcher notes, in order to ensure that the understanding gained from using these methods is accurate (Yin, 2009; Stake, 1995, 2010).

Defining the case

The cases of interest focused on how the medium of information itself supported Japanese parents’ ability to access and gain knowledge on special education advocacy in more meaningful ways. One set of cases focused on parents receiving a comic intervention first, then the text narrative, while the comparative cases included parents receiving the text narrative intervention before the comic intervention.

The rationale behind recruiting Japanese immigrant parents and using comics for this study is that a comic or a *manga* format is culturally accessible for them to read and understand, as *manga* is one of the more widespread forms of mass media in Japan. It is not uncommon to find *manga* narratives and other visual formats focusing on larger societal issues (Bryce, Matthews & Wakeyama, 2014). In addition, Japanese styles of communication tend to focus more on "high context" cues that privilege nonverbal communication such as gestures, actions and behaviors (Lebra, 2004). A comic format would thus be ideal in representing the culturally specific ways of Japanese communication and in ensuring its accessibility. The epistemological approach to this study will be *interpretative*, which involves understanding meanings and contexts as perceived from different perspectives. This approach will be useful in trying to understand individual and shared social meanings.

Developing a narrative for text and *manga* intervention tools

Based on Dewey's (1934) theory of art as experience, I wanted to explore how parents would respond to an arts-based resource compared to standard text when learning about a topic such as special education advocacy and law. The first step before conducting parent interviews was to create a narrative that would be developed further into two different mediums (tools)—*manga* and text. These tools would include the same content and information but would be different in presentation and format.

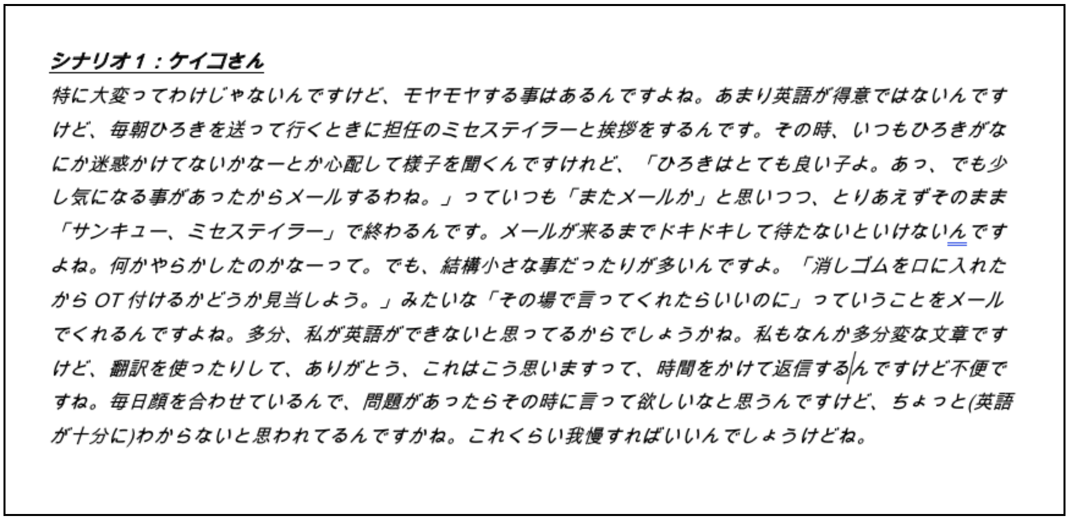
Because I was interested in centering the Japanese cultural experience around parent advocacy in American special education, I wanted to ensure that the narrative would not only make sense but be relatable enough for the participants. I engaged in multiple forms of gathering culturally situated knowledge around disabilities and special education support as part of this narrative development process. For example, I had informal conversations with parents from the previous study (Omori, 2016) to begin thinking about the narrative content and to identify some of the issues that these parents had faced, especially around cross-cultural issues of parent advocacy in special education. Their experiences pushed me to think about developing “scenarios” within the narrative to highlight some culturally specific issues that they had faced. For example, figure 1 depicts the experience of Keiko, who was a Japanese parent that was interviewed in the 2016 study. In this scenario, Keiko shared a personal experience where she was having ongoing communication difficulties with her son’s teacher and was confused by different cultural expectations and norms around parent-professional dynamics in U.S. special education. Figure 2 depicts the same scenario but in a text format.

Figure 1

Manga scenario with Keiko based on 2016 study

Figure 2

Text version of scenario with Keiko



シナリオ１：ケイコさん

特に大変ってわけじゃないんですけど、モヤモヤする事はあるんですよね。あまり英語が得意ではないんですけど、毎朝ひろきを送って行くときに担任のミセステイラーと挨拶をするんです。その時、いつもひろきがなにか迷惑かけてないかなーとか心配して様子を聞くんですけれど、「ひろきはとても良い子よ。あっ、でも少し気になる事があったからメールするわね。」っていつも「またメールか」と思いつつ、とりあえずそのまま「サンキュー、ミセステイラー」で終わるんです。メールが来るまでドキドキして待たないといけないんですよね。何かやらかしたのかなーって。でも、結構小さな事だったりが多いんですよ。「消しゴムを口に入れたから OT 付けるかどうか見当しよう。」みたいな「その場で言ってくれたらいいのに」っていうことをメールでくれるんですよね。多分、私が英語ができないと思ってるからでしょうかね。私もなんか多分変な文章ですけど、翻訳を使ったりして、ありがとう、これはこう思いますって、時間をかけて返信するんですけど不便ですね。毎日顔を合わせているんで、問題があったらその時に言って欲しいなと思うんですけど、ちょっと(英語が十分に)わからないと思われてるんですかね。これくらい我慢すればいいんでしょうけどね。

In addition, I also spoke with several Japanese parents who were not involved in the 2016 study nor this current study, but were parents of children with disabilities themselves and had firsthand experiences with the challenges of navigating special education in the U.S. It was insightful to hear what would be helpful for these parents as well, as it informed me on what was considered “useful” information to them and to frame all the details in a way that made sense from a culturally Japanese perspective. I also received input about my narrative from personal contacts in Japan, as well as Japanese professionals in the disability and special education field in Washington state to ensure that the narrative made sense to a Japanese audience.

After many discussions with various Japanese individuals, I decided that the best way to present everything would be to include some brief sections pertaining to the law and parent rights (procedural safeguards), as well as a section with several scenario examples of Japanese parents navigating special education and how their challenges could be addressed by exercising their rights.

I also looked at several English language publications and resources on parent rights, law and advocacy (e.g. Wrightslaw, 2006) to use as references to develop the structure and informational content of the narrative. Given that the concept of advocacy was (culturally) challenging to describe in Japanese, I felt that it was important to reflect how parent advocacy has been discussed in the context of laws and rights in English language publications as a way to model this information in as meaningful of a way as possible for Japanese parents. For example, in figure three, a brief history of IDEA and how special education came to be implemented in the U.S. was included in the main narrative to provide a historical context to understanding how and why special education services currently exist in the U.S. In addition, Figure 4 is the text version of the same page in figure 3.

Figure 3

Page from manga on IDEA and a brief history of special education in the U.S

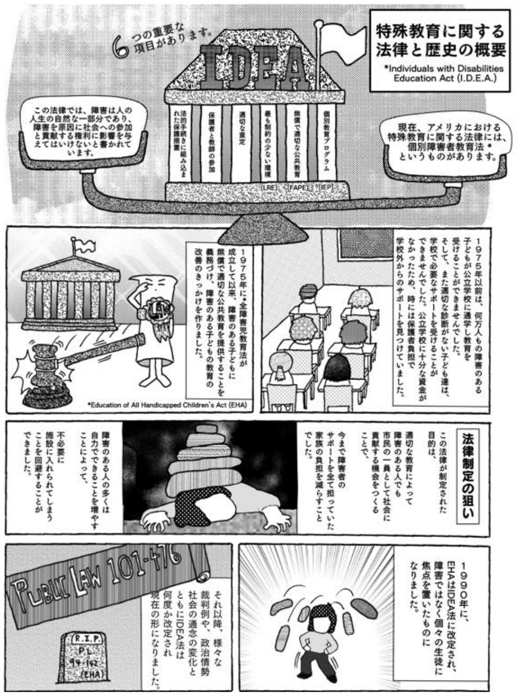
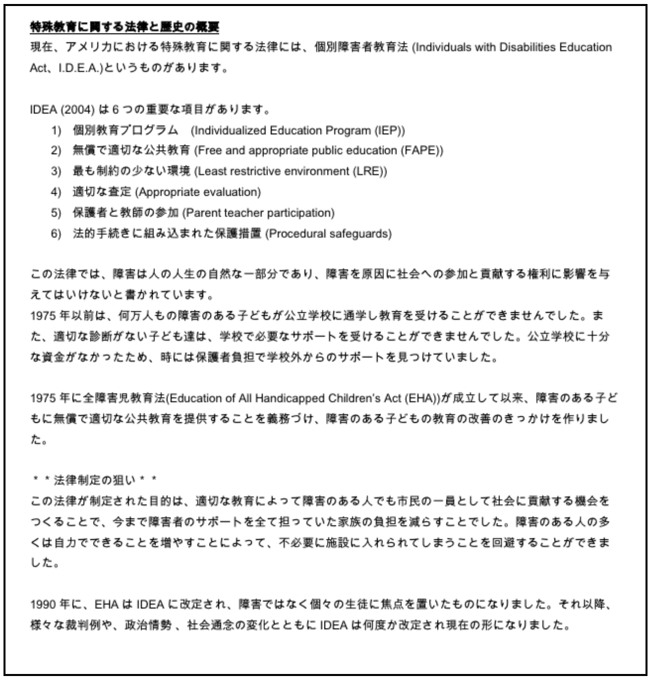


Figure 4

Text version of figure 3



特殊教育に関する法律と歴史の概要

現在、アメリカにおける特殊教育に関する法律には、個別障害者教育法 (Individuals with Disabilities Education Act、I.D.E.A.)というものがあります。

IDEA (2004) は 6 つの重要な項目があります。

1) 個別教育プログラム (Individualized Education Program (IEP))
2) 無償で適切な公共教育 (Free and appropriate public education (FAPE))
3) 最も制約の少ない環境 (Least restrictive environment (LRE))
4) 適切な査定 (Appropriate evaluation)
5) 保護者と教師の参加 (Parent teacher participation)
6) 法的手続きに組み込まれた保護措置 (Procedural safeguards)

この法律では、障害は人の人生の自然な一部分であり、障害を原因に社会への参加と貢献する権利に影響を与えてはいけないと書かれています。
1975 年以前は、何万人もの障害のある子どもが公立学校に通学し教育を受けることができませんでした。また、適切な診断がない子ども達は、学校で必要なサポートを受けることができませんでした。公立学校に十分な資金がなかったため、時には保護者負担で学校外からのサポートを見つけていました。

1975 年に全障害児教育法(Education of All Handicapped Children's Act (EHA))が成立して以来、障害のある子どもに無償で適切な公共教育を提供することを義務づけ、障害のある子どもの教育の改善のきっかけを作りました。

＊＊法律制定の狙い＊＊
この法律が制定された目的は、適切な教育によって障害のある人でも市民の一員として社会に貢献する機会をつくることで、今まで障害者のサポートを全て担っていた家族の負担を減らすことでした。障害のある人の多くは自力でできることを増やすことによって、不必要に施設に入れられてしまうことを回避することができました。

1990 年に、EHA は IDEA に改定され、障害ではなく個々の生徒に焦点を置いたものになりました。それ以降、様々な裁判例や、政治情勢 、社会通念の変化とともに IDEA は何度か改定され現在の形になりました。

After my initial research and discussions were complete, I began developing and refining different sections of the text narrative in English first and then translated it into Japanese. I revised this main narrative and structure several times based on input and feedback from different Japanese community members during this process. Once the text narrative was complete, a *manga* version using the same narrative content was developed. The final product included four sections: 1) Brief introduction of four main characters (parents from 2016 study) and purpose of the resource; 2) Short facts about IDEA and challenges facing CLD families; 3) Three scenario examples with Japanese families; 4) Procedural safeguards and 'solutions' to earlier scenarios through exercising parent rights (see figure 5 and 6). Both versions of the tool were shared for feedback with some of the same parents, professionals and community members, where it underwent several minor revisions before they were ready to be used for interviews.

Figure 5

Two examples from a manga panel of how parents from the earlier scenarios can exercise their rights to begin resolving their issues.

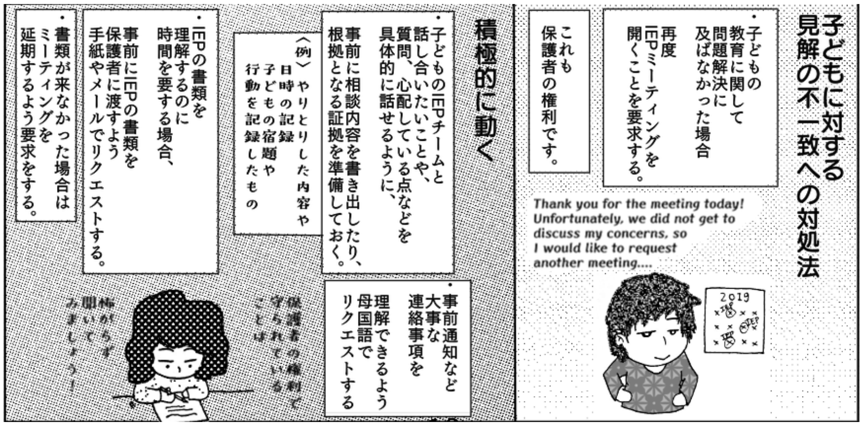
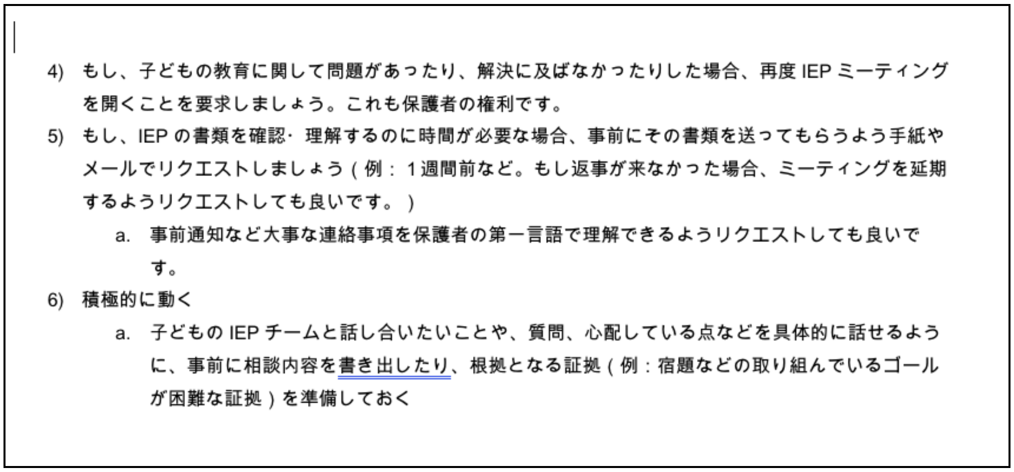


Figure 6

Text version of the same panels in figure 5



4) もし、子どもの教育に関して問題があったり、解決に及ばなかったりした場合、再度 IEP ミーティングを開くことを要求しましょう。これも保護者の権利です。
5) もし、IEP の書類を確認・理解するのに時間が必要な場合、事前にその書類を送ってもらうよう手紙やメールでリクエストしましょう（例：１週間前など。もし返事が来なかった場合、ミーティングを延期するようリクエストしても良いです。）
    a. 事前通知など大事な連絡事項を保護者の第一言語で理解できるようリクエストしても良いです。
6) 積極的に動く
    a. 子どもの IEP チームと話し合いたいことや、質問、心配している点などを具体的に話せるように、事前に相談内容を書き出したり、根拠となる証拠（例：宿題などの取り組んでいるゴールが困難な証拠）を準備しておく

Researcher Positionality

As part of my own positionality in this study, my role has been both as an insider and outsider to different degrees. As a Japanese immigrant and insider to the Japanese culture, I have a strong understanding of the types of cultural and language barriers that Japanese families face when living abroad from Japan. To native Japanese people who were born and raised in Japan, I may seem more like an outsider, as I was not educated in the Japanese system and have lived outside of Japan for the majority of my life. However, because I was raised in a Japanese household with access to Japanese culture, I developed the Japanese communication skills and cultural (insider) knowledge I needed from my family and the existing Japanese community growing up in Malaysia. My identity has always been Japanese. I am bilingual and fluent in both English and Japanese. Since becoming an adult, I have always been connected to different Japanese immigrant communities in the different cities and states that I have lived since moving to the U.S. (including southern and northern California, Hawaii and Washington state). In essence, these experiences have all contributed to my understanding and experience of the growing Japanese diaspora and identity outside of Japan. Thus, I consider myself knowledgeable on culturally specific and language issues for Japanese immigrant families in the U.S.

Moreover, although I am not a parent of a child with disabilities, I understand the Japanese stigma around disability, disablement and difference, not only due to my own non-heteronormative identity and having an invisible disability, but also from having a family member with a disability who was never officially diagnosed due to the negative stigma of being disabled. Having these insights have strongly impacted my awareness and sensitivity to how "difference" can be treated across different (Japanese) contexts. It has also helped me tremendously in my experiences supporting and working with Japanese and other diverse immigrant families of children with disabilities for over ten years in the U.S. I have volunteered my time with a local Japanese support group for the past ten years and developed strong rapport with a group of around 40+ Japanese parents of children with disabilities through participating in various events.

As a professional, I also have more than five years of experience running community-based programs supporting diverse immigrant and refugee parents, their children with disabilities (of all ages) and the professionals who work with them. I have extensive knowledge from firsthand experience when it comes to working with these underrepresented families and communities on issues related to special education and disabilities, in addition to the knowledge I have gained as a researcher.

Participant recruitment

A recruitment flyer about this research study was created in Japanese and disseminated to parents at a local Japanese parent support group for families of children with disabilities. Eight mothers were recruited from this parent group through snowball sampling (Patton, 2015). All eight parents were Japanese immigrants who were born and lived in Japan until their adult years and had at least one child with disabilities receiving special education services in the U.S. Parents' length of residence in the U.S. ranged from three years to 30 years, where approximately half of the group had been in the U.S. for 15+ years, and the other half had less than six years. Of the eight families, there were six boys (four boys with autism; one with ADHD and one with both autism and ADHD) and two girls (both autism). The youngest child was five years old, where the oldest was 15. Five participants had Japanese spouses, where the remaining three married internationally (two white; one Asian). Due to the nature and makeup of the parent group, only mothers volunteered to participate. Fathers were invited to join as well but none responded.

For each parent, I collected personal information using a demographic survey to compile details such as age and disability type of children, age of parents, family's length of residence in the U.S., citizenship/visa status, English language proficiency, socioeconomic status, parent education level, occupation etc. These factors provided some supplementary information into the backgrounds of the participating Japanese parents. In addition, there were several questions at the end of the demographic survey asking parents to indicate their level of comfort communicating with their child's Individualized Education Program (IEP) teams, level of satisfaction with their child's IEP, as well as knowledge around special education laws.

Interview protocols

Once a parent was recruited for the study, they received a letter of introduction to the study, as well as several forms to complete including a demographic survey and an informed consent form. All documents were provided in Japanese. Once the forms were completed, an interview date and location were determined at the convenience of the parent. Each parent was randomly assigned into one of two groups (*manga* or text) to determine which intervention tool they would be receiving first.

I conducted qualitative open-ended, semi-structured interviews in Japanese for this comparative case study. The interviews were divided into three phases, where the initial part (i.e., pre-intervention) of the interview focused on (Japanese) parental experiences of advocacy and gaining insight into how these parents made sense of the concept of "advocacy" through their various experiences with different people, professionals and institutions. The interview protocol for this first part of the study was based on Omori (2016), which explored the cultural barriers to parent advocacy for Japanese and Korean immigrant parents. In order to understand the cultural challenges of Japanese parent advocacy for these parents, it was important to gain insight into 1) how parents understood and conceptualized their child's disability; 2) their (cultural) attitudes and values when talking about disabilities and their child with disabilities; and 3) their experiences and comfort level in communicating with professionals and schools in English. Thus, these questions were incorporated into the beginning of each interview (see *Appendix A*). Examining how Japanese immigrant parents with varying English language skills communicated with schools when dealing with potential conflict and disagreements was important, in order to understand the culturally specific challenges that these parents faced when advocating for their children.

The second phase of the interview focused on the specific intervention tool that the parent received after the first interview phase (randomly assigned). Parents were given as much time as they needed to read through the tool they received. During this time, I took field notes and did not interact with the parent unless they had questions. Upon reading the intervention tool, parents were asked to describe and reflect on their general impression of the tool (either *manga* or text format), as well as how useful and helpful the information was to them in connection to the experiences they had shared earlier in their interviews.

After completing the second phase of the interview, parents received the other version of the tool and were asked to read and reflect on it in a similar process to the first intervention, as part of the third phase. I attempted to delve deeper by asking parents what worked for them in particular about the tools, their experiences of engaging the same content but through different mediums, and to explain their preference for one tool over the other (if any).

Data analysis

All interviews were audio-recorded, transcribed verbatim and translated selectively for further analysis. Field notes were collected before, during, and after the individual interviews, which supplemented the analysis of the collected data and provided more insight into how parents responded to the topic of parent advocacy and rights in the context of different intervention tools. Interview transcripts (with pseudonyms) were reviewed and analyzed through an open-coding system, in which I searched for common themes within the data that I collected through the interviews (Patton, 2015; Spradley, 1979).

In order to begin building each case record for this qualitative comparative case study, I gathered all the data I collected on each family including the interview transcript, field notes, demographics form, self-reflexive memos and other miscellaneous memos and notes on my rapport and ongoing interactions with specific parents (e.g. through parent group events and activities). I wanted to ensure that I would be able to provide an intensive, holistic description and analysis of each case record. I organized and compiled all relevant details for each family, in order to conduct within-case analysis and cross-case analysis later on as well.

I started by reading over the interview transcript once. After getting a general sense of the parent interview, I began analyzing the interview data systematically through line by line analysis and content analysis using open coding methods (Merriam, 2009). I generated codes inductively through constant comparison methods (Glaser, 1965). For this first round of open coding, I engaged in this process in both English and in Japanese, to allow the data to “speak to me.” I intentionally left this open for myself to see if I picked up any specific cultural nuances from what the parents were sharing in Japanese. I found this to be useful especially when making side comments on the transcript. It felt more authentic to respond in Japanese to something that the parent shared that felt very culturally Japanese. I assigned each code to specific excerpts throughout the interview and created brief comments and notes around their significance.

In my second round of coding, I focused on these codes and notes for the entire interview to begin grouping similar codes together. By establishing common codes and related themes and grouping them into specific categories, I was able to collapse them further in order to make the analysis of the data much more coherent (Coffey &Atkinson, 1996; Corbin & Strauss, 2007). Member checks were also conducted to triangulate the cultural codes that were found within the data. I repeated this iterative process with the remaining interview transcripts, where I generated separate lists of codes, comments and memos for each case.

Chapter 4

Findings

This next chapter provides individual case descriptions of the eight parents who were interviewed in this dissertation study. I will share some brief details about their background, as well as their special advocacy experiences to provide more insight into who these parents were. I also included parent responses to the intervention tools. This section will be followed by a cross-case analysis and examination of all parent responses.

Case profile of Kazumi

Kazumi was the mother of three young children and had been living in the U.S. with her husband and children for around five years. It was in Japan when she first noticed that her oldest son Minoru acted and played very differently from other children when he was just two years old. Kazumi shared,

> これは何かあるなと思って、自分で病院に行って、診断してくださいって。頼んだの、病院に。 (*I felt that there was something different (with Minoru's behavior). So I went to the hospital and asked for him to be evaluated.)*

After seeking support from the family doctor, Minoru was evaluated but his doctor was initially hesitant to give him an official diagnosis due to his young age and that his symptoms were seen as on the milder end of the autism spectrum. However, upon her insistence (and advocacy), Minoru received a diagnosis of autism spectrum disorder. Kazumi was one of the few parents in this study whose child was diagnosed in Japan and thus, had some experiences dealing with the Japanese cultural stigma around disabilities in Japan; for example, many parents expressed a lot of concern and discomfort when her son Minoru started attending kindergarten. Kazumi shared,

> うん、本当に、もう自閉症イコール障害っていうふうに見られた、日本だと。っていうのは、やっぱり自閉症ってどういうものなのか全然知らなかったり、何かされちゃうんじゃないかとか、そういう見方をされて。で、やっぱり、あの、ミノル君自閉症なんだけど、どうなん

> ですかって。やっぱり、担任の先生に連絡が来たんだって。大丈夫なんですかって。なんか、クラスむちゃむちゃになったりしないんですかっていうので。幼稚園に連絡が来たりしたんだって。(*Yes, I swear, in Japan, autism is understood as being equivalent to being severely disabled. But the thing is that most people don't even know what autism is and are afraid that people with autism will cause harm in some way towards them. And it turned out that there were parents who were calling the classroom teacher, asking all these questions about Minoru and his autism, whether he was causing trouble and turning the classroom upside down. His teacher told me that there were a lot of concerned parents calling her.)*

However, Kazumi was able to build strong relationships with the teachers and principal, which led to some collaborative efforts distributing information about autism to inform parents to have a better understanding of what autism was. Despite the positive relationships she was able to develop with Minoru's teachers, she constantly felt the judgment of other people (especially parents) and had the added pressure of having to watch Minoru to make sure he was acting in a socially appropriate way. In addition to these issues, Kazumi also felt that she did not have enough knowledge about autism and how to best support Minoru's needs. She mentioned that even when she asked questions at school, many teachers themselves did not have the knowledge or proper training when it came to working with children with disabilities. However, after discussing her concerns with one of Minoru's teachers, the teacher invited Kazumi to attend a training together on using picture exchange communication system (PECS). Thus, Kazumi learned how to use some basic PECS at home with Minoru.

As Kazumi was dealing with different ongoing issues around disability needs at her son's school, she began to realize through her own research that finding a good fit for Minoru's education moving forward would be extremely challenging, as the Japanese educational system was severely lacking when it came to supporting the education of students with disabilities. Because their options were much more limited in Japan, Kazumi and her husband realized that their best chances might be in the U.S., as there was more individualized support and a different educational system from Japan overall that was touted by even the Japanese teachers at Minoru's kindergarten. Thus, they made arrangements to move to the U.S. and to initially live with Kazumi's parent-in-laws who were living in the Pacific Northwest region.

In order to prepare for their transition, Kazumi researched the internet for different resources for Japanese families of children with disabilities around the local area and eventually came upon *Himawari-kai*, a Japanese parent support group for families of children with disabilities that met not far from where her in-laws were living. It was there that she was connected to a local nonprofit organization, *Families First* (FF) that provided parent trainings on special education related topics and disability support services. Kazumi repeated throughout her interview that without the support of FF and their Japanese staff member, she would not have the knowledge that she had and that she would have faced more challenges in navigating special education support. This was especially the case as Kazumi revealed that she did not receive any information or resources from Minoru's school. With the support of FF, Kazumi gained some basic understanding of what IEP services were available and how to request them. Of the eight parents in this comparative case study, Kazumi was one of the very few who had some working knowledge about special education and IEP support, despite having very limited English communication skills.

Response to intervention

Kazumi received the *manga* first and upon first glance of the drawings, was immediately taken by her own excitement. She shared her initial reaction as,

> すごいな。ちょっとこれ。全然内容が入ってこないもん、この絵ばっか見ちゃって。(*Wow, this is amazing. It's almost hard to focus on the content with all of these drawings!*)

As part of the introductory page, I had included some panels about my background, in terms of my professional interests around supporting Japanese families, as well as some general background on research around parent advocacy and special education in the U.S.. Her initial enthusiasm was apparent as most of the details she was noticing and commenting on was around the aesthetic and appeal of the *manga* panels. As she read through the first page, Kazumi asked questions about my background and about my interests in drawing and creating *manga* on special education related topics. This brief exchange at the beginning strengthened the ongoing rapport that we had already developed, as she continued on to read the rest of the *manga*.

During the pre-intervention part of her interview, Kazumi had stated that she had never heard of the term “advocacy” or “advocate” before. However, because she was knowledgeable in some areas of special education due to the training and support she received from FF, most of the information around advocacy from the *manga* was apparently not new to her. Upon finishing the *manga,* I asked Kazumi what she thought of the resource overall. Her immediate response was a lengthy six minute response detailing several experiences she had had with Minoru’s school that closely mirrored one of the scenarios in the *manga.* She went on to mention that if she had not received support from FF, she would have most likely struggled in a similar way to Keiko (from the first *manga* scenario), where different (cultural) expectations and communication styles would have complicated the situation further. For Kazumi, it was clear that having these scenario examples resonated positively with her and provided a platform for her to reflect on her own experiences with Minoru’s school. She elaborated on her thoughts around having these scenarios and how relatable they were for her:

> 例があると一番分かりやすい・・・なんか頭に残るのは、その例が付いて、解決法が付いててくれたほうが、あの、頭に、あの、記憶に残る。あの、あっ、ああいう時、ああいう例だったな、みたいな。あー・・・うん。うん。うん。見せる例がすごい分かりやすい。あー、あるあるっていうのは。(*Having these scenario examples makes everything much easier to understand…it stays much more in my head if there are examples and that with them, there are also strategies to resolve specific issues. It would be so much easier for me to make that connection if I was in a situation and there was an example that was similar to it. Hmm, yes yes yes. So much easier to understand what’s going on with examples that you can actually see.)*

More specifically, it was having these scenarios that helped to make sense of the factual details around special education law and parent advocacy. Kazumi mentioned several times that although it was easier for her to take in the details of the information (due to its format), whether or not it stayed in her memory was a different issue. Having specific examples from scenarios that connected back to the law helped Kazumi to understand the more implicit details around parent advocacy in special education. She shared,

> これもね、確かに今読んだら、あの、分かるんだけど、記憶に残るかっていうと、これ抜けちゃう気がするんだよね。こういうことって、あ、法律はあったけど何だっけみたいな。でも例があって解決法が書いてあると、あ、あーって、なんかそういうところに繋がってたよなみたいなのがあるから、自分が困った時にパッって頭に出てきそう。残りそう。うん。
> (*So, it definitely makes sense when I'm reading (about the law and parent rights) but whether or not I'll remember everything…I have a feeling that it'll be hard. It's more like, "Oh yeah, wasn't there something about the law about this? What was it again?" But when there are scenario examples and different strategies to resolve any difficulties with schools, it's like, ohhhhh okay. That's how that comes together with the law, that's how it connects. And so, even when I'm worried and faced with some kind of conflict, I feel like those visuals will pop up into my mind, that they'll be easier to recall.)*

When asked to elaborate further on what she liked about the *manga* format, Kazumi replied that having the combination of words and pictures made it easier for her to visualize the issues more concretely, that it was more like a "simulation" that she could see clearly. Having a clearer understanding of the issues made it easier for Kazumi to relate to specific issues that the *manga* characters (i.e. Arisa from the second scenario) were going through and thus develop feelings of shared experiences. She elaborated further,

> でもこれをアリサさんじゃなくてかずみさんにして、子供の設定すると、あー、ミノルもあるあるみたいな、なのが、こうすり替えられる。自分と自分の気持ちと息子との例がちゃんと入れ替わるから、こういう時は確かにこれ困ってたんだよねっていうのがやりやすい。
> (*It's like if I were to put myself in Arisa-san's shoes and look at her child's situation, I can see how it could be very similar for Minoru as well, like I could just take out her son and put Minoru in his place. And if I do that, it would be like I was in that situation, me, my feelings and my son and you know, it's so relatable that I can completely understand why this would be so challenging and worrisome.)*

In addition, having a narrative divided into different sections of facts and scenarios helped Kazumi to understand the larger picture and what it meant to be an advocate for her child. For example, Kazumi described trying to make sense of the term, "advocate" from the *manga*, where having relatable scenario examples built on top of the definition provided in the unfolding narrative was critical to her depth of understanding on what it was exactly and what it meant for her as a parent.

> だからすごいとても良いと思う。最初はこうやってパーって読んでて、「ふんふんふん、ふん？って、advocate、何だっけ」って思ったけど、「え、聞かれても多分分かんない、これ読んでも」って思ったけど、この後ろを読んでいくことで、あ、なるほどっていうふうに解決できる。(*What I thought was great and really worked was that at the beginning, I was reading through everything like, okay, okay, okay, hmm? Wait, advocate, what is that again? If someone were to ask me what an advocate is, I don't know that I'd be able to explain it clearly. But if you keep on reading, it makes a lot more sense in the end with how it connected to different issues and finding resolutions to them [with schools].*)

In contrast to her response to the *manga*, Kazumi's take on the text only version was markedly different. She shared,

> もう文字見ただけでうわーってなっちゃう。なんかもうアメリカって来てるだけでうわーってなってるのに、また文字か、みたいなものがあるじゃない。*Just even seeing all that text makes me want to scream. I mean, it's already hard enough moving to the U.S. and everything feels so overwhelming. But it's that feeling like, there's alway*s more text, more words to read. You know?

It was clear for Kazumi that reading everything in a *manga* format worked better for her, as her understanding of advocacy deepened after her experience with the graphic tool. It is interesting to note that the term 'advocacy' and its cultural implications did not initially resonate with Kazumi. However, through her experience with the *manga*, 'advocacy' became more than just a word, as the larger connections between advocacy and special education became clearer for her. In contrast, her experience with the text tool revealed a more (emotionally) complex situation, where Kazumi found it harder to focus on the facts.

Case profile of Izumi

Of the eight parents, Izumi had lived in the U.S. the longest, where she had first moved in order to pursue undergraduate education in the U.S. and eventually stayed on after meeting and getting married to her white American husband. They had been married a while before their son, Yukio was born. He was now 12 years old and Izumi had been in the U.S. for 30 years at this point. Izumi described how Yukio grew up in a slightly less traditional household, where his father was the main caregiver and Izumi went to work at an office every day. However, she still had a very close relationship with Yukio where she described most times, their dynamic was more like that of siblings than mother and son. When asked how she knew this, she shared,

> 私には何でも言えると思ってる。で、私には––の前では、もう、こう、何て言うの。わがままも言える？ママだったら許してくれるだろうと思って言うような。うん。だから、あの、自分、自分の素を出せると思ってるみたい。でもお父さんはやっぱり怖いから、やっぱり、うん。あの、優しいけど、本当に怒らせたらめちゃ怖いから。*(He thinks he can say whatever he wants when he's with me. When he's with me, it's like, how do you say it, he just acts in whatever way he wants? It's almost like he thinks that he can get away with anything because I'm his mom. Yeah. Like he can show me who he really is, his true self. Because you know, his dad can be pretty scary, yeah. I mean, his dad is also very kind but if you make him mad, he is really scary.)*

Izumi described Yukio as an outgoing and energetic boy, who was generally social and liked to be around people. She was open with others about Yukio's ADHD diagnosis, as she said that she did not feel the need to hide his disability or be ashamed of it

> 別に、どこでも言います。うん。だって…隠しててもおかしいけど。隠すことでもないし。というか、それを恥だとも思わないし…私なんかどっちかっていうと、オープンにしてそういうことがあるから、あなたもそういうふうに対処してくださいみたいな。(*Sure, I'm open [about his disability] no matter where I am. Yes. Because hiding it would be…a little weird. And it's also not something that needs to be hidden. I don't feel that it's a shameful thing and when I really think about it, it's almost like I'm being open and up front about it, so I would hope that the person I'm talking to would also be open with me in return.)*

This proved to be a good strategy for Izumi, especially when searching for and enrolling Yukio in different programs such as summer camp or summer school. However, before he received his diagnosis, there had been ongoing issues with Yukio, especially at the local (Japanese) preschool program he was attending. Izumi shared that in her experience, she ran into more obstacles when within the Japanese (immigrant) community than when dealing with (American) schools and teachers. Izumi described how even though Yukio had not been diagnosed at the time he was attending the preschool, she knew that he was a little delayed developmentally. However, as his disability support needs became more apparent through ongoing escalating behaviors, the school informed Izumi without any advance notice that Yukio could not continue to attend. Although there had been some discussion around supporting his needs prior to his expulsion, there had been no follow through with the original support plan and Izumi was forced to consider other options for Yukio.

In fact, Izumi shared that it was mostly within Japanese community spaces in the U.S. such as the preschool, that she faced more experiences of the (Japanese) cultural stigma of disability. Izumi stated that they did not face these kinds of issues after he started elementary school and later on in middle school, as she reflected on her thoughts between the cultural norms of Japan and the U.S.. She felt that the (social) standards that people in the U.S. followed were more flexible in the U.S. than in Japan.

> これ何かがあったらもうこう、ここで sue されるから、やっぱり対処しとかなきゃあかんね。で、そこで文句を言えば言うほど、ね。対処してくれるっていうのは、本当はそうじゃない。ま、なんぼでも、でもそれはしょうがない。でも日本って、文句を言ったら変にブラックリストに乗せられるとか、その、すごく逆のところがあるでしょう？相手にされないとか。何かその、それはちょっと変えないといけないですよね。で、本当にでも思う。*(I guess if something [bad] were to happen, it's always possible that [schools] could get sued, so they know they need to deal with whatever is going on. And I really think that it's true that the more you complain and let them know what's going on, the more likely that they will do something about it. But in Japan, if you complain, you can be on a kind of blacklist, clearly the opposite extreme. Like you get ignored. That part, I think, should change, really.)*

Thus, although the preschool was established in Washington state, the school still very much followed the strict cultural norms and standards of Japan.

> 日本はどうしても、こう、日本人の先生って、こう、みんなが同じことをできて、みたいな。こっちはなんか、別にこっちがやってても、こっちは関係ないやと思ってるから。別にそこまでみたいな。そういうのもあると思うよ。その、みんなが同じ、どれぐらいのレベルにやってけなきゃいけないとか。こっちの先生は、そんな、まあ、人まちまちだし、別に、何−−けがしなかったらいいじゃんっていう、そういう態度もあると思うから。（*In Japan, with Japanese teachers, they really try to make sure that everyone is able to do the same things in the same way. Over here in the U.S., even if someone does one thing, [teachers] won't worry too much about what others are doing. It's not as extreme. I really believe that's what might be going on. That everyone is treated as the same and how they all have to keep up at the same level for that [in Japan]. But the teachers here, well you know, everyone is different here, so it's almost as if, as long as no one gets hurt, they act like everything will be fine.)*

Izumi's experience with (American) schools and community-based programs were very different, where because she found people's attitudes to be more relaxed compared to Japanese perspectives, it was easier to communicate in general in English. Izumi described different experiences with Yukio’s summer school and summer camp programs, where she was able to establish good rapport with his educators ahead of time by asking questions and letting them know about his disability support needs. In fact, Izumi became very proactive about asking questions about the staff involved or what their daily schedule would look like and generally had the impression that the staff involved were well-prepared and were ready to accommodate changes where necessary. This was in direct contrast to the experience with the Japanese preschool, where there appeared to be very little transparency between the teachers and Izumi. In the end, Izumi’s efforts to advocate for Yukio within a Japanese community setting were not successful. Of all the different programs that Izumi had enrolled Yukio in, none of them had ever told Izumi that Yukio had to leave the program due to his disability.

Response to intervention tool

Izumi was provided with the comic first. She first responded by saying that the content and information would be especially helpful to parents who were just starting out in American special education. But to Izumi, the language of the narrative was a little challenging for her at times, especially due to its more serious tone. She took a slightly more critical stance on the *manga*, as she reflected on what worked and did not work for her in terms of how information was presented.

> うん。だからこれはすごくいいと思いますよ。この辺とかはすごく。はい—-あ、こういう悩みがあって、あ、こうなんだな。ただ、やっぱりちょっと難しい。だからそこが一番難しいんだと思うんですよ。難しい言葉が入ってくると、どうしてもやっぱりちょっと、目に。「読まなきゃいけない」っていうことに駆られちゃって、せっかくの漫画のその威力、パワーがやっぱり失われちゃうからもったいないな、っていうのはあります。(*Yes, So I think that this is really great…This part where there were all these[parent] concerns and you could see what was happening with them. And that it was obviously kind of challenging. And that’s the part that I thought was the most difficult too. When you see all these difficult terms, it’s almost like a distraction for my eyes. I feel pressured, almost like “I really have to read this part.” And manga has so much potential. It feels like we’re not tapping into the true power of the manga, which feels almost like a lost opportunity.)*

Although Izumi did point out much of what worked for her in the *manga,* she was also quick to point out how the format had the potential to go much deeper in terms of engaging Japanese parents. For Izumi, the language of the narrative became distracting, which left her feeling as though she had to choose between focusing on following the written text of the *manga* over the illustrations. Thus, her experience of reading the *manga* did not feel as complete. She repeatedly shared how she felt that it was a “missed opportunity,” as she perceived the true power of *manga* as being something that was emotionally easier to relate to through it’s combination of visuals with words. Thus, when asked what stood out the most to her in the *manga*, Izumi replied that she really liked how advocacy was defined and broken down into smaller bits of information that were much easier to absorb. Unlike the sections pertaining to IDEA and procedural safeguards, she felt that the visuals and language used in the advocacy section was extremely accessible to parents. To Izumi, that example reflected the true power of *manga* as a learning medium.

When presented with the text version, Izumi echoed a lot of her previous comments by saying that the serious tone and language of the narrative were still difficult to follow. However, unlike the *manga*, the text tool left a different impression on Izumi, where she felt that having everything in text was not as effective as having visuals.

> ただこれを全部書いちゃうと、やっぱりどうしても小説みたいになっちゃう。小説というかガイドブックみたいになっちゃうから。それはやっぱり、その、せっかく漫画でやってるからそこのところは、ね。なるべく絵で表した方が頭に入らすんじゃないかなと思います。せっかくもったいないもん。*(So if you look at everything when it’s written out like that, it feels so much more like a novel. Novel or maybe more like a guidebook. And you know, if you’re going to have a manga version, it seems like it would be much better to show visuals instead, since that would stay in your head much longer. If not, it’s just a waste.)*

As Izumi compared the two tools, she indicated a stronger preference for the *manga.* However, it was not that straightforward in terms of why she chose the *manga* instead of the text version. Izumi gave a lot of suggestions in terms of what she thought would be a more positive and beneficial resource, as far as taking advantage of the arts-based format. She shared how she thought the narrative should be restructured to focus more on the unique and specific experiences of the scenario parents, in order to help the reader make stronger connections between their own challenges with schools and IDEA/parent rights. Thus, although Izumi preferred the *manga* format, it appeared as though her experience of the *manga* was more about the potential it held over text as a powerful learning tool, as opposed to how the tool "changed her worldview."

Case profile of Junko

Junko was another Japanese parent who had lived in the U.S. for over 20 years after initially moving for her college education. She currently lived with her white American husband and their two children in a suburban neighborhood where her older son, Hitomu had been diagnosed with autism at the age of four. He was now 12-years old. Throughout her interview, Junko described herself as a goal-oriented individual, who did her best to learn about autism and special education support after Hitomu was diagnosed. However, that was not always the case where Junko shared how she had very little knowledge at the beginning and felt that it would be better to simply not talk about Hitomu's disability. It was her husband who encouraged her to be a "more critical thinker" around how she felt about the disability stigma and to be more proactive about advocating for Hitomu. As a result, Junko slowly began to attend public lectures by autism experts to learn more, as well as through parent training workshops offered by the school district and various community-based parent advocacy organizations.

> そうそう。等身大で、そう。心配で。そうそうそう。何か、どこから、でも、話を聞いたんだと思うんです。自分でそういうふうに思ったっていうよりも、やっぱり何か、こう、レクチャーに行ったりとか、ワークショップに行ったりとか…大人になった自閉症を持っている方たちの話を聞いたりとか、そう。何か色々なことをしている時に、多分それで繋がったと思うんですけど。(*Yes. Realistically speaking, I was worried. Yes I was. I went everywhere just to see what I could learn. It wasn't so much that I figured things out on my own but more that, I went to*

> *different lectures and workshops and also listened to the experiences of adults with autism. And as I was doing all of this, that's probably when everything began to click together.)*

After many years of participating in various parent training community groups, Junko was eventually connected to the local Special Education Advisory Council (SEAC), where she became an active member. Thus, over time, Junko's involvement at the school district level helped her to see and understand special education on a larger, systemic level than most other (Japanese) parents. Although it was clear that Junko actively participated in various parent support networks and did her best to not only advocate for her son, but also for all parents whose children were receiving special education services, she also stated that she was not naturally a very open person, especially around disability issues

> いつ話をしているか、どうして話をしているか、によって変わってくるんですけど。どこまでオープンに話せるかっていうのは。まぁオープンに話すこともあるし、そうでない時もあるだから、まあ、だからオープン。まあ、手段としてオープンになっているんじゃないかと思うんですけど。性格的にはオープンじゃないと思う。[laughs]. (*When I talk about [disability issues] or why I'm talking about them depends so much on what's going on. You know, when it comes to how openly I can talk about it. There are times when I'm much more open about it and then there are times when I'm not but I'm open to it. Well, sometimes I think that me being open about it is also a means to an end. Personality-wise, I would not say that I am the most open person. [laughs]).*

Because Junko had lived in Japan until her early adult years, her initial (cultural) frame of reference around disability was very Japanese. One of her biggest concerns for her was around other (Japanese) people's "misinformed" negative perceptions of autism and other disabilities. For example, Junko shared that even though she had been in the U.S. for a long time, she still worried about how she talked about disabilities to other Japanese parents, as she did not want to accidentally offend anyone. However, she also recognized the power and impact of being open about Hitomu's disability, especially in English. In fact, being open about Hitomu was a strategy she had adopted over time, as she recalled how emotionally challenging it had been for her when Hitomu was still little

> 例えば何かその、帰ってから、例えば友達に会う、その、友達と話をする時に、その、ええと、どの時期、どの時点で、その、ひとむのことを話そうかっていうのもすごく考える。小さい頃はまだね、話せなかったんだよね。で、あの、みんな友達、ほとんどみんな子供がいるんだけど、まあ、会っても、ほら、ここに住んでるから日本語であまり話さないし、アメリカ人だからこうなのかなって訳の分からない。［laughs］アメリカ人ってオープンすぎる。[laughs] (*So let's say we went back to Japan and I were to meet up with some friends and chat with them, umm, I would probably spend a lot of time thinking about at what point in the conversation should I bring up stuff about Hitomu? When he was still little, it was really hard for me to talk about him to them. And my friends over here, most of them have kids too. But when I meet up with them, well, you know, we're living over here now so I don't speak in Japanese and I don't know what it is about Americans. (laughs) They are way too open. (laughs).)*

When asked to share about her experiences working with Hitomu's IEP team, her response was not the most positive, as she stated that she perceived his school district to be overly optimistic and was constantly underestimating how to implement his IEP goals. She described an experience in the past where she had worked with Hitomu's IEP team to determine how to set up his supports through the aid of a paraeducator. She described her extensive knowledge of special education through this example, as she described how everything looked "great on paper." However, when it came time for implementation, there was very little accountability and follow through. In fact, she found out later on that the school had not been transparent about how there were no available paraeducators to support Hitomu, even though the IEP team had all signed off their agreement on it. Thus, when it came time for Hitomu to start the new school year, there were no paraeducators that were available to support his IEP needs and goals. Although the school eventually found a temporary substitute paraeducator for Hitomu, data was not collected and tracked consistently, due to the lack of structure and clarity around roles. Thus, when it came time for the IEP team to reconvene to discuss Hitomu's progress, there were a lot of issues that needed to be properly addressed before they could move forward again.

Experiences such as these made Junko feel very uneasy as she felt strongly that the larger issue was not about Hitomu and his disability; Rather, she stated that the school district was the "one with a disability" and that the problems around inconsistency and unaccountability was not directly about her child. In addition, Junko also shared

> いや、まず、パラをもらえること自体があんまりないと思う。私が—— 何だろう、思うのは、どこまでしても、この、甘いがために、あの、due process だとか、結局だからその保護者が余分なお金を出資をしない限りは、どこまで行っても変わらない。そうそうそう。で、district 自体にも、「もうこりゃどうにもできないね」「できないからもう保護者に due process とかでもしてもらったら、もしかしたら大丈夫かな」って、そういう、そういう考え方が甘い。そういう考え方が甘い。*(So the thing is that I really don't have much confidence in [schools] that we'll actually get a paraeducator. I, hmm, I think that no matter how much we try to advocate as parents, because they underestimate the situation and even with due process, as long as the parents don't have the funds to take legal action, nothing will ever change. Yes yes yes. And when the school district itself realizes that there is nothing more they can do to change the situation, it's almost as if they believe that everything will be okay if the parents end up filing due process. That kind of thinking is just too overly simplistic. They don't take things seriously enough.)*

Junko's comments revealed a very different perspective on special education services and support from the other Japanese parents who were interviewed, where she could clearly see the "cracks" within the system. Unlike other parents, Junko understood that the focal issue was not about her child's need for support due to his disability, but that they were not always operating within a fair system that benefited students and families. In fact, Junko's more critical comments towards special education also provided some insight into how "advocacy" was not always so straightforward nor simple, whether it aligned with one's (cultural) common sense.

Response to intervention tool

Junko began reading the text version first. She read each page slowly and carefully, taking the time she needed to process what she was reading. She began her response by saying that the tool itself was not too long or too short in length. She found the information to be useful. However, she also felt that whether a Japanese parent would know what to do in terms of next steps was questionable

> はい。Helpful だとは思います。けど、これを見て「よしやろう、実際にここからやろう」って思えるかどうかは、その保護者の方の——ready 度？どこまで ready かによるかもしれない。更に、実際のこの、サポートをしてくれる人？が、必要だと思う。これだけだと、これだけで、こう読んで、「よし」って言って実際にできる人は少ないかもしれないと思う。

> *(Yes. I thought it was helpful. But I'm not sure that a parent would say, "All right then. Let's start [advocating] from this point here" after reading this. It might depend more on how "ready" that parent felt overall? And to what extent they felt ready too. And also, whether there would be someone to support them in their advocacy as well. If they were to read just this [tool], I think that in reality, not a lot of people would feel ready to take action.)*

But from her personal perspective, Junko found that the information on IDEA and procedural safeguards to be very informative, as she admitted that she still had a lot to learn on these specific topics. She commented that she liked the scenarios, as well as the learning about the "basics of parent advocacy", as it helped her to think about these details in Japanese more clearly. As she reflected on the scenario examples, Junko also shared her own personal experiences that were connected to what the scenario parents were going through. For example, she read through the third scenario example of a Japanese mother discussing her ongoing challenges with finding a good interpreter for IEP meetings. Although Junko was able to communicate fairly well in English, she shared that she requested an interpreter anyway, as this was the first IEP meeting at that specific school. The interpreter did her job relaying what the IEP team said but Junko was not reassured by what the IEP team was promising for Hitomu. It was after Junko expressed (in Japanese) to the interpreter about her doubt and negative experiences with schools in previous years that the interpreter implicitly understood why Junko seemed so wary of what the IEP team was telling her, despite their seemingly positive intentions. As a result, the interpreter took the initiative to advocate for Junko and to clarify Junko's position on the matter. Junko shared that because of the interpreter's advocacy actions, the IEP team became a lot more understanding of where she was coming from, which led to a much more meaningful and satisfying IEP team meeting overall.

In response to the *manga*, Junko stated that she liked this format as well, since reading through the content was much easier than with the text. However, she also stated that if she had to choose between the text and *manga* versions of the same tool, she would want both. For Junko, having two different versions would fulfill different needs for her; where in times of desperation, she felt that having the text version would be more helpful, as she could focus on the details more clearly than in the *manga*. She shared that the text version felt more “neutral” and thus, helped her to take action more objectively; the *manga* was filled with a lot more emotions and thus felt more supportive to what she was going through. Junko stated that because she was already familiar with most of the information in the tools, the most appropriate tool for her would depend more on the situation at hand.

Case profile of Chiaki

Chiaki had been in the U.S. with her family (her husband and three sons) for around three years, where her middle son, Kenji had been receiving special education services in Japan for over 10 years prior to their move to the U.S.. Kenji was now 15 years old, where Chiaki shared her observations that he seemed to have adjusted fairly well to the U.S.:

> そうなんです。本人の adjustment、なんか私が思ったよりも上手くいってるんじゃないかなっていう感じがしますね。なんか言葉が分からないなりにも、なんか本人は周りを気にしないのか、周りが優しかったのか、普通に通ってました。*(Yes, so the fact is, with Kenji’s adjustment, I feel that he has really adjusted much better than I thought he would. Even though he doesn’t understand much English, and maybe he’s just not* bothered by the people around him or the *people around him are really kind to him but it’s like he just goes on with everything with no issues at all.)*

However, Kenji was not performing well academically nor making adequate progress with his IEP goals, especially on his (English) language and communication skills. Despite his parents’ efforts to advocate at his IEP meetings to focus on implementing more supports for him, Chiaki stated that his teachers and IEP team were not very responsive to their requests, as they perceived his limited English skills to be the primary reason behind his lack of progress.

Because Chiaki and her family had been in the U.S. for the shortest amount of time amongst the eight families in this comparative case study, Chiaki also expressed that she had had a hard time adjusting to the U.S. at the beginning, where she rarely left her home for fear that she would have to converse in English with strangers. However, over time, Chiaki was able to feel more confident in her spoken English skills; she also found her sense of belonging through volunteering at a local (Japanese) library run by Japanese community members and through joining *Himawari-kai*, the Japanese parent support group for families of children with disabilities.

Having had years of experience in Japan around Kenji receiving special education services, Chiaki shared the different types of support that he had received and what the process was like for them before and after moving to the U.S. Chiaki realized during the interview that Kenji's school in the U.S. had never taken the time to explain what special education services entailed for him and that although she had received documents from schools such as prior written notices and procedural safeguards, there was very little support beyond receiving documents in English. When asked about "advocacy" and what it meant to her, Chiaki responded that she had never heard of it. Most of the knowledge she had acquired around special education had been through other parents at *Himawari-kai* meetings. She mentioned that she had heard of a law in the U.S. on special education but did not know what it was about. For Chiaki, her biggest concern was the lack of information and accessible resources, especially since Kenji was almost an adult and getting closer to graduation age.

Response to intervention tool

Chiaki was provided with the text tool first. Upon reading it, her first response was a slightly apologetic one. She shared,

> はい、終わりました。一応。ごめんなさい。ちゃんと読めてるか・・なんとなく分かりました。Advocate、advocate が。*(Yes, I'm done now. Moreorless. I'm sorry. Not sure how much I really got…but I think I got it moreorless.)*

She then shared what her understanding of advocacy was from her reading the tool. She explained in her own words and described the concept quite accurately. She added that the way the information was structured with a narrative flow made it easier for her to understand the content much better.

> ここの、これだけ読んでも多分分かんないから、この流れをちゃんと、こう、こういう、何て言うんですか、具体例っていうか、具体例があって初めて、ああ、そうか、そこでadvocacyが出てくるのか、最後に出てくるのかみたいなのが分かります。*(If I were to read this section, only this part, then it might be harder to understand. But the flow, if you follow the flow properly and what do you call these, these concrete examples and you look at these examples and it's like, ohhh I see, that's how that connects to advocacy. It makes sense if you follow it to the end.)*

In addition, when asked what worked particularly well for her in the text, she responded that being able to read the conversational style of one of the scenarios helped her to connect to the example more deeply. Chiaki shared:

> 文面。うーん。この普通の会話、会話文っていうか、会話文はやっぱり分かりやすいですよね。入り、入ってくる。すぐ。*(This text. Hmmm. These ordinary conversations… Having these interactions written out, they make it much easier to read and understand. It goes straight into my brain.)*

She also reflected that the language used was also a little challenging to process while reading, as they were not generally used in daily conversation but were specialized terminologies.

As Chiaki was reflecting on her experience of the text tool, she also shared that perhaps having visuals and charts within the tool might be helpful, such as what the structure of IEP meetings should look like or what to expect in these meetings. Having more examples that would essentially "pop out" at her (through visuals) would be easier to remember. Chiaki disclosed that it was generally harder for her to focus and retain information through text, especially as a "housewife who was not used to reading this type of material."

I probed her with more questions to see what kinds of connections she was making between the concept of advocacy and IDEA. Although Chiaki had shared her interpretation of advocacy earlier in the interview, it became apparent that she still had a lot of questions around advocacy and what it meant to be a good parent advocate for her son. She shared some frustrations she was facing at the time with trying to be a better support for Kenji in school and at home.

> でも、これ思ったんですけど、私の子供はもう15歳で、親がどこまでやればいいか分からないんですよね。もう、小学生だったらこうやって、こう、ちょっとなんか言ってたことを親が代弁して言ってあげることはすぐできるんですけど、中学生は自分で考えて行動してる部分もあると思うんですね。高校生で。で、言わない。親に言わない。だから学校で何してるか分からない。で、親が聞いても答えないけど、もっと聞いて、もっと聞いて伝えたほうがいいのか、もう学校のことは本人に任せて、先生と一対一でやってもらったほうがいいのか。どこまでその advocacy を、こう、やらなきゃいけないのかっていうのが難しい。*(So I was thinking about this and the thing is, my child is 15 years old now and it's really hard for me to figure out how much I should be doing for him as his parent. When he was in elementary school, I could at least say something as his parent and take care of anything that he mentioned to me but in middle school, there was also the part about letting kids have some say in what they do. But in high school, no, nothing. He says nothing to me. So I have no idea what's even going on at school. And so even if I don't get a response, should I keep asking and asking to figure out if I should say or do something or if I should just let him figure out school stuff on his own with the help of his teacher or what. It's really hard for me to figure out how much or to what extent I need to do this advocacy thing.)*

Although she did not directly respond to my questions on connections made around advocacy and IDEA, the concerns she shared in her response indicated what she did understand and her challenges around applying advocacy practices in real life. For example, Chiaki felt that she was not making much progress at home with Kenji in terms of understanding how to help him become a stronger (self) advocate, as she wanted to respect his growing need for space and to make his own decisions. At school, Kenji had recently received a new diagnosis of autism, which complicated the IEP process further for Chiaki and her husband as they did their best to keep up with the new recommendations that the IEP team was making.

Because Chiaki had already mentioned earlier in the interview (before reading the text) that having visuals might be helpful for her to understand the context and details better, I was curious to see how she would respond to the *manga* version. Her immediate response when I gave her the *manga* was excitement, which was evident in her enthusiastic comments when she said,

> ああ、すごい。あー、すごい。ちょっと面白そうです。すごい。素晴らしい。もう見てるだけで楽しくなります。*(Wow, this is great. Ahhh, cool. Looks so fun. Really great. Just looking at this makes me feel excited.)*

As Chiaki read through the *manga*, she shared that it was so much easier for her to process the information in this format. She shared further,

> うーん。私はこっちのほうが絶対頭にスッて入ります。その、やっぱり図が。イメージしながら聞くと、ああ、こういうところで、こう、なんて言うんですか、こう、何ででしょう。なんでか分かんないけど頭に入ってきます。(*Hmm, I think that this [manga] version definitely makes a lot more sense. It's, I think because of those visuals. When the images are there and you're reading it, it's like ohhh, how do I say it, with things like this, well, why is that the case? I guess I'm not really sure why but they really stay stuck in my head more.)*

Chiaki then compared the same pages of the comic and text next to each other and stated that she strongly preferred the *manga*, as it helped her to feel more emotionally at ease with learning new concepts. When asked to elaborate further, Chiaki said that despite the content being the same for both tools, the biggest difference for her was that having a comic and being able to see the facial expressions of the different (parent) characters made her feel less isolated, She felt like she was a part of a "larger" community of parents who were dealing with similar issues

> はい。一緒ですよね。これ、人の顔が入ってると、やっぱり他の人も悩んでるんだっていうのが分かるのと、客観的に、人がちゃんと考えてる、自分だけじゃない、他の人がちゃんと考えてるっていうのが多分共感できるからですかね。分析すると。一人じゃない–。一人じゃない感じがします。コミュニティで話してる時のような感じがします。私はこれを見ると、こう、自分がそこに、中に入れるんですね。その漫画の世界に。だから一人じゃなくてみんなと話してるような気になって–　なんか話をしてるように聞こえる。読んでるんじゃなくて、声になって聞こえる–　から・・理解がしやすいんじゃないかなと思います。*(Yes, so the content is the same, right? When you can see people's faces like that and you can feel that there are other people with the same worries thinking the same things, it's easier to understand more objectively that there are other people who are going something similar and I can really relate to that. If you think about it. It's not just me. I don't feel so alone anymore. I have that same feeling I get when I'm part of a community. When I see this community, I realize that I am a part of that too. Inside that manga world. So it feels more like I'm talking to everyone and it's almost like I can hear what they're saying. I'm not reading their words anymore, I can "hear" what they are saying. So, perhaps it's just to easier to understand what's going on there.)*

In fact, she felt that she could easily insert herself into the scenario narrative and imagine herself "interacting and communicating" with these *manga* parents, as it was almost like she could "hear" what they were saying instead of "reading" what they were saying. For Chiaki, she was impacted the most by the faces and facial expressions within the *manga*, where she felt she would remember details about advocacy much better through relating to what the *manga* parents were experiencing in the scenarios. She reflected on her own observations as she shared,

> うん。そうですね。これより分かりやすいですね。何でだろう。何でだろう。顔があるからかな。大きいから。確かに・・・あったほうがいいです、絶対。うん。面白いですね。人間の心理って。 (*Yes, I guess it would be easier to understand that way [with faces]. I wonder why. I really wonder why. Is it because there are faces? Because everything is so visible, maybe….but definitely better to have them, yes. So interesting isn't it, how human psychology works.)*

Interestingly, after reading the comic, Chiaki stated towards the end of her interview that having only visuals and charts (i.e. without faces and people) might not be the most helpful for her in terms of retaining information. However, visuals and charts would still be more effective than text alone. For Chiaki, there was something about being able to see and relate to the emotional expressions of other parents that made her learning experience much more positive and meaningful.

Case profile of Manami

Manami and her family of her husband and three sons had been through a lot in a short span of time. They had moved to the U.S. twice, where they had two different sets of experiences navigating U.S. special education, as well as some time navigating the school system in Japan. Their move to the U.S. had been due to Manami's husband's job, where they were expected to live in the U.S. on a temporary work visa. This was not uncommon for many Japanese immigrant families, where many families typically returned to Japan after the company contract was completed. The first time Manami's family moved to the U.S., they lived in Washington state for three years and Manami's third son had not been born yet. Her oldest son, Daisuke had received a diagnosis of autism in the U.S. during this period, where he also received special education and other disability support services. Both Manami and her husband began attending parent training workshops at *Families First* early on and gained some basic knowledge around special education. However, they knew they would only be in the U.S. for three years and that they would eventually return to Japan. So they did not invest as much time in understanding U.S. special education very thoroughly.

Upon their first return back to Japan, Manami expressed her surprise at how everything was set up so differently there compared to the U.S. It was as though her expectations had been molded by her experiences and the knowledge she gained in the U.S. and it left her feeling disoriented when everything would not go according to what she expected.

> アメリカで最初にそうやって診断を受けて、サポートを受けてたので、日本に帰って幼稚園に行って、まぁ同じようにこう、色々なこうサポートと言うか先生のヘルプとか受けられるかな、と思って、あの、病院に、発達外来？っていうのがあるので、そこに行ったり。ええと、教育委員会、市役所に行って学校に、今度小学校に上がるのに向けてお話を聞きに行ったりしたのと。日本はアメリカよりすごくふわっとしていて…最初日本に帰国した時はすごく空回り。*(So Daisuke was first diagnosed in the U.S. and received support here as well. So when we went back to Japan and I enrolled him in kindergarten, I thought that he might be able to get a similar type of support or help from the teacher. There was an outpatient clinic at the hospital, which we went to as well. And then there was the school board of education. We had to go to city council to figure out his schooling and figure out what we had to do for Daisuke to go into elementary school there. Japan is so different from the U.S. because everything is so much more ambiguous…so when we first got back to Japan, it felt like we were going around in circles.)*

After about a year of navigating through different systems and (cultural) standards in Japan, the family found themselves back in the U.S. again due to Manami's husband's work obligations. This time around Manami was having some ongoing issues with Daisuke's IEP team that she had not experienced before. When he was much younger, Manami felt that she could rely on his teachers to make the right decisions, as they were generally on the same page about his needs and goals. However, that was no longer the case. Manami was slightly confused about some of Daisuke's IEP goals but when she did her best to ask his teacher for more clarification and concrete examples around how they planned to implement his activities, the teacher would simply respond that "those were great questions" and never provided any clear answers.

> ああやっぱり聞かないともうちょっと深いインフォメーションは出てこないんだな、っていうのは、何か、すごいよく感じるので。何かもっと自分に、色々聞き方と言うか、質問する力を付けないと進まないんだなっていうのは思う。何か上辺でさら一っと終わっちゃう。っていうのをすごく感じます。*(Something that I figured out is that unless you ask questions, you just won't get very much information. I'll have to figure out different ways of asking questions, and that if I don't figure out how to do that well, I won't be able to make any progress at all. Everything will just stay at surface level and go nowhere.)*

Manami was, in her words, not a confident English speaker at all and relied mainly on her husband to communicate their concerns in IEP meetings. She had attended IEP meetings by herself as well and in those cases, always requested an interpreter. She mentioned that she did not know what advocacy was and that she did not know much about IDEA or parent rights. Most of her concerns and questions around special education were not having enough knowledge beyond the basics. She shared:

> そう。何か知識として色んな情報を書いてもらっても、私たち実際自分の子供に当てはめて、学校の先生と話をしましょうってなると、どうしても何か、ね。詰まると言うか。何か、日本ってあんまりこう、討論をするような教育をしてない。一方的に受ける教育が多いので、こう、「何か質問ありますか？」って言われても、「特にないです」って言っちゃうんですね。で、でも、具体的にパッとすぐ思いつかないことが多いから。家に帰って、「ああ、そう言えばあれを聞けばよかったかな」とかいうことが後から出てきても、その場で、その場で「何か意見はないですか？」って言われても、結構すぐ「特にないです」って言っちゃうんです。何かそういう、それ、自分の弱いところだなと思うんだけど。*(Yes, the thing is that even if I were to get a lot of information to build my knowledge on what to do, the reality is that if I knew I had to talk to a teacher about something, it's almost as if every time, I have no idea what to say. I feel that in Japan, we're not really educated in that way where we debate and discuss matters. It's mostly a one-sided process in schools so even if they ask me if I have any questions、I would just end up telling them that I didn't have any. But it's also that a lot of times, it's hard for me to come up with something concrete in that moment. After I get back home, it might occur to me that "Oh I should have asked about so and so." But in the moment, if a teacher asks if I have anything to share, I end up telling them that no, I don't. I guess that part, that part of myself is my own weakness.)*

Manami described how her experiences with building her knowledge and putting them to practice in real life were at times disconnected. This made having smooth communication with schools much more challenging, where on top of understanding the cross-cultural differences in expectations in parent-teacher dynamics in the U.S., parents were also expected to be prepared with questions or comments. Thus, these subtle differences in cultural norms made the process for parents like Manami more complicated.

Response to intervention tool

Manami read the *manga* first. Her first response after reading it was that the scenarios resonated very strongly with her. She expressed that she could relate to how the parents were feeling very well. When asked about what else stood out to her in the *manga,* Manami replied that everything was easy to understand and that she would likely be able to finish reading the *manga* if the information was presented in that way. However, she also expressed a desire for more examples like in the scenarios. She shared,

> この例えば…具体的な例っていうのが、すごく「ああ、なるほどな」って思うんですよね。例えばこの例が無くて、ここだけを読んだ後も…例えばこういうことを話す、 って言ったら、絶対的にこの例がある方が「ああ、なるほどそういうことか」ってなるんですね。だからこういう、何か、色んな、例えば、例がすごくたくさん知れたらいいなって思う。この、子供によって、ね。まぁ、ダイスケがその消しゴムを食べたとかっていう問題は実際に起こしたことはないけれど、でもこういう例を知ってると応用ができるので。「あ、こんな話を付けて行けばいい」みたいな。この例がいっぱい知れたらいいなって思いました。*(So for instance, these specific examples [scenarios] felt like this moment of clarity, like “Ohh that’s how it works.” So if this example wasn’t here and I was reading about so and so in that section, it would definitely be so much clearer if the examples are there. So I feel that I would really learn a lot if there were a lot of different examples that I can pull from. It would depend on the child, well, Daisuke has never chewed on erasers or had any problems like that [referring to the first scenario example]. But if I knew of examples like this, it would be very practical. I would think, “I just have to follow this scenario example.” So, I really wish that there were a lot more examples that I could learn from.)*

Manami explained further that with the help of these examples, she would be able to better navigate different issues of her own. Even if her issues did not mirror the scenario examples exactly, there would be a more structured way to think about resolving any issues through them. She also shared that she really liked the drawings and that they were easy to remember

> すごい上手。絵がすごくいいと思う。何だろうな、このイラストと、この書いてあることの、何だろうな。すごくマッチしてると思うんですよね。うんうん。でも、こういうのは、その、伝えたいことと言うか、が、すごく入って来やすい。だから情報としてはすごく、何だろう、入って来やすい。*(The drawings are good. They look really good. I wonder what it is…I felt that these drawings and what was written about them matched up really well. Yes. So the message or what it’s trying to say is really easy to understand. The information is really accessible.)*

When presented with the text version, Manami felt that the comic would still be easier to read. However, she stated that she didn't mind the text version as she enjoyed reading books in general. She suggested that because the drawings were very impactful on their own, it would be nice to add a few drawings at the end of the text tool.

> ただ、イラストがあった方が分かりやすいから、こういうイメージ？イメージイラストと言うかね。こういうのがあるとすごく、何だろうな、最後にこういうイラストが入ってると、何かすごく、いい。いいなと思います。うん。だけど、こういう具体的な、こう例えば、うーんと、こういう例とか、は、には別に無理にイラストを付ける必要はないと。*(The thing is because everything is so much easier to understand with having those illustrations, Or images? These illustrated images then. When you see these images there, I wonder what it is but if there were to be some illustrated images at the end, I think that would be really great. Yes. But with these specific examples, hmm, maybe it wouldn't be necessary to have illustrations for the whole thing.)*

Manami's suggestion of including images with the text revealed how even if the tool was not in a purely visual format such as *manga*, having images in general was beneficial and seen as a powerful strategy, as they added a certain aesthetic quality that text alone did not have. Thus, Manami felt that adding specific images would enhance her experience of reading mostly text.

Case profile of Natsumi

Natsumi and her family had moved to the U.S. six years ago due to her husband's job at a global tech company. Her oldest son, Shun had been diagnosed with autism back in Japan ten years prior when he was just four years old. Natsumi described the different types of challenges she had faced in Japan to get an evaluation for Shun. Although Natsumi was finally able to get an appointment at a well-renowned university hospital, she was informed by the doctor that it was "probably autism" but there was nothing that the doctor could do or recommend at that point. Natsumi enrolled Shun into a local daycare after the unsuccessful attempt to get him evaluated, where although he was well-behaved and followed instructions for the most part, his teachers noticed how different Shun was compared to the other children. They recommended to Natsumi that he be evaluated as well. After waiting for about six months, Shun was finally evaluated and received a diagnosis of autism.

Shun was around seven years old when his family had to relocate to the U.S. Natsumi stated that everything had been very confusing for her during that time when they first moved to the U.S. and were settling down. It was not as much a matter of understanding and communicating in English but more so being unfamiliar with specialized terminologies, acronyms and jargon.

> 省略字とか、何て言うか、もう3文字か4文字の、あの、訳、アルファベットの訳したのがいっぱいあるわけじゃないですか。あれ見たらもうイラっとしますよね。成績表見てもそうなんだけど。あの、あれが。で、そうそう。もう何書いてあるか分からへん。その、英語が読めるとかじゃなくて、もうこれがなんなのかよく分からないってところからスタートで。だからそういう中でやってるので、良い選択っていうのは選択を知っていて、それで中身が分かっていたうえで選択できるんですけど。来た時にアメリカは選択肢が多いからってさ、選択肢が多いかもしれないけど、漠然的に広がる意味の分からなさはずっと感じましたね。うん。でもここはよくやってくれると思いますよ。 (*Like acronyms, um, like the ones that are three to four letters, um, that there are many shortened words written in alphabet letters, right. Looking at that makes me irritated. Not only in the progress report. Ah, that...yeah, I don't understand what it even means. It's not about whether you can read English or not, it literally makes no sense and that's where I started. And that has been the case for us. So making a good choice means you know the available options, and you can make a decision if you understand each option. When we moved to America, we heard there are many options here, but just because there are many options didn't change the fact we were still clueless about what to do. Yeah, but here (school district), they are doing a good job overall.*)

For Natsumi, understanding documents such as progress reports (and presumably IEP-related materials) was not a matter of understanding the English language, especially when specialized terminologies such as acronyms complicated her reading process. This made the process of understanding special education even more challenging for Natsumi, as she did not have a reliable method of building her knowledge. However, in Natsumi's case, she felt fortunate that her son was attending a good school district where he was getting the support he needed.

As far as learning about Shun's disability, Natsumi described how she deepened her knowledge about autism mainly through online blogs written by Japanese mothers of children with autism. She related strongly to the different examples and "case studies" presented on these blogs and felt that the information was useful in a very practical way. Natsumi also disclosed in her interview that she had a medical condition herself that made it easier for her to empathize with Shun when he was faced with challenges of his own. Thus, she was always willing to do things "differently" with Shun, to help him feel better about himself and learn to make his own decisions

> その、やっぱりシュンにとって、こちらに来てとても大きかったことは、あの、とりあえず、昔は本当、俗に言う受動型っていう、何となく周りの流れに付いていって、周りを見て、自分がどうすればいいかを一生懸命考えて、っていうのをして。ま、集団行動の中でやってきて。それをこちらで来て、その、どうする、だんだん「あなたはどうする？」「これは、君はどうするか？」ということを。で、「君はどうしたいのか？」と。そういうことを、ま、より突きつけられるようになって。その、周り見てこうしてああしたりじゃなくて、っていうことじゃなくて別にいいんだと。じ、自分がこう、どうしたいかで、それを表明することで、が、大事なんだというのが、それがやっぱりこう積極的に人に対して、こう、コミュニケーション、アピールをしていく。やっぱり非常に重要な、あの、素地にはなったと思うの。 (*So for Shun, what was the most impactful thing was that, in the past, he used to be very "passive," where he'll follow along with others, observe surroundings and think really hard of what he is expected to do. Back home, he had been learning what to do within the group, whereas when coming here (the U.S.), it gradually shifted to being asked "what would you want to do?" "what about this, what would you do?" and "what do YOU want?" that became more of the emphasis. Unlike before, where he needed to observe and act accordingly to people around him, it's okay to do what he wants. Learning how to express yourself is important, and how to be proactive about communicating and appealing about yourself, I think, became a really important foundation for him.*)

In this sense, Natsumi's openness about Shun's disability needs allowed him to understand his own needs better. This openness extended to how Natsumi talked about autism to her two younger children and their friends.

In terms of Natsumi's experience working with schools and Shun's IEP team, she responded quite frankly that it was difficult for her to gauge whether the support that Shun was receiving was good or not. Natsumi felt that without enough prior experiences in U.S. special education, there was not much she could compare her more recent experiences to. However, she also stated that she mainly had positive experiences with Shun's schools and especially before his transition to middle school. His elementary school teacher had advocated for Shun to attend an inclusive educational program in middle school, which ended up benefitting him tremendously. In addition, Natsumi mentioned that she had worked with the same interpreter for many years, which made her participation in IEP meetings much smoother overall. Although there were mostly positive experiences, Natsumi also faced small obstacles along the way as schools were not always transparent with how Shun's services would be provided. However, in this sense, Natsumi stated that she felt that they had been very lucky, as her overall experiences had been fairly smooth.

Response to intervention tool

Natsumi read the text version first and described what worked well for her in terms of the narrative and presentation of the tool. She described her experience, as she made a connection between the scenarios in the tool and the "case studies" in the autism blogs that she used to read. She stated,

> あの、ケーススタディになってるんで、分かりやすかったですよね。その、こう、座談会風なところから入って。で、そこから困っているところを抜き出していって。で、それを、より問題解決のために必要なエッセンスを抜いていって。じゃあ法的にどういうふうに解決していくのかっていうのは。それはすごい分かりやすかったと思います。あの、その、すごくこう、素人が読む分に分かりやすい、って。やっぱり、あの、やっぱり、あと、こう切り出されたこういう、その問題のエッセンスって、やっぱり日本人が一番困りやすい部分のところをやっぱり、あの、一番上手いことちゃんと追及して。すごく分かりやすくて良かったと思う。(*Um, because there were case studies, it was easy to understand. Like, how it started with group discussion. And highlighting issues they had, and then taking out the essence you need to solve the problem. So how would you resolve this legally, that was easy to understand. Um, like, it's really easy for those who are new to the topic. and yes, um, like, the issues highlighted here, was relatable because it narrowed down what's common issues for Japanese families. so, it was easy to understand and good.*)

Most of Natsumi's response to the text tool centered around her experience of making sense of the concept of advocacy. She reflected out loud on her understanding when she said,

> あの、あの、障害があったり、少しこう認知症って、そういう方のための、につける、民法の。補佐人とか後見人とか、そういうのがあるんですけども。それに近い言葉なのかな、というか。要はその、自分が自分のことを主張しきれない息子、子供のために、ええと、要は、権利を守るために、あの、外と交渉しながら、代行力になると思うことなんで。ま、敢えて言うならですけど、だから、後見行為というか。あの、補佐人とか後見人はこんなんなんだ

> ろうなとは思いましたけど。敢えてこう、うん、言葉を上手く選ぶ、日本語で何か言葉がないだろうかというのであれば。やっぱりこれ自体がやっぱり法律なので。対応する言葉としたら、やっぱりそれが一番フィットするような気はしますね。今読んでいて。(*Like, for those people, who have a disability or have dementia, there is civil law that assigns legal aid or guardian. I wonder if that's the closest word. Basically, if a son cannot advocate about things on his own, for that child, he basically needs someone who can take over a negotiation to protect his rights. If you presumably say it like that. then it's like guardianship. Um, I thought that legal aid or guardians would be the one. if you need to choose a good word that makes sense in Japanese, then those words are about legal matters. So to find a word that corresponds to [advocacy], I think that fits well the most, as I'm reading it.*)

For Natsumi, her experience of the text tool focused mostly on processing what advocacy meant to her as an abstract concept. However, after she began reading the *manga* version, she stated that having visuals made everything a lot easier to understand, where having a multimodal format allowed her to make stronger connections between the concept of advocacy and what it would take to advocate as a parent.

> そういうのもすごく、これは良い感じだと思う。その、私たち自身が当事者なので、この問題はですね、障害の当事者じゃないんだけど、こういう advocate っていうののための当事者なので。じゃ、どういうふうに考えたらいいのか。こう、法律で主張できる情報まで。エッセンスを減らしたり、こう絞り込んだり、っていうプロセスがすごく分かるので。これすごく私は良いと思いました。*(I thought [the manga] was really nice, I mean, the thing is we, as parents are the party of concern, and these issues, even though I'm not the self-advocate with disabilities, I would be the person who is going to advocate on behalf. Then, what should I think about, in order to be able to get information and legally represent (my child). I could see the process of simplifying and narrowing down the problem. so i think that was good for me.*)

In addition, she stated that the narrative was much easier to follow through the *manga*, especially when there were "case studies" or examples of specific parents and their experiences. For Natsumi, it was harder to retain information when there were large chunks of text and having the visuals helped her to stay on track with the narrative. She summed up her thoughts on her experience with the *manga* when she shared,

> まだ漫画のほうがやっぱりビジュアル的なのが、読みやすさがすごくあるっていうのがもちろんなんですね。あと、章立ても、多分もっとこう、あの、「ここは！」とかいうところの。でも、ケーススタディのバーッて羅列になっていくと、少し、あの、焦点がどうしてもボケがちに。文章ってどうしてもそうなりますよね。だけど、これだと、ここはまとめ部分、そっちのプロセスは、ね、こういう会話でワーって来てるんだよって、段階ごとに追ってるって、そういう感じ。やっぱりこういうのは、ケーススタディは、漫画はやりやすいですよね。*(Manga still is more visual and easier to read. Even by chapter, like highlighting "this is*

> *the point!" But when case study is written out one after the other [in text], it's a little bit hard to get the point across. Texts inevitably have those kinds of issues. But, in manga, it's clear that the part that needs to be summarized, can be done as a conversation, and lead to the point, I get that kind of sense. I think these things, like a case study, manga is much easier to do.*)

Natsumi highlighted the benefits of having information in a *manga* format compared to text through the excerpt above, by emphasizing how much easier it would be to provide a more holistic picture of how all the details were connected. This was, according to Natsumi, in contrast to information that was strictly in text. Thus, having a *manga* resource worked well for Natsumi as she clearly stated her preference for the graphic format.

Case profile of Tomoko

> あ、IDEAとかっていうやつですか。あー名前だけ知ってます。もらえて、法律で絶対しなきゃいけないという法的な--うん。すごくいいなと思います。ありがたい。
> *(Oh, you mean that thing called IDEA? Uhh I've only heard the name before. What the law states that must always be done, yes. I think it's really great. I'm very grateful.)*

Tomoko has been living in the U.S. for 16 years, where her first two years were in graduate school in Pennsylvania state. She moved to Washington state soon after and has lived there ever since. She is currently married to another Japanese immigrant and has a five year-old daughter, Risa who was diagnosed with autism. Tomoko had heard of the term advocacy before and described what it meant to her in her interview:

> うーん、例えば両親は娘の一番のアドボケートだってよく言うんじゃないですか。何で--主張？主張というか、リクエストする。とりあえず、娘のこういうところが苦手だから、こういうサポートがうまく行くので、それをクラスルームでもしてくださいとか。 *(Hmm, I've heard how they say that parents are the number one advocate for their children. Why…because we can assert ourselves? Or not assert but make requests. So basically, it's letting (the school) know what my daughter needs help with and the kinds of supports she needs and asking for that in her classroom.)*

However, Tomoko disclosed that she had never read the procedural safeguards document from school nor was she aware that she had rights as a parent. She shared that her experiences with Risa's teachers were mainly positive; Nothing stood out to her that was negative and that she felt very grateful to her daughter's teachers. She stated she had never experienced getting denied services when advocating for Risa and that oftentimes, she was surprised by how much Risa's teachers went above and beyond to give Risa the support she needed.

> 悪い印象は全く。嫌な思いをしたことはなくて。結構手厚く、あ、やっぱり職業柄？あの--お子さんのサポートに関わってる人たちとしか会わないので、いつも、いつもありがとうございますみたいな感じで。サービス拒否されたこともないし。むしろここまでやってくれるんだ、みたいな感じです。*(There is no bad impression. I haven't had any negative experiences. I wonder if it's because of their profession? I only meet those professionals who support children. So, I'm like thanks, thank you all the time. I don't think I was denied of services. In fact, I'm impressed how much they do [for Risa].)*

In fact, she found that she was typically on the "same page" as the teacher when it came to understanding what was best for Risa, as seen in the following quote,

> スピーチの…スピーチ、OT、Special Education の先生がかくかくリサちゃんのゴールを説明して、設定して、こんな感じですけどどうですかねっていうふうに、書類を見せられて、そこから大体、あ—私もいいと思います、みたいな感じで終わるんですけど。結構、こう、同じページにいるという印象が。私があれ？と思ってることは、多分先生もあれ？っていうふうに思ってるし。その辺は。(*With speech, umm, the speech therapist, OT, and the special education teacher, they will take the time to explain Risa's goals, how they will be implemented…and they ask me what I think about them after showing me the paperwork and from there, I say, yes. That make sense. That's usually how it goes. I feel that for the most part, we're on the same page about everything. Like, if I were to be like "huh?" about something, her teacher is usually thinking the same thing.)*

However, it occurred to Tomoko during the interview that she rarely asked questions during IEP meetings, almost to imply that she trusted Risa's teacher enough to follow her lead. When asked to elaborate further on some reasons why she didn't ask questions in the meeting, Tomoko shared that it was not only that she didn't feel she had enough knowledge to ask the "right" questions but also that advocating for Risa was not so straightforward for her.

> 知識がないのと、なんかあんまり質問しつづ--し過ぎたりとか、要求しちゃいけないんじゃないかな、みたいな。気おくれですか。なんか娘が障害があるからアドボケートは必要だと言うんですけど、あんまりアドボケートし過ぎても、何か--すみません、みたいな感じの態度でいつも言ってしまう。ご迷惑をお掛けしますけど、よろしくお願いします、みたいな態度になっちゃう。それで家に帰って、そこまで私、下下に出る必要もなかったんじゃないかなと思う時もある。正直。*(The fact that I don't have enough knowledge and that feeling like I shouldn't ask too many questions or demand too much. Feeling too timid maybe. I mean I know that I'm supposed to advocate because my daughter has a disability but what if I advocate too much or like, I always say it in apologetic ways. I get into this mode like "I'm sure it must be a lot of trouble but*

> *thank you so much." And then I go back home and I'm like, was it really necessary to talk and present myself that way. I'm serious.)*

In fact, Tomoko mentioned repeatedly throughout her interview that the main issue for her was not a language barrier. What was challenging for her was to communicate in a way that would not make her a burden to her daughter's teachers and knowing what were appropriate things to ask, as well as how to ask them. She shared:

> うーん、英語は--英語力はすごい得意な方なんですけど、やっぱり英語力というよりも、娘の教育関係になると、人と人とのコミュニケーションとか関係を築くという方の方が、そっちの方の方が私は難しいなって。えーどういうふうに--先生に、こう、なんか鬱陶しい親だなとか思われないように、うまく娘をサポートしてもらうように言い方とか。英語というよりも、そっちの方が。あとＥメール、これしていいのかなとか。直接話した方がいいのかなとか。*(Hmm, my English…I feel my English skills are probably on the stronger side or rather what I should say is when it comes to my daughter's education, building that strong relationship with her teachers; well, what's been the hardest part for me is building strong relationships. Hard like how? Well, I really don't want to be thought of as that annoying and troublesome parent. It's more about making sure that I know what to say so my daughter gets the support she needs. It's more about that than my English skills. And email too. Is it okay to email this and that or would it be better to talk directly?*

In another example, Tomoko also shared that writing emails was challenging for her at times, where having access to a sample template letter allowed her to see how to communicate in a more concise and clear way.

> シンプルな英語で必要最低限のことしか書いてないけど、親がメールすると、もう長いんですよね。だからもう書いて、必要ないところは、消して、なるべく、もう5行くらいに毎回、メールになるように。日本語だと結構くどくどいうんですけど、英語だと一つの単語でまとまるときってよくあるじゃないですか。あの、さっきもどこかに書いてあったんですけど、サンプルレターで使われている言い回しを使うと、もっとスムーズに行くんじゃないかという。で、そうして言ったほうが、「親もよく知ってるんだな」って先生からも思われるし––*(I'm trying to write as simply as possible in a way that addresses some issues at the very least but it's always too long when parents write emails, you know? So it's about trying to write down everything I can and then deleting all the unnecessary details, to get everything down to 5 sentences in my emails every time. There is something about the Japanese language that's really tedious sometimes, where you know, in English, there are ways to say things that get straight to the point. I was thinking just now about something I read about (special education) sample letters and how if I use their language, maybe it might be clearer and smoother. And if I do that, I'm sure the teacher will think that I'm on top of my stuff.)*

When asked to explain why she felt this was so important to her, she replied that through establishing good communication and developing strong rapport, she would be able to ensure Risa received the support she needed in the end. Tomoko shared:

> その人間関係、うまくコミュニケーションをとるのと、うまく人間関係を築いて、親と先生が。で、結果子供に良いサポートが行き届くように。*(The interpersonal relationship, to have good communication, and building good relationships between parent and teacher. That would result in providing good support to the child.)*

Tomoko's response above was a typical (parent) response that reflected Japanese norms and values around wanting to preserve positive relationships with teachers at school, for the child's benefit. For Tomoko, she felt strongly that she needed more knowledge to know what to say to create a better impression, whether it was in person or over email. Even for someone like Tomoko who shared that she was conversationally fluent in English, knowing how to create these positive impressions was different and more challenging for her.

Response to intervention tool

I gave Tomoko the text tool to read after she shared details about Risa and her past experiences with schools and IEP's. Her immediate response was positive and that it was exactly the kind of resource that she was looking for and asked if she could read it right away. そう。こういうのがほしいんです。 *[laughter]* 今読んで良いですか。*(Yes. This is exactly what I want. Can I read it?).* There was an air of calmness around her as she said this and from my observations, it was hard to tell how excited she actually was. We were also sitting in a public library at a small table, where we were trying our best not to talk too loud or draw attention to ourselves. While Tomoko was reading the text tool, I jotted down notes and comments about different things I had observed and heard her talk about during the interview. After she finished reading the text tool, I asked Tomoko what her general impression of the tool was. She took a moment to calmly think about my question, flipped through the pages and pointed to a section towards the end. She stated:

> 一番印象だったのが、ここですね。特殊教育や保護者の権利の理解が進むほど、子供の教育のプランニングに意義ある参加ができる。*(The part that really left an impact is right here. The more you know about your rights as a parent, the more you can be a part of planning your child's education in a meaningful way.)*

She went on further:

> 実際のやっぱり同じ障害者を持つ、保護者で、かつ自分の娘よりもおそらく年上の方の経験上の悩みなので、今後同じような状況になるときに、なんか役に立ちそうだな。*(I think this will be very useful for parents who have kids with the same disability diagnosis who are a bit older than my daughter, especially if they run into similar situations.)*

She read the statement that she pointed to earlier to herself again and flipped through a few pages while I waited. I asked if anything else in particular stood out to her but there was silence as she flipped through the pages further. I waited for several minutes and sensed that there was not much more she had to share. I then introduced the *manga* version to Tomoko who suddenly looked more visibly excited, as she exclaimed, おお、面白そう。 (*Oooh, looks fun.*) She began flipping through the *manga* pages as she looked at the illustrations and shared her thoughts:

> 一緒に感じないんですけど一緒なんですよね、全く。こっち買います。多分。字じゃなくて。やっぱり、なぜでしょうね。うーん。多分漫画自体に親しみがあるのと堅苦しくないのと、こう、ポイントがパッパッパッて目につくんで。分かりやすい。あと何ですかね、法律の話とか出てくるじゃないですか。真面目な形だし。なんか逆に堅苦しい文章ばかりで余計分からないのに、さらに文章ばかりだと大変だなって感じなんですけど、これだと楽しく読めるし。絵が印象に残るから頭にも残る。*(It almost doesn't feel like (the content) is the same. But it's the same right? I would buy this one (comic). Probably. The one without the words. Hmm, I wonder why. It might be that comics are just more fun to begin with and all the important points jump out at you like boom, boom, boom. Easy to understand. And what else is it? Well, you know, the topic itself is really serious. It's almost like the opposite of the comic, where there's just so much serious text and I already don't have enough knowledge and going through the text feels like a lot. But with the comic, I can read it more leisurely. The drawings stay in my head more.)*

When faced with both the *manga* and text tools, Tomoko felt that the former was the more obvious choice for her. This was not only due to how important information was highlighted graphically, which made details easier to understand and retain. It seemed that *manga* also provided more space for Tomoko to take in information that would typically be harder for her to digest (without the proper knowledge, according to Tomoko). Thus, it appeared that the *manga* essentially provided access to information by using visual cues that helped Tomoko feel more emotionally at ease.

Tomoko shared her reflections further and acknowledged that she was now in a position where she felt that she could take in the information much better than in the past. She stated that might not be the case for a parent who is just learning that their child has a disability and especially on thinking about the law and what they would be expected to do as advocates. Tomoko also mentioned at the end that she felt more motivated to read up on her rights.

> 特に私今、読んでるんですけど、別に何か読める。前ほど、えって感じはないよ。多分私の知識も増えてるからだと思うんですけど。うん。やっぱりいきなり最初の方で、最初の方っていうのは障害があるって分かって、これから学校とどうのこうのっていう時に、これから入ったらすごい保護者の人って、うわ一ってなると思うんですけどね。そんなことまでやらなきゃいけないのって。考えてないし、あるって聞いても、何か自分と関係ないことなんじゃないかって思ってしまう。法律ってそんな身近じゃないじゃないですか、日本って。ちょっと読んでみようかなって思うんですけど。*For me, so I'm reading this now and I think I can handle it. I'm okay. It's not as much of an "oh my god!" feeling anymore. It might be that I just know more now. Yes. I mean, if I was back at the beginning, the beginning being when I first found about my daughter's disability and I would be wondering about what will happen with her education and I would need to advocate, it would be too much. Like, I have to do what…and to that extent?? It's not like I would be thinking about that to begin with and so even if I heard about (advocacy), I would feel like that doesn't have to do with me. The law isn't exactly something that most Japanese people are familiar with. Maybe I should read up a bit more about it.)*

Tomoko's comments from the excerpt above revealed how special education advocacy felt intimidating to many (Japanese) parents including herself in the past. Although she recognized that she had come a long way since her daughter was diagnosed with autism, she was also personally familiar with the emotional stressors that many Japanese parents faced when navigating disability and special education support in the U.S.. The uncertainty of navigating so many unfamiliar situations in a different cultural context in a different language, and about a topic that was already challenging to talk about in Japanese made reality that much harder, especially in the context of being expected to advocate.

Case profile of Yuki

Yuki was the mother of three children living with her Japanese husband in a suburban neighborhood of Washington state. Her two older children were identified as having different degrees of autism, where the older child, Mariko was non-verbal and her second child, Touma was considered as being on the milder end of the spectrum. All of Yuki's children were born in the U.S., where Yuki had lived in the U.S. for 18 years by the time of the interview.

When Mariko began attending school, Yuki was initially impressed with the type of services that were available for students with disabilities. Mariko was receiving speech therapy and occupational therapy on a weekly basis and transportation services were offered to and from school. However, Yuki mentioned that she did not have enough knowledge of special education at the time to know if what Mariko was receiving in her IEP services was adequate or not. Although Yuki was not a confident English speaker, she was able to communicate using basic English vocabulary and typically requested interpreters, where possible, to help her in her communication with professionals. She learned from other Japanese parents through the Japanese parent group, *Himawari-kai*, that it was important to explore and find as many learning opportunities for their children (with disabilities) as possible and to not simply rely on schools alone. It was through conversations with such parents that Yuki began to learn more about special education at the beginning. She developed a strong friendship with another parent in *Himawari-kai* who had two sons with autism and learned how important it was to be proactive in setting up positive learning environments for children with autism at home and in school, among other tips and advice.

It was also through *Himawari-kai* that Yuki learned of a parent training program for families of young children with disabilities at the nonprofit organization, *Families First*. Through attending and participating in this parent training program for two years, Yuki was able to learn more about what it took to support Mariko and her needs more effectively and to navigate special education, as well as other disability support services, more strategically. By the time I interviewed Yuki, she was no longer the parent who was struggling to understand special education as she had described earlier. There was an air of humility around her as she also did not act or speak in a way that one might expect from a parent who had gained so much knowledge, skills and experience around advocacy in such a short amount of time.

Yuki shared a more recent example of how she resolved some conflict with Mariko's teacher at school, where the teacher had initially denied Yuki's request to allow Mariko to use her iPad as a communication device in class. Despite Yuki's attempts to advocate for Mariko, the teacher felt strongly that the presence of an iPad would be highly distracting to other students and thus, impact the overall learning environment for all students in the classroom. Instead of giving up on the situation, Yuki expressed her concerns to Mariko's speech therapist who also felt that Mariko could benefit from using an iPad in her classroom. The speech therapist decided to advocate on Yuki's behalf and spoke to the teacher to explain why and how it would benefit Mariko to use her iPad as a communication device. Moreover, the speech therapist informed the teacher directly that making sure that students were paying attention in class was part of the teacher's job and that Mariko should not be the one to blame if the class was acting up. As a result, Mariko was able to use her iPad in class soon after that incident. Yuki reflected as she shared her example,

> なにこの違い？って。そうね。そうだよねみたいな。やっぱー親、親としての発言力は弱いのかなっていう。*(What is the difference here, I swear. Sure. Sure it's that way, I guess. I mean, as a parent, our voices carry less weight maybe [compared to that of professionals]?)*

Yuki stated that it was not due to a lack of effort on her part when she did her best to advocate on her own for Mariko. However, it seemed that no matter what she said, schools were always quick to deny her requests and list off all the reasons why they could not accommodate them. However, over time, Yuki realized that the best way to be heard was to involve other professionals who could advocate on her behalf, much like the speech therapist had done. In another example, Yuki shared how she had developed a good relationship with Mariko's BCBA (behavior specialist) who began to attend Mariko's IEP meetings with her.

> 今はあのBCBAが一緒に毎回IEP行ってくれるけど。うーん。そう。専門の人をやっぱり１人連れて行ったりとかすると、だいぶ印象が変わるなっていうのはすごい思った。*(So right now, there is a BCBA who comes with me to the IEP meetings and hmm yes. What I realized is that when I bring a professional with me to these meetings, their [IEP team's] perception of me and everything really changes.)*

Yuki also had experience working with the Washington state Office of Education Ombuds (OEO) to resolve disagreements with schools when it became absolutely necessary and quickly realized the benefits of advocating for herself. She shared,

> でもね、なんかあそこもやっぱ１回じゃすぐに返事とかも来てくれなくて、結構待たされて。いやもう、「こっちはemergency」って、「緊急なんだ」っていうのをやっぱ言って、電話して言ったら、意外にすぐに、そういう、なんか多分こっちの必死さを言ったら、やって、やってくれるっていうのがあるから。うーん。やっぱ言ったもん勝ちだよなっていうのが結構あるかも。*(But you know, it's not like they get back to you right away after you contact them and I ended up waiting quite a bit. So I called them again and told them that this was an emergency and very urgent. Maybe it's because I really tried to convey how desperate I was feeling but they responded very quickly and said they would be able to help me. Hmm. When I think about it, I suppose there are a lot of instances where it really helped that I spoke up.)*

Yuki realized that as beneficial as advocacy was to her especially when seeking support in more urgent cases, it was not always easy getting a timely response back. In this sense, Yuki learned over time not to wait in such situations, but that it would require her to advocate multiple times where knowing how to communicate effectively helped her to achieve the results she wanted.

In addition to getting connected to different professional support services, Yuki shared that she also tried to attend different community and parent organization events to see what she could learn from them and explore the resources they had and if anything, whether she felt that she could be a part of their parent community.

> で、１回はとりあえず行ってみようと思って。多分性格もあるけど、気になったら行ってみようみたいな。うん。で、そこで合わなかった、白人ばっかでね、やっぱりね、自分がのけ者っていうかちょっと疎外感を感じたら、もうそれ以上は行かないけど、みんなやっぱ悩んでる、悩みは一緒だから、必死な英語もちゃんと一生懸命聞いてくれて、「そうだよね、そうだよね」って言って、で、自分もこうなんだよっていうのをやっぱ分かり合えるから。うん。それは色々かな。*(I usually feel that I should try to attend at least one event. Maybe it’s just my personality but if I hear about something that sounds interesting to me, I want to check it out, yes. And if I really feel that I don’t quite belong, you know, with all the white parents there and I feel like a bit of an outsider or the odd one in the crowd, then maybe I might not go back there. But then again, I see that everyone there has the same concerns as parents and because our concerns are all the same, everyone does their best to listen to me despite my English and can completely relate to what I'm going through and also share what they’re going through. We have a way to share together, yes. There was a lot of that for me.)*

Yuki described in the excerpt above how she tried to step out of her own comfort zone and attend as many disability-related community events as possible. It was through such community explorations that she realized she generally had more in common with other parents of children with disabilities than she had initially thought. Thus, despite any language challenges, Yuki felt that she could share and essentially advocate for herself and her children in these spaces. It should be noted that most parents in this study described how they did not venture outside of the Japanese community to seek support. Yuki was one of very few parents who shared that this was important to her, especially in gaining more knowledge and access to resources. In her interview, Yuki was also the only parent who had defined advocacy as something that was done for you. In other words, she understood the term primarily as a noun, i.e. a person or professional who acted as an advocate on someone else’s behalf, in contrast to doing it herself. However, Yuki also described her own acts of advocacy, where she did not rely on other professionals. Thus, it appeared that Yuki's interpretation of the concept of advocacy was not only complex but also context specific.

Response to intervention tool

Yuki was given the comic tool first. Unlike most of the other parents, she talked and read through each page at the same time, which gave me some immediate insight into what she was thinking and how she was responding to individual panels and pages. As Yuki progressed through the *manga*, she showed a general and quite basic knowledge around IDEA and parent rights. She commented that everything was easy to read and understand and that she was impressed with how the content was presented entirely in Japanese. She also stated that while she would prefer the *manga* in Japanese, there was also a part of her that felt reading the information in English might make more sense and perhaps easier for her.

> うん。分かりやすい。うん。絶対日本語であったほうが。でも日本語だと、私の場合、もっと難しく感じちゃう。英語で読むほうが、何だろう、単語も見慣れた単語がやっぱ出てくるけど、日本語だと単語が難しく感じちゃって。*(Yes, easy to understand. Yes. I definitely think it would be better in Japanese. But if it's in Japanese, in my case, I feel like it might actually be harder for me. Reading everything in English, I wonder what it is. There are terms that I'm just used to seeing [in English] and if they were in Japanese, I feel like it would make everything more challenging.)*

Yuki mentioned this several times throughout her interview, where she stated that having information in English was easier to follow in some ways like in the excerpt above. Yuki's response following that was filled with knowledge around special education, as well as some comments around how she tried to be more proactive with her son, Touma after he was diagnosed. This was mainly due to how she felt that she had failed Mariko in some ways by not acting sooner.

When presented with the text version, Yuki initially laughed out loud and commented on how much text there was to read. She stated within less than a minute of reading through the text that the *manga* version was the better option. When asked why she felt that way, she responded,

> なんか、字ばっかりで分かりにくい。 あれで英語だと分かりやすいかなって。うーん。単語が目につきやすいから？ *(It's like, having so much text everywhere makes it harder to understand. If it's in English, maybe I can pick out some familiar words?)*

As she continued to say that the *manga* version would be the better format for this resource, I curiously asked her if she had read the procedural safeguards document from schools since it was in English and she had stated that reading certain information in English might be easier for her than in (translated) Japanese. Yuki stated that she had not read it and that she would most likely not read a translated version of it either. She shared further,

> 何だろう。あんまり興味がないというか、あんまり、そうだね・・・だって知識は必要だけど、あっても使わないと意味ないじゃん。だから必要な時に、大体こういうとことか、トピックさえさ、見ればさ、あ、大体こういうこと書いてあるんだっていうのが分かるじゃん。だからそういうのを見といて、どっかに置いとけば、あ、やばい、こういうことがあった、どうしようっていう時に、もしかしたらこういうのを。一応全部置いてあるのね。家には。読まないけど。でも何かのために、あったら、これを見ればいいのかなっていうのを調べる時に使えるかなっていう程度にしか思ってない。*(I wonder what it is. I have to say that it's that I'm just not very interested in reading it (procedural safeguards). Not really, no….I know that it's important to have knowledge, but there's no point to having it if you don't do something with it. So when I need something, if I moreorless know what the topic is about and I look over the information and I'll know what's been written on it. So as long as I look over this information and I keep it somewhere safe, when something happens and it's like oh my god, so and so happened. What should I do? And maybe I can do this or that. I have everything together at home. I haven't read them yet though. But if something happens, anything happens, I was thinking that I would have all this information to refer to and use.)*

It should be noted that although Yuki exhibited the greatest amount of knowledge, skills and experiences around parent advocacy, she stated that she did not see herself as a strong advocate. This was mainly due to her feeling that she still had so much to learn with regard to her children's future and that she was not always confident about how to begin planning for their lives as adults. She also stated that most of the information around advocacy would be helpful for parents who were just starting out in special education but in her case, she needed information that allowed her to see a larger picture beyond school (i.e. systems navigation) and that with the right information, she would feel more prepared about advocating for her children and calling herself a strong advocate.

Chapter 5

Cross-case analysis

In this section I provide a cross-case analysis of the eight cases who received both *manga* and text tools but in a different order. I explored the affordances of *manga* over standard text by examining some underlying themes in parent responses by comparing how parents made meaning of their experiences with each tool. I then examined whether order effects made a difference in these experiences. Parents also shared their views on what the tools should include to be more effective and useful. It was evident that parents experienced each tool very differently when re-envisioning its possibilities and reflecting on what it takes to become effective parent advocates in special education.

Responses to *manga* and text tools

The research questions that I set out to explore through this dissertation focused on how parents made meaning of two very different formats: graphic (*manga*) and written text. Given the differences in format and presentation, my goal was to examine how parents made sense of their experiences with these tools to better understand the types of affordances that *manga* could provide over standard text.

Experiences with manga

One of biggest affordances of *manga* according to the general consensus of parents across all cases was that having its multimodal format made special education advocacy and exercising parent rights under IDEA much easier to understand. As seen in the individual cases, parents spoke about having positive experiences with the *manga*. They shared how they liked the *manga* for a variety of reasons, most of which the benefits of using images and visuals in conjunction with words. Izumi summed it up very simply by stating, やっぱり絵で、絵で表現す

るというのが一番いいと思いますよ。 *(Having these visuals and being able to convey so much with visuals is really the best way to do it, I think.).* Kazumi echoed similar sentiments when she shared, やっぱり絵で見てるからだと思う。文字だけで来ると、自分の中で想像できない。*(It's probably because I'm looking at the visuals now. But when I see it in all text, I have a harder time imagining it in my head.*）She elaborated further by stating,

> 法律だけバーって書かれると、うーん、そうなんだで終わっちゃうんだけど、私、何のためになるかなっていうのが繋がってこないけど、絵とか説明とかがあると、は、私必要じゃん、この法律っていうふうになって、自分の中に残る。(*When the law is all written out like that, boom…umm, for me it ends up being like, "Oh okay" and that's it. It's not really clear how it all connects but when there are images or explanations there together, [the law] ends up staying in my head as something that I need to know.)*

For Kazumi, having visuals made a difference in terms of how everything was connected; in other words, the visuals helped to make what she was reading more concrete than having text alone. Having visuals and words combined also proved to be useful when parents read over the section with different scenario examples, where many shared that they could easily relate to and connect with what the characters were going through. Manami shared how helpful these scenarios had been for her when she stated,

> この例えば…具体的な例っていうのが、すごく「ああ、なるほどな」って思うんですよね。例えばこの例が無くて、ここだけを読んだ後も…例えばこういうことを話す、 って言ったら、絶対的にこの例がある方が「ああ、なるほどそういうことか」ってなるんですね。だからこういう、何か、色んな、例えば、例がすごくたくさん知れたらいいなって思う。(*So for instance, these specific examples [scenarios] felt like this moment of clarity, like "Ohh that's how it works." So if this example wasn't here and I was reading about so and so in that section, it would definitely be so much clearer if the examples are there. So I feel that I would really learn a lot if there were a lot of different examples that I can pull from.)*

In Manami's case, it wasn't just having visuals that made information more concrete and thus easier to understand. For Manami, having examples of potential challenges that other Japanese parents had faced made the overall context much more relatable and easier to understand. Similarly, Natsumi shared her reflections on her experiences with both the text and *manga* and came to the conclusion that *manga* and its visual elements were well suited for highlighting different scenarios in contrast to text. She elaborated further,

> まだ漫画のほうがやっぱりビジュアル的なのが、読みやすさがすごくあるっていうのがもちろんなんですね。あと、章立ても、多分もっとこう、あの、「ここは！」とかいうところの。でも、ケーススタディのバーッて羅列になっていくと、少し、あの、焦点がどうしてもボケがちに。文章ってどうしてもそうなりますよね。だけど、これだと、ここはまとめ部分、そっちのプロセスは、ね、こういう会話でワーって来てるんだよって、段階ごとに追ってるって、そういう感じ。やっぱりこういうのは、ケーススタディは、漫画はやりやすいですよね。
> *(I suppose it's true that the fact that the manga is more visual would make it easier to read. And having the different chapters also made it easier to pinpoint certain information. But when you have the case studies (scenarios) all organized one after the other , I tend to space out on the main points. There's something about reading long text that does that to you. But with this manga, the way that it's put together, this process, where you see all the conversations that are happening and you see what [parents] are dealing with on a daily basis, well in that sense, I feel like having these case studies [scenarios] as a manga is much easier to accomplish.).*

For Natsumi, utilizing a *manga* format made a lot of sense to her, especially in how information on special education law, advocacy and parent rights were organized and put together for the reader. This was especially useful in how the case studies or scenarios had been arranged in the tool itself, as Natsumi commented on the more interactive nature of *manga* and comics in general. For Natsumi, it was easier to stay on track with what the *manga* was trying to say compared to the text, as she expressed that she often lost her place when reading through large chunks of text at once.

Parents also shared their insights into how *manga* provided more emotional support for them, where they also felt that the format itself made the topic less intimidating and more inviting overall. For example, Kazumi shared,

> でもこれをアリサさんじゃなくてかずみさんにして、子供の設定すると、あー、みのるもあるあるみたいな、なのが、こうすり替えられる。自分と自分の気持ちと息子との例がちゃんと入れ替わるから、こういう時は確かにこれ困ってたんだよねっていうのがやりやすい。
> *(So let's say that [in this scenario] this is no longer Arisa but it's me instead and if you take a look at how the child is doing, it's like ohhh, Minoru has that same issue! And it's easier to relate and switch over into their roles. Because I would be able to change places with her in this example, it would be about me, my feelings and my son and in instances like this one, it's so easy to relate to her and agree on what felt troubling.)*

For Kazumi, having examples that she could relate to, where she felt she could easily connect on an emotional level, provided a way for her to make more meaningful connections in her learning experience. Other parents expressed similar sentiments in their interviews as well, where having relatable and realistic examples helped them to see the larger picture around parent advocacy more clearly. This was especially clear when parents stated their preference for the *manga* by sharing that they would need not as much time to be mentally and emotionally prepared to read it, compared to the text version.

> こうやって要点をね、分かりやすくね、やってくれると、字ががーって書いてあるよりはやっぱ見やすいよね。そんなやっぱ字、一個一個読まないじゃん…だから、やっぱ目につきやすい字で。うん。うん。(*If the main points are all there and easy to understand, I think that it would be easier to read [in a manga] than if it's alllll there in just text. Well, you know with text, it's not like you read every last word either, so I would definitely prefer something that catches my eye and is easy to read.)*

Both Yuki and Kazumi emphasized in their interview how it would be preferable to have a resource that was easily accessible, not only in content and also in presentation. With both parents, as well as others, there was a sense that gaining this knowledge was not an easy process but an emotionally exhausting and time-consuming one. Thus, having a (visual) *manga* format helped to make this learning process smoother by helping [the reader] to feel more motivated, unlike the text version that left Kazumi feeling as though she had taken in too much information at once.

For Izumi, although she stated that she preferred the *manga* over the text version, she also pointed out very quickly how wordy everything felt to her in the *manga* and how having to read over difficult terms and language so carefully took away from having a more positive experience. She had also mentioned in her interview that the tone of the narrative felt a little rigid at times when she shared,

> うん、すごいいいと思いますが、えっと、率直な感想は字が多すぎる。ちょっと多分、漫画にするんであれば、もう少し、あの、うーん、ちょっと字––何とかもうちょっと柔らかい、何て言うの、うん。多分読んでいくうちにやっぱりちょっと硬い気がします。だから––あの、漫画はすごくあれなんだけど、どうしてもやっぱり結構字数が多いし、漢字もいっぱい入ってるから、結構そっちに必死になって読んじゃう部分があって。あの、せっかくの漫画なのに漫画の方に目が行かない。*Yes, I think it's really great but to be quite frank, there are just too many words. I think that if this is going to be a manga, you need to uhh, hmm, the language…if there is a way to make it a little softer, how do I say it/ I just feel that as I read more of it it, the tone of it feels a bit serious. And so, yes, the manga is the better one but because there are so many words everywhere and a lot of kanji characters as well, so I end up putting in quite a bit of effort just reading everything. It's like, it's too bad that because even though the manga is all there, my line of vision goes elsewhere and not on the manga [images] themselves.)*

Because *manga* were seen to be more emotionally accessible in general, Izumi felt strongly that it would be more beneficial to use less jargon and more common, everyday language, with a variety of different scenario examples to read through to make the overall information much more meaningful for the (parent) reader. In this sense, Izumi emphasized throughout her interview how important it was for the tool to include language that was emotionally accessible. It was not just a matter of creating a narrative in a *manga* format but also the importance of presenting information that made (cultural) sense to Japanese parents in an emotionally relatable way. In this sense, the language and tone of the narrative of the *manga* did not always line up with the (emotional) accessibility of the *manga* for Izumi, thus leading to slightly less fulfilling moments in her *manga* experience. However, Izumi saw using visuals and having many scenario examples as positive strategies to incorporate when she shared,

> うん。全然全然。ただやっぱりちょっとどうしても内容が硬いから、その硬い部分がやっぱり字になっちゃってるじゃん。それを如何にやっぱりその、もうちょっとレベル下げて、絵と会話でできたらな。*(Oh yes, definitely [prefer manga]. The only thing is that because the topic is so serious, that seriousness is now all in text. I wonder if there might be a way to bring it down a level and use the visuals and the conversations to convey the information.)*

Izumi continued to emphasize the importance of having information that was easy to relate to as parents of children with disabilities and elaborated further in this following excerpt,

> Relatable、easy to understand この IEP の meeting、こう、こういうのとかね。すごく relatable だと。本当の現実のことだから。だから、それはすごく relatable だと思うし、これもそうだと思う。あ、何、子供が、例えば「16 歳の子に、うちではちゃんとした？なんて聞いても

> 決めたがらないじゃない？」とか、そういう、そう、すごく、この case はすごく私もよく分かる。で、その具体的な、何て言うの、その actual、何て言うの？その具体的な例を、very on ね？だから「消しゴムを口に入れる」とかさ。そういう、その、そういう、うん。そうそうそうそう。（*Relatable, easy to understand this information on IEP meetings. Things like this. Very relatable, I think. Because that's how it really is in real life. So, I think it's very relatable and this example too. What was it… the child was for example 16 years old and mom asking him whether he had finished his homework but him not being sure whether to do it or not….things like that, it's really..this case is so easy to understand and relate to. So with having those examples,* how do you *say it, those actual, what are they called, those scenarios were very on point. Like the one where he puts the eraser in his mouth. Things like that, yes. Exactly, yes yes yes I get it.)*

Izumi was one of the few parents who had more knowledge of special education and advocacy than other parents who were interviewed, which was evident in how she voiced some opinions that were different from the rest of the parents such as her feedback on the narrative text. She also showed a deeper level of understanding about the issues facing Japanese parents by taking a more objective view of the information itself, while acknowledging the need to present details in a way that was in essence, sensitive to the (parent) reader. Thus, Izumi continued to emphasize how having examples that reflected the real-life challenges that parents were facing helped her to feel more engaged with the presented information.

The *manga* appeared to make a strong impression on Chiaki, who as described in her individual case description, shared that she felt less isolated through feeling connected to other Japanese parents facing similar challenges navigating special education. Chiaki had lived in the U.S. for the shortest amount of time out of all the interviewed parents, where she was facing different and arguably more complicated issues with her school's IEP team due to his transition into U.S. special education as a teenager. Moreover, Chiaki had also expressed that her own language shortcomings were a barrier, where it was harder for her to feel like make personal connections and build relationships with the people around her. Thus, upon reading the *manga*, Chiaki expressed that she felt as though she was a part of this (imagined) community of parents. In fact, being able to relate to the different facial expressions of parents (in the *manga*) felt very comforting to her. Even in her response to the text version, she shared that the conversational exchanges in the third scenario felt the most real to her out of all the scenarios, as it was the most emotionally relatable. Thus, it was clear across all cases including Chiaki that Japanese parents valued the emotional components of *manga* and its ability to provide a cushion of support, especially when it came to reading about special education advocacy. Moreover, incorporating emotionally relatable elements into the narrative and embedding the perspectives and experiences of other parents worked well due to the Japanese cultural norm and expectations of group harmony and interdependence.

Experiences with text-only

When the parents who read the text tool, their experiences sounded markedly different from when they read the *manga*. Although parents also shared positive comments of the tool, their focus appeared to be more on the usefulness of the information itself, what they already knew, and how much it made sense to them. In the cases of parents such as Chiaki and Natsumi who had not heard of ‘advocacy’ before, they were able to gain some insight into what the term and concept entailed. For Tomoko, although she stated that she had heard of ‘advocacy’ and knew what it meant, she had never made the connection between advocacy and having parent rights. As described previously in her individual case description, Tomoko had shared a short response when she pointed out a parent tip towards the end of the tool that she found to be particularly insightful in how she thought about parent advocacy. When asked to share what else stood out to Tomoko, she did not share much more. Chiaki had shared that she had never heard of the term ‘advocacy’ before but that she had a slightly better understanding through the scenarios that were included. She explained,

> ここの、これだけ読んでも多分分かんないから、この流れをちゃんと、こう、こういう、何て言うんですか、具体例っていうか、具体例があって初めて、ああ、そうか、そこでadvocacyが出てくるのか、最後に出てくるのかみたいなのが分かります。*(Right here, if I just*

> *read this [section on advocacy], it wouldn't make much sense to me. But if you follow this flow, these, how do you say it, these concrete examples, with these examples, you start seeing how advocacy comes up and I see that how it all connects at the end as well.)*

Chiaki shared that it was through the scenario examples that the information she had read on advocacy started to make sense. Without that context, she stated that she might have struggled to make sense of what she was reading about advocacy (in its specific section) and how it might apply to parents in special education. In contrast, Izumi had shared in her interview that the section on advocacy and what it entailed stood out the most to her with its use of simple visuals and breakdown of definitions. Thus, when comparing the experiences of parents such as Chiaki and Izumi on how they responded to the same information (on advocacy) but through different tools, it was clear that having visuals worked to Izumi’s advantage, where Chiaki had to continue reading to make more explicit connections between what she was reading and her understanding of parent advocacy.

Junko and Yuki shared some insightful and different ways of thinking about the emotional support that these tools offered parents. Junko stated that whether she chose to read the *manga* or the text version would likely depend on how she was feeling and what she needed at the time. More specifically, Junko shared that if she was feeling desperate and was unsure of what steps to take, she would choose the *manga* as the visuals would help her feel more (emotionally) ready to take action.

> あの、何だろう、その−−　結構 anxiety、心配してて。 心配が大きくて。心配度が高くて。で、なって。で、情報をまずは…こっちのこと知らなきゃっていう気持ちだったら、多分私は、私の場合はこっちに行く。*(Hmm, I wonder what it is, well, let’s say a parent is feeling a lot of anxiety and is worried. Very worried. The level of worry is so high. And if that’s the case, with getting information…if the parent felt that it was important to know all this…well, for me, if that was me, I would choose this [manga].*

However, if that was not the case, she stated that she found the text to provide a more objective view of the information, which would be useful when preparing ahead. In Junko’s case, she was the only parent who indicated that she would want both versions of the tool. It should also be noted that she had the most extensive knowledge of special education of all parents through her ongoing involvement at the district level. In her interview, Junko reflected further on the usefulness of the text version when she shared,

> はい。Helpful だとは思います。けど、これを見て「よしやろう、実際にここからやろう」って思えるかどうかは、その保護者の方の−−ready 度？どこまで ready かによるかもしれない。更に、実際のこの、サポートをしてくれる人？が、必要だと思う。これだけだと、これだけで、こう読んで、「よし」って言って実際にできる人は少ないかもしれないと思う。*(Yes, I think [the information] is helpful. But whether after reading this I would feel like, 'All right. Let's do this. This is where I can start right now' would depend on the parent and how ready..they are? It might really depend on how ready they feel. I think that in reality, parents would need someone who can provide that support to them. If all they have is this [information] and they read it, I think that in reality, there would be very few parents who would feel ready to take action.)*

From Junko's perspective, she found the information to be useful. However, she also recognized that for some parents, it could be more complicated as it would not be immediately obvious how to make use of the information provided to them. Thus, it seemed that having more knowledge of special education allowed her to be critical about how the information was presented in general. Junko saw the benefits of both tools to utilize in different ways that served her purpose at the time. However, for a parent with less knowledge of special education in general, Junko felt strongly that it depended much more on how "ready" a particular parent was to take the necessary actions to advocate more effectively. In that sense, the text version was not as helpful compared to the *manga*. However, she also suggested that having a combined version with both the *manga* and the text could potentially be very helpful.

Yuki also shared how the language (of the narrative) was challenging to get through due to complex words and terminologies that they were difficult to read in Japanese. Yuki had shown that she had a very different understanding of advocacy in her interviews that had worked for her so far. She had been the only parent that stated that it might be easier for her to have an English version of the *manga,* as it would be easier to identify the terms she already knew to keep building her knowledge.

> うん。分かりやすい。うん。絶対日本語であったほうが。でも日本語だと、私の場合、もっと難しく感じちゃう。英語で読むほうが、何だろう、単語も見慣れた単語がやっぱ出てくるけど、日本語だと単語が難しく感じちゃって。*Yes, it's easy to read and understand. Yes, it would definitely be good to have everything in Japanese. But I have a feeling that in my case, it might feel more challenging if everything was in Japanese. Reading it all in English is, I wonder…maybe it's because I come across words [in English] that I'm already used to seeing but in Japanese, I get the feeling that the words [in Japanese] would be more difficult to read.*

It is worth noting that Yuki stated that she was not bilingual and did not feel confident at all in communicating in English. However, she also found some level of comfort in reading materials that she had grown accustomed to. She did not feel that same level of comfort and ease with the material in Japanese, as the words themselves were complex terminologies and literally challenging to read. In that sense, it was as though she had built a rapport with English language resources, where none existed in Japanese. Thus, although Yuki stated that it would be useful to have this information in Japanese, having information in English would serve a practical purpose for her, as she would not have to figure out which Japanese-translated terms and concepts would correspond specifically to what she had learned in English. Overall, Yuki said that she felt more favorable towards the *manga*, as she read them often and that in her opinion, the text version was harder to get through as she shared, 字ばっかりで分かりにくい、なんか。(*Too many words everywhere and so it's harder to follow, kinda.).*

It is interesting to note that regardless of the English language capability of these parents, having knowledge about special education appeared to play an important role in deciding what would be considered useful to them and what would work best. Parents such as Junko and Yuki shared their different perspectives on these tools and were able to justify how they felt using their special education knowledge and experiences.

Order effects: Manga-first group

Parents in the *manga*-first group responded positively to the *manga*, as described previously in the different examples above. Preference for the *manga* was also clear where upon seeing the text version (after the *manga*), parents immediately commented on the visible aesthetic differences of the two tools and how much of a difference it made to include visuals. When looking overall at the *manga*-first group, there was less focus and fewer comments overall on the text tool when compared to the *manga*, as the attention was mainly focused on the *manga* during the interviews. One parent, Kazumi skimmed through the text version after reading the *manga* and shared how she felt about the two tools and especially the text version. She stated,

> もうね、これ読んだだけで疲れてお腹いっぱいになっちゃう感じ。これだったら、あー、なんか共有しながらできる。これ、気合を入れないと。今日子供寝かしつけて夜読むぞみたいな感覚。*(You know, reading this [text] one makes me feel tired as if I just ate a big meal. If it's that [manga] one, I feel like we might be able to make it work together. With this text version, it's like I have to get fired up to do it. That sense of, I'm going to read this tonight after I put the kids to sleep!") [Kazumi]*

For Kazumi, it was not simply that the *manga* was more fun to read and more accessible in general. She also shared that with the *manga*, she felt that she could "make it work together" with the *manga*, implying that she would be more open to reading it in general compared to the text version, which would require her to get extremely motivated and to make time by planning ahead.

Order effects: Text-first group

Parents from the text-first group had fewer responses in general and did not share as many comments in their experience of the text tool (first post-intervention interview) in contrast to the *manga* (second post-intervention), where they appeared to be much more engaged through their visibly heightened emotions, as well as their overall response to the *manga*. This was evident through the rich details that they shared and the amount of enthusiasm they exhibited when talking about special education advocacy in the context of the *manga*. In this sense, the differences between how parents were making sense of their experiences of the two tools and what worked for them were made clearer by the extent to which they were able to re-envision the tool.

All four parents who read the text first appeared to be very quiet and more focused when reading through the text. There were more silent moments throughout these interviews compared to the group who read the *manga* first. Thus, there was not as much of a heightened emotional response, as there was a more intellectual response, where parents like Natsumi and Tomoko reflected on what they had learned about parent advocacy, as well as the idea of exercising their rights as parents.

In contrast, when the parents in this text-first group were given the *manga* version to read, they appeared to be much more excited and enthusiastic compared to when they first read the text. For example, Tomoko shared after reading through the *manga* version,

> うーん。多分漫画自体に親しみがあるのと堅苦しくないのと、こう、ポイントがパッパッパッて目につくんで。分かりやすい。（笑）そっくり UW（笑） あと何ですかね、法律の話とか出てくるじゃないですか。真面目な形だし。なんか逆に堅苦しい文章ばかりで余計分からないのに、さらに文章ばかりだと大変だなって感じなんですけど、これだと楽しく読めるし。絵が印象に残るから頭にも残る。*(Wellll, it's possible that I just enjoy reading manga more in general but the [important] points all just jump out at you and it's easier to absorb. (laughs) looks exactly the same UW (laughs)。And I wonder what else it is, well it is about the law, isn't it? And it's in this serious form as well. And there's already so many serious/formal sounding words that are hard to read and if that was all just text, I would feel like it would be a lot of work. If it's [a manga], I can read it more leisurely. The drawings would leave an impact on me so it's more likely to stay in my head.*

In this example of Tomoko above, she shared her positive reflections on her experience with the *manga*. Her responses with this second intervention tool was different from the text tool in that she shared a lot more comments and reflections around the *manga* itself. Moreover, she was also quick to point out familiar visuals in the *manga*, to highlight how she was engaged with the *manga* beyond just the narrative and information provided in positive ways. She was much more attuned to how the information was presented, which appeared to contribute to her overall positive experience. There was a lot more attention focused on different details, where Tomoko verbalized her responses out loud in a more enthusiastic way as she read through the *manga*.

Experiencing the tool through re-envisioning its possibilities

By looking at how parents interacted with the two tools, I took a Deweyan approach to examining how their experiences with an arts-based or aesthetic tool would compare with one that was purely text. One of the differences that was evident in how parent experienced the two tools was how they responded to the question in their first post intervention of what would make the tool better from their own perspectives. When comparing the initial responses of both parent groups to their respective tools, parents who read the *manga* version first provided richer, more elaborate examples of what would be useful information compared to the parents who read the text first. Parent in the *manga* group also shared how they felt the information should be presented (e.g. visual or not), so that it could address what they didn't know and where they felt they lacked knowledge.

For example, parent made several suggestions about incorporating more scenarios that would essentially "teach" parents what would be appropriate to say to teachers and schools, how to communicate that and essentially how to work more effectively by knowing the "social rules" of American cultural norms. Kazumi shared her cultural insight when she stated that Japanese parents would need to be told explicitly that it would be acceptable to disagree with teachers if necessary and what it would actually mean to be seen as an equal partner with schools. Both Kazumi and Manami also stated enthusiastically in this part of their interviews that they would like to have as many examples (scenarios) as possible so that they could be more (emotionally) prepared by knowing what to expect. Izumi suggested using flow charts and using decision trees to help parents understand the larger picture and roadmap of special education to advocate more effectively.

> うん。シナリオとかね。うん。そうそうそう。だからシナリオ、私の考え方では、シナリオは始めから終わりまで1つに続いていく方がいいんじゃないの？何か始めにこう、じゃ、これだったらシナリオは行くんだったら、私はもうcase study No.1。1 to 0、what--1 to 10まで行って、またcase study No.2。1 to 0って言った方が、「あー」というふうには思うけど。それか、それとあと、例えば、じゃ、decision treeみたいのを描いてくれたらちょっと見やすいかなと思って。（*Yes, definitely the scenarios. Yes yes. So with the scenarios, what I was thinking was that maybe it would be better if there was just one that you could follow from beginning to end. So at the beginning, you could, if you're going with that scenario, stick with it as a case one and present all the way from one to ten, and then case number two, from start to finish and I think that it will all make sense like an 'aha!" moment. Either that, or maybe in addition, there could be for example, a decision tree and that could make everything easier to see and understand, I think.* (Izumi)

> 本当に使ってもらおうと思うと、やっぱりなるべくそういうふうな、みんなでやっぱり1つの例じゃなくて、何？せっかくこれ、いいシナリオがあるから。じゃ、それ、でもこれは本当にもう4つだけのシナリオで、みんなに当てはまらないし。でもそうとなると、やっぱりそのプロセスのこれを元にできるものがあったら、「あ、こういう場合はこうしたらいいんだな」っていうようなのをくれるとすごく助かる。（*If you really want parents to be able to use this, if possible, instead of having each example with all these people, because you know, you have all these great scenarios already. And it's possible that not all parents will be able to relate to these four scenarios. But if that's the case, if there was a way to understand the process from the beginning, it would be so helpful because then you would think, "oh this is what I should do if I was in this situation.)* (Izumi)

There were also many suggestions about using visuals and images in different ways to highlight what were the most important things to know about American special education and how they were different from Japan. Junko shared some ideas of how to make information from the *manga* even more transparent for parents when she shared,

> なんか、こう、だから、コラムが2つあるみたいな。うん。で、シナリオの時は、この、絵の方を大きくなって、その、大きい部分に絵が来て、小さい方にキーポイントみたいなのが来るとかでもいいかもしれないですけど。どうだろう。*(You could maybe, you know, have two columns or something. Yes and when there is a scenario, make these drawings bigger and then using these drawings as the main part but also have a smaller section where you list out the key points of things to know. That could be really helpful, I think.)*

Parent had shared in their interviews that it was challenging to find information on special education that was also easy to understand. Thus, it made sense that Junko would suggest making the already existing information more transparent for parents to understand. By utilizing both drawings and also ways to highlight the main takeaway points, Junko felt that the tool had the potential to become a more powerful learning tool.

From the individual case descriptions, most parents had shared that they continuously faced challenges when knowing what to expect from theAmerican educational systems, especially in special education. Although some of the issues were structural problems, parents also stated that they often did not know how to take proactive steps in an American school setting. Given that the issue for most immigrant parents including Japanese parents was not having enough special education knowledge, as well as access to the cultural capital needed, highlighting these issues through using visuals and scenarios in a *manga* format provided an engaging experience for most Japanese parents that was also easy to read.

Moreover, another important affordance of *manga* over standard text was its ability to provide emotional support to parents, especially when dealing with unfamiliar situations and challenges with schools, IEP team meetings etc. Due to the fact that all parents had their own unique circumstances in addition to immigrating to the U.S., it is impossible to conclusively say that all Japanese parents would benefit in a similar way to the *manga* or text tools. However, the fact that the *manga* was seen as more emotionally supportive reveals how for these parents, knowledge and information were inextricably intertwined with social relationships. Thus, having a resource that was tailored to them not only as parent advocates but also as Japanese parents made their learning experiences more engaging overall. In this way, many parents expressed how having information in a visual format helped them to feel more emotionally ready as well. Thus, when learning about special education advocacy and the law, using *manga* was useful in not only conveying complex information in a more accessible way but also in providing some level of emotional support and validation to the parents who continue to advocate for their children with disabilities.

Chapter 6

Discussion

This comparative case study sought to explore how Japanese immigrant parents of children with disabilities experienced two different tools aimed at supporting their role as advocates for their children in special education. In order to understand how presentation of information can provide more meaningful learning experiences for these parents, I explored the affordances of using a nontraditional format such as *manga* over a standard text format. Results from parent interviews described how most parents had a more meaningful and engaged experience with the *manga* over the text version. However, their responses also revealed how they related to the tools in different ways. The following discussion section examines three themes across parent experiences and responses to both tools including: 1) Exploring emotional and intellectual responses to tools; 2) Connections between Dewey and parents' aesthetic experiences; and 3) Cultural aspects of parent experiences.

Experiences of tools: Emotional and intellectual parent responses

The interview data from both the individual case write ups and cross-case analysis revealed that parents found the *manga* to be more emotionally supportive and helped them to feel more (emotionally) prepared to navigate special education advocacy. This was evident from examples that parents shared where they stated that having a *manga* made the overall topic much more accessible and less intimidating to them, such as when Chiaki shared that she felt less isolated and more part of an "imaginary" community of Japanese families facing similar challenges together. Junko also shared that if she was going through a particularly difficult time with schools, she would also choose the *manga* over the text version for its ability to validate and acknowledge specific (parent) emotions and experiences. In contrast, parents who read the text first shared a more intellectual response around making sense of advocacy and special education.

Although parents who read the text first shared a slightly different and arguably less emotional perspective on their experience with the text tool, that was not to imply that the parents who read the text version did not respond in emotional ways to the tool. Both Chiaki and Natsumi described in their interviews how the narrative of the text tool helped them to understand advocacy on a much deeper level, which in turn helped them to connect emotionally with making sense of prior experiences that they had with schools. Although *manga* appeared to elicit stronger emotional responses from parents, the text version also helped parents in making emotional connections to what they knew and had experienced. Thus, both emotional and intellectual responses were present with how all eight parents experienced the two tools, where emotional responses were not simply restricted to just the *manga* and intellectual responses to just the text tool.

In fact, their overall feedback revealed how parents shared elements of being both emotional and intellectual, where parents shared more positive emotional responses overall with the intellectual content, especially when information was supplemented with visuals in a *manga* format. Without that visual element, parents appeared to rely more on their past experiences and their knowledge of special education in general to make sense of the intellectual content and how they responded to it (emotionally). For example, as a parent with more special education knowledge, Junko replied in a markedly different way from Tomoko, who in contrast, had shared that she had never given much thought to what it meant to have parent rights in the past. Both parents responded in emotional ways to the text version; however, Junko’s comments focused more on her frustrations with school districts and her perceptions on systemic issues around accountability, while Tomoko's comments focused more on what she could do differently with teachers and schools moving forward. Thus, how parents made meaning of their experience with the text tool appeared to depend more on who these parents were, what they had experienced in the past and what they understood about special education.

In this way, there were individual differences with how parents experienced the *manga* and text, which also spoke to how arts-based modes of knowing made a difference in their experiences overall. Similarly to Eisner (1985) , Bruner (1985) discussed how people generally had two main modes of thought, one relying on logical proof and empirically based truth (i.e. paradigmatic), and the other focusing more on stories that dealt with human intention and action (i.e. narrative). It appears that while there were also benefits to having a format that reflected a paradigmatic approach (text version), having a narrative approach provided more meaningful ways for Japanese parents to connect with the information overall.

Connections between Dewey and parents' aesthetic experiences

By examining the different forms of the tools, interviews revealed that parents were responding to the tools based on how information was presented through an aesthetic (or arts-based) format or through text alone. Both tools employed form in different ways, where as Eisner (1985) stated, "Whether collective or individual, the common function of the aesthetic is to modulate form so that it can in turn, modulate our experiences."

Parents consistently reported having more positive and meaningful experiences with the *manga* and that it was more emotionally accessible and relatable in comparison to the text tool. Given Dewey's (1934) theories on art as experience and with emotion being the "cement that holds the experience together," it was not surprising to find parents sharing stronger emotions overall with the *manga* compared to the text version. In fact, through Dewey's perspective, emotion was seen not only as the result (Hohr, 2010) but also a cause of the way they thought about their advocacy role and experiences in special education. From the interviews, it seemed that having visuals contributed to a much more satisfying experience for the parents, as they did not have to rely on the information alone to make sense of what they were reading. In this sense, having visuals appeared to add to the parents' experiences of the tools, as the arts-based format also elicited stronger emotional responses that in turn unified their overall experiences in a more cohesive way compared to the text tool. Even in cases where some parents such as Izumi pointed out what did not work for her in the *manga* (i.e. the tone of the narrative language etc), her responses overall reflected an emotional trajectory which despite any moments of doubt during her experience, was fulfilling for her in the end.

This is not to imply that parents did not have an aesthetic or emotionally satisfying experience with the text tool. The data suggested that parents still had meaningful experiences with the text tool, especially in cases where parents obtained more information and knowledge about special education that they previously did not know. Thus, the connections that parents were making in the present relied on their experiences of the past, which in effect, transformed their understanding of special education advocacy for the future.

Both Dewey (1934) and Eisner (1985) stated that all experience is the product of both the features of the world and one's relationship (to the different objects and events) within that world. Our experiences are influenced by our past, as it interacts with the present. This was evident with the parents of this study, as their knowledge of and experiences with special education in the past informed how they responded to the tools in the present. In addition, Eisner described how it would be critical for the viewer to have some level of competence to experience the form (of the tools), where the responses would likely vary from individual to individual. All parents in this study had prior experience in special education; they were all positioned to understand the information that was provided to them, where they responded in both similar and different ways. Based on parent responses, I would argue that all parents in this comparative case study had an aesthetic experience with the tools, according to Dewey (1934). Moreover, because the context was slightly different due to using specific tools, parents described their aesthetic experiences in different ways. Having an *manga*-based format proved to be useful for Japanese parents when learning about special education advocacy, as they shared that the visuals helped to enhance and intensify their overall experience.

Cultural aspects of using *manga* as an educational medium for Japanese parents

It was evident from the interviews and data analysis that culture played a significant role in how parents made sense of the information presented to them. The majority of parents also shared that they would prefer the *manga* due to their (cultural) familiarity with the medium. Given the widespread use of visuals and multimodal educational mediums in Japanese culture (Ito, 2005; Cohn, 2011), it made sense that parents would make more affirmative connections due to having more exposure to *manga* and other arts-based formats in general. The familiarity of the *manga* format, as well as the use of visuals to highlight information apparently made the experience for these parents more relevant. This was especially the case with how emotions were conveyed through the images and text used within the *manga* in culturally recognizable ways for Japanese readers as Bryce & Murakami (2004) described. Therefore, it is important to consider how Japanese parents might benefit from having information and resources that are not only in a visual/*manga* format but also culturally accessible through the ways information is presented; that take into account Japanese cultural perspectives of disability and considers what makes sense to a Japanese audience when speaking to the topic of disability, parent rights and special education.

Research on Japanese families with children in special education (both in Japan and in the U.S.) has consistently described how maintaining strong and harmonious relationships with professionals was generally the expectation and cultural norm of Japanese families (Lebra, 2004; Kayama, 2010; Kayama et.al., 2017). Parents in this study preferred information that depicted actual people, their feelings and how families navigated social relations with schools, in contrast to factual information about special education and the law. This was the case whether parents were reading the *manga* tool or text tool. Thus, it would be important to consider how culture and cultural perspectives around disabilities and special education can be taken up in creating resources that also address the cultural disconnect in parent advocacy.

In the parents' re-envisioning of the tools in their interviews, they shared how they wanted information that helped them to essentially access the cultural and social capital of American parents. In other words, they wanted to know appropriate ways to make requests or to communicate more effectively, to not only maintain positive relationships with their child's schools but to better understand the expectations of schools in relation to their own expectations. Because the cultural norms around parent-professional dynamics are different in Japan compared to the U.S., having information that could be broken down into specific phrases, questions and ways of communicating was what the parents shared would be most useful to them. This was in line with what Clark (2018) discussed with how 'culture' should be redefined for CLD parents to gain the appropriate knowledge and behavior skills to advocate. Knowing how to communicate and act with teachers and schools in ways that lead to maintaining positive relations require a certain type of social and cultural capital, as discussed by Clark (2018). The objective was not simply about getting facts and information on special education for these parents but also information about how to act on this information and the strategies needed to achieve results. Ong-Dean (2009) stated that without access to the appropriate social and cultural capital, parents would face challenges in advocating for their children with disabilities. In this sense, using *manga* as a medium to explore issues related to parent advocacy for this dissertation proved to be a step in the right direction. Having a *manga* and including scenarios within it made information much more accessible and easier to understand for Japanese parents. Thus, utilizing this *manga* format created more opportunities to focus on specific cultural issues for Japanese parents and to highlight the challenges of U.S. special education advocacy.

Limitations of the study

The first and most important limitation of this study focuses on the overall research design and methodology used. Because this area of American special education research on Japanese immigrant and Asian families in general is still relatively underrepresented and not well understood, it was imperative that I gained more insight into these issues first through an exploratory approach. This qualitative comparative case study design allowed me to go deeper into the experiences of Japanese parent advocacy in the U.S. through examining the ways that Japanese parents responded to different questions and tools around special education advocacy. While I was able to gain the needed insight into how these Japanese parents responded to these tools, it was impossible to capture everything through one qualitative comparative case study. Thus, follow-up qualitative studies would be needed to further explore this area of special education advocacy for Japanese immigrant parents of children with disabilities that go beyond case studies. Other qualitative research designs should be considered in order to better understand how these issues come together. In addition, understanding these issues through a quantitative design may also help to further establish causal relationships between the tools and the parents' experiences.

A second limitation of this study is that it focused only on the experiences of eight cases of Japanese immigrant parents of children with disabilities in the U.S. Because the sample sizes were small, these experiences may not be generalizable to other Japanese families in the U.S. Moreover, this study recruited parents who attended the same parent support group, *Himawari-kai*. Although having prior rapport with the mothers who participated in this dissertation study was not necessarily a limitation, it is possible that parents might not have felt as comfortable in sharing personal details about their children and family if they had not known me prior to the interview. Thus, it would be interesting to implement a similar study where Japanese parents with no previous connections to the researcher/interviewer are recruited and interviewed.

Another limitation of this dissertation was that it focused only on the experience of mothers. Understanding the roles and experiences of Japanese fathers could yield more insight into understanding parent advocacy for Japanese immigrant families. From the demographic surveys, many participants had indicated that they attended IEP team meetings with their spouses. Thus, it would be worth exploring how (immigrant) fathers are involved in the special advocacy process as well.

A fourth limitation was that interviews with parents consisted mainly of families of children with autism spectrum disorders and two with attention deficit hyperactivity disorder (ADHD). This was due to how parents were recruited (through snowball sampling), as the majority of parents who were connected to *Himawari-kai* knew each other and had children with autism and ADHD. This would limit the understanding of how Japanese parents of children with other more visible disabilities and chronic medical conditions might respond to the tools developed on special education advocacy.

The final limitation of this study was that parents were informed that I personally drew the *manga* illustrations as a part of this research study. Given that Japanese parents tend to be very respectful towards professionals as a way to maintain positive relations, there would be no way to determine how differently they might have responded to the tools, if they had been created by a different artist with no ties to the community.

Future directions for research

Future studies need to consider different approaches to understanding these issues, whether they be through follow-up qualitative studies or quantitative studies including more rigorous experimental designs. Future qualitative studies might also consider exploring these issues more longitudinally to examine how Japanese immigrant parents conceptualize and apply advocacy practices in special education. Addressing these issues through a mixed methods approach combining both qualitative and quantitative methods may also help to obtain more conclusive results that are based on both qualitative data, as well as reliable and valid measures.

Future studies should also include larger sample sizes of Japanese parents of children with a range of disabilities to understand how these families make sense of parent advocacy in special education using different mediums. In addition, it would also be interesting to explore how race and nationality may play a role in how Japanese parents in interracial/transnational marriages make sense of advocacy. It is worth noting that within this study, the mothers who were married to non-Japanese men shared more positive experiences and connections with the concept of advocacy, as they described their spouses providing a lot of emotional support in dealing with the cultural differences of Japan and the U.S.

Future qualitative research should explore developing more *manga*-based or visual resources for Japanese families navigating special education support. Moreover, such resources should not only be limited to helping Japanese families but also other immigrant families from diverse cultural and language communities. Although it might not work for all families across diverse cultural and language backgrounds, having different modes and mediums of information that are arts-based could make details much more understandable and accessible, especially for immigrant parents with less American cultural capital. It would be important to not only include visual aspects but to also consider the cultural perspectives of CLD families and to support them in understanding the cultural disconnect within the law and in accessing the cultural capital needed to advocate for their child in culturally responsive ways. By thinking more about culture at the forefront, future studies can investigate the possibilities of creating resources that would be engaging to other families of diverse cultural and language backgrounds and what we would need to know from a research perspective, in order to develop these resources.

Tapping into research around culturally sustaining pedagogy (Paris, 2012) could also provide a potential platform to consider what resources could look like for other communities as well. Developing such resources with different families and communities could also inform educators and professionals on what best practices can look like when supporting immigrant CLD families and their children with disabilities in special education.

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Appendix A

Table 1

Parent demographics of "manga" parent group

Survey items	**Parent 1**	**Parent 2**	**Parent 3**	**Parent 4**
Parent name	**Izumi**	**Manami**	**Kazumi**	**Yuki**
Child name	Yukio	Daisuke	Minoru	Mariko
Age of child	12	12	9	10
Sex of child	Male	Male	Male	Female
Diagnosis	ADHD	Autism	Autism & ADHD	Autism
Child's birthplace	WA	Japan	Japan	WA
Siblings	N/A	2 brothers	Brother/sister	Brother/sister
Years in US	30	5	5	18
Years in WA	30	5	5	15
Married to (husband race/ethnicity)	White American	Japanese	Taiwanese	Japanese
Primary caregiver	Mother/father	Mother/father	Mother	Mother
Father's educational background	HS diploma	BA	BA	MA
Mother's educational background	BA	HS diploma	BA	BA
Father's occupation	Bus driver	IT engineer	Accounting	Company
Mother's occupation	CPA & startup CEO	Housewife	Housewife	Housewife
Income	More than 100K	More than 100K	75-100K	More than 100K
Community	Suburban	Suburban	Suburban	Suburban
Language at home	Japanese & English	Japanese	Japanese & English	Japanese
How comfortable speaking in English?	Very	Not at all	Not really	No
Reading and writing in English?	Very	Not at all	Not really	No
Attend IEP meetings	Yes	Yes	Yes	Yes
Years receiving SPED	9	5	6	7
Satisfied with IEP	Yes, but can be improved	Unsure	Unsure	Yes
Comfortable speaking up at	Very	Not at all	Very	Comfortable

IEP team meetings				
SPED outside of US?	No	Yes	No	No
Knows sped laws?	Yes	No	Yes	Yes

Table 2

Parent demographics of "text" parent group

Survey items	**Parent 1**	**Parent 2**	**Parent 3**	**Parent 4**
Parent name	**Tomoko**	**Chiaki**	**Junko**	**Natsumi**
Child name	Risa	Kenji	Hitomu	Shun
Age of child	5	15	12	14
Sex of child	Female	Male	Male	Male
Diagnosis	Autism	Autism	Autism	Autism
Child's birthplace	WA	Japan	WA	Japan
Siblings	N/A	3 brothers	Sister	Sister/brother
Years in US	16	3	20	6
Years in WA	14	3	20	6
Married to (husband race/ethnicity)	Japanese	Japanese	White American	Japanese
Primary caregiver	Mother	Mother/father	Mother	Mother
Father's educational background	MA	BA	MA	MA
Mother's educational background	MA	BA	BA	BA
Father's occupation	Engineer	Technical manager	Sales	Sales
Mother's occupation	Housewife	Housewife	Elementary school staff	Housewife
Income	More than 100K	More than 100K	More than 100K	More than 100K
Community	Suburban	Suburban	Suburban	Suburban
Language at home	Japanese	Japanese	English	Japanese
How comfortable speaking in English?	So so	Not really	50-50	No
Reading and writing in English?	No language issues but other challenges	Not really	50-50	No
Attend IEP meetings	Yes	Yes	Yes	Yes
Years receiving SPED	2	3	8	6
Satisfied with IEP	No	Unsure	Unsure	Unsure
Comfortable speaking up at IEP team meetings	Comfortable	No	Comfortable	Comfortable

SPED outside of US?	No	Yes	No	Yes
Knows sped laws?	No	No	Yes	No

Appendix B

Interview protocols

Preamble: *I am interviewing Japanese parents of children with disabilities to better understand their experiences related to special education and the types of resources needed to support their child more effectively. The interview will be for 1-2 hours. I will be asking you about general questions about you and your family; your perspectives on disability; your positive and negative experiences with schools; knowledge about special education law and parent rights; and anything that you would like to share that is related to how you have learned to navigate special education services in the U.S..*

私は、障がいを持っている日本人のお子さんの保護者が、療育やお子さんのサポートにあったリソースを見つけるのにどのような経験をされてるかをより良く理解するためにインタビューを行なっています。このインタビューは１－２時間程度を予定しています。インタビューでは主に、ご家族に関しての質問や、お子さんの障害について、学校とのよかった経験・悪かった経験・Special Education に関する法律や保護者の権利についての知識・そしてアメリカで Special Education のサービスをうける中でどのようなことを経験・学んでこられたかについて伺いたいと思います。
また、インタビュー中にシェアしていただいた個人情報はすべて保護されることを保証します。

<u>Parent background and (cultural) perspectives of disability</u>

- Adjusting to and living in the U.S.
    - How long in the U.S.? Citizenship/PR status?
        - アメリカには何年お住まいですか？在住権はVISA、グリーンカードをお持ちですか？それとも市民権をとられましたか。
    - Family dynamics at home?
        - ご家庭の様子を教えてください。
    - Communication proficiency in English?
        - あなたは英語でのコミュニケーションが得意なほうですか？
    - Japanese community involvement vs non-Japanese community relationships?
        - こちらの日本人コミュニティーにどのくらい参加して／関わっていますか？
        - アメリカのコミュニティーにはどのくらい参加して／関わっていますか？
    - Cultural differences between Japan and U.S. in terms of how disability is seen?
        - アメリカ・日本とで障害に対して見解が違うと感じることはありますか? それはなぜですか？
    - Knowledge and openness of child’s disability and needs with other parents?
        - 他の保護者の方たちと話をすることはありますか？

        - ご自身は他の保護者の方たちに比べてお子さんの障害に関して話すのに抵抗がないほうだと思われますか？

<u>Experiences with special education & parent advocacy</u>

- What have your experiences been like in special education, especially in IEP meetings?
    - Special Education の経験について、特に IEP ミーティングなどでのこれまでの経験について教えてください。
- What is your relationship like with your child's IEP team?
    - お子さんの IEP チームとの関係について教えてください。
- What was your experience like when you first started attending IEP team meetings?
    - 最初の頃の IEP ミーティングはどのような感じでしたか？
- Example of something that went well with schools.
    - お子さんの療育について学校とうまくいったことのある経験についてお聞かせください。
    - Why did it go well? 何が上手くいきましたか。
    - What were your expectations as a parent? 親として何を学校に期待していましたか？
- Example of a challenge with schools　お子さんの療育について学校と上手く行かなかったことのある経験についてお聞かせください。
    - What happened? 何がありましたか。
    - What did you do to resolve the issue? どのように問題を解決しましたか。
    - How satisfied do you feel with how it was dealt? 納得のいく解決は得られましたか。
    - When faced with challenges with school, what is your general response with schools and why? 学校と問題があった時いつもどのように対応していますか？またそれはなぜですか。

- Any other examples? 他に何か学校との出来事で印象に残っていることはありますか。

Knowledge about IDEA and parent rights

- What do you know about U.S. special education law and how it relates to SPED services in general?
    - アメリカの療育に関する法律について知っていることをお聞かせください。
- Coming from a different cultural context, how do you feel when you hear that U.S. has a special education law?
    - アメリカに療育に関する連邦法（れんぽうほう）があることについてご存知ですか？また、そのような法律があることに関して、どう思われますか。
- What do you know about parent rights? If you don't know, what would be helpful for you to know?
    - 療育における保護者の権利についてご存知ですか？

  - ご存知でない場合、保護者の権利について疑問に思うこと、こういうことがわかると助かるというものはありますか？
- As a Japanese parent, what would be helpful to you in terms of understanding how special education works?
  - アメリカの療育について他の保護者が一番知っておくと良いと思うことはなんですか？
- When you hear the term, "advocacy" or "advocate" in special education, what do you think it means?
  - アドボカシ—またはアドボケートという単語をスペシャルエデュケーションの場で聞いたことはありますか？
  - ご存知の場合、他の日本人の保護者にアドボカシーについてどのようにどのように説明されますか？

Questions about comic or text tool (post-intervention)

- Tell me about your experience reading the comic/text booklet.
  - 資料を読んだ感想をお聞かせください。
- What did you learn that was new knowledge for you? What was the most surprising fact for you?
  - 資料を読んで、保護者の権利や法律について、何か新しい情報がありましたか？
  - 印象に残ったものはありますか？
- Was the format helpful for you to understand special education law and rights, as well as "parent advocacy"? If yes, why and how so? If not, explain.
  - 資料のフォーマットは「保護者によるアドボカシー」、そして療育に関する法律と権利について理解するのに役立ちましたか？
- Thinking about the future, do you think you will be able to apply what you learned from this resource to any real-life situations? Why or why not?
  - 資料を読んで得た知識で、今後役立つことはありましたか？またそれはなぜですか？
- Which images OR text had the most impact for you and why?
  - 資料の中の絵／文面で印象に残ったものはありましたか？それはなぜですか？
- What other information would be helpful to add to make this resource better?
  - 資料をより良いものにするために、こういう情報があったら良いと感じたものはありますか？

Is there anything that I did not ask that you would like to share?
質問で聞かれた内容の他にも何かご意見・感想がありましたらお聞かせください。

Appendix C


アメリカ特殊教育における
日本人家族の
ペアレントアドボカシー
ってから、から連絡がなかったのでませんでした。
は、CLD家族が学校とのやりとりで難として以下をあげています。
言葉の壁
常識・価値感の違い
何を期待すればいいのか
情報の不足
CLD家族の経験は、庭や英語のみ話すたものでした。
冒頭に触れた通り、１９７５年以前は、障害のある子どもの教育に関して
学校は一切の責任を持ちませんでした。
アメリカには特…関する法律がある…をご存知ですか？
ペアレントアドボカシーの研究では、学校・家庭間の５つのよくある問題が指摘されています。
隠れた問題
情報不足
真面目に取り合ってもらえない
コミュニケーション不足・脅迫
何を学校に期待すればいいのかわかんないので、大切な情報に当たるかどうかって本当に
「宝くじ」
みたいに感じます。
MOMS RULE
PROUD SPECIAL NEEDS MOM

インタビューに協力してくださった日本人家族の紹介

ケイコさん

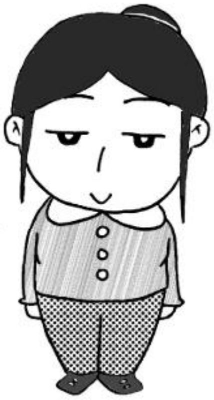
米国在住5年。
日本人の夫と二人の子供の４人家族。長男（７歳）が広汎性発達障害（PDD-NOS、現在の自閉症スペクトラム）の診断をアメリカに移住する前に受ける。
駐在のため日本に帰国予定。
英語の読み書きはできるけれど会話は苦手。

ありささん

米国在住17年。
アジア系アメリカ人の夫と長男の３人家族。
長男(16)はチック症の診断と自閉症スペクトラムの傾向がある。
家庭では夫が日本語を話さないため英語と日本語を普段から使っている。

まゆさん

米国在住17年。
アメリカ人の夫と二人の娘の４人家族。
長女(14)は5歳の時に発達性言語障害（Semantic-Pragramatic Disorder）の診断をアメリカで受ける。
療育をフロリダとワシントン州で受けた経験あり。
家庭内では英語が飛び交っています。



みさとさん

米国在住14年。
日本人の夫と３人の息子の５人家族。
成人した長男(21)は幼い頃に日本で自閉症の診断を受け、渡米前は日本で特別支援学級へ通学したことがある。
家庭では日本語で会話をする。

こんにちは。ワシントン大学教育心理学の博士課程に所属している大学院生の大森清香です。

日本生まれ、マレーシア育ち、そして在米20年になります。

ハワイとワシントン州で13年間障害者支援・特殊教育の現場で障害のある子ども、保護者、そして専門家と働いた経験があります。

その中でも特に、文化・言語が多様なCLDと言われる移民・難民系の家族のサポートを

アジア系移民のご家族を中心に行ってきました。

この冊子は日本・韓国からの移民の家族を対象に、

アメリカは日本と全然違いますね…

何がわからないかもわからないです。

アメリカの特殊教育を受ける中でどんな困難や壁にぶつかったかなどの経験をインタビューしわかったことをもとに作りました。

インタビューからわかった日本人家族の困りごと

学校側からの提案を基本的に尊重する

「多分これは私の文化だと思うんですけど、私のスタンスとしてはあんまり相手を否定することはしないです。尊重します。」

子どもの障害について知識がある保護者ほど、他の人にもオープンである

「私は別に普通に話しますよ。話しちゃった方が楽…最初から言っちゃいます。」

「共通点がなかったら特にそれ以上は話さないかもしれないですね。例えば、うちの子自閉症なんですよって言われたとして、あーそうなんですか、で終わっちゃうかもしれないですね。」

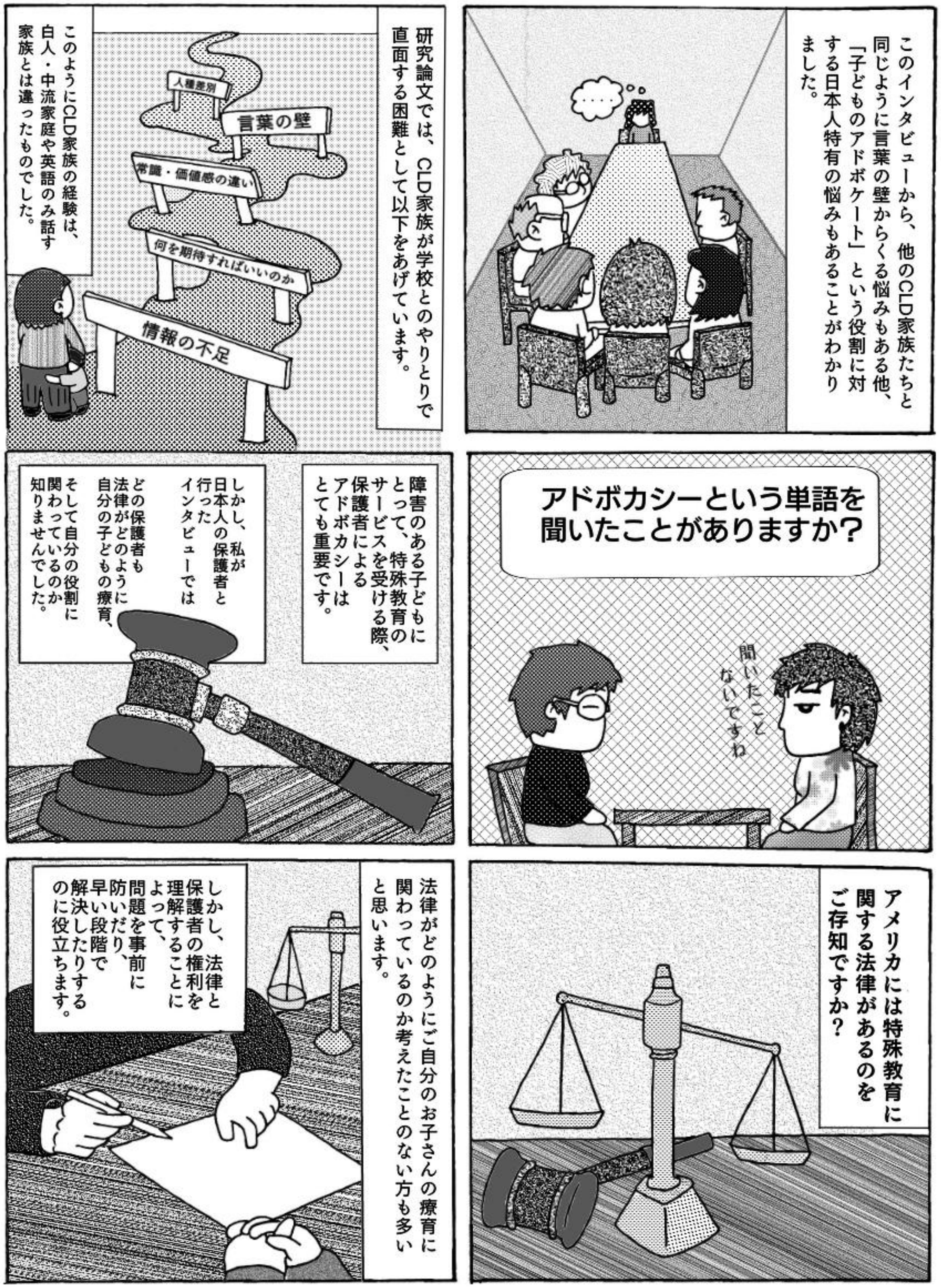
他の日本人で障害のある子を持つ家族との繋がりがとても大切

「同じ環境で障害のあるお子さんのお母さんたちとお話ししたり、まぁ、相談したり、日本語でお話できるそう言う環境はすごくありがたいな。」

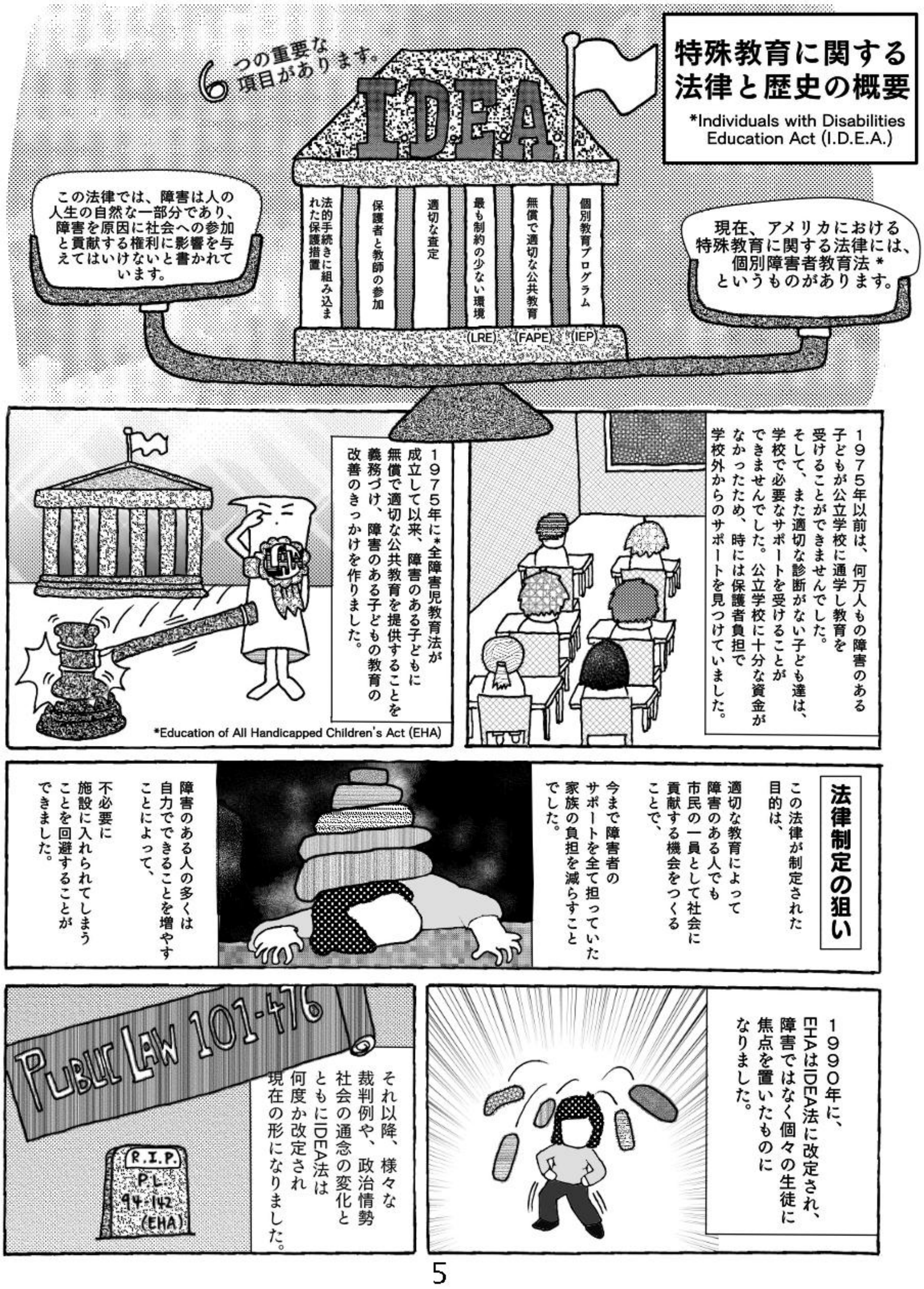
先生や専門家などとのコミュニケーションで言葉の壁を感じる

「やっぱり会って話すことが大事だったりとか、まあ電話の方がね、こう口調がちょっとね、伝わったりとか、するので。でもなんか、なんかしゃべれないし。そういうとこすごく、残念だなって思いますね。」

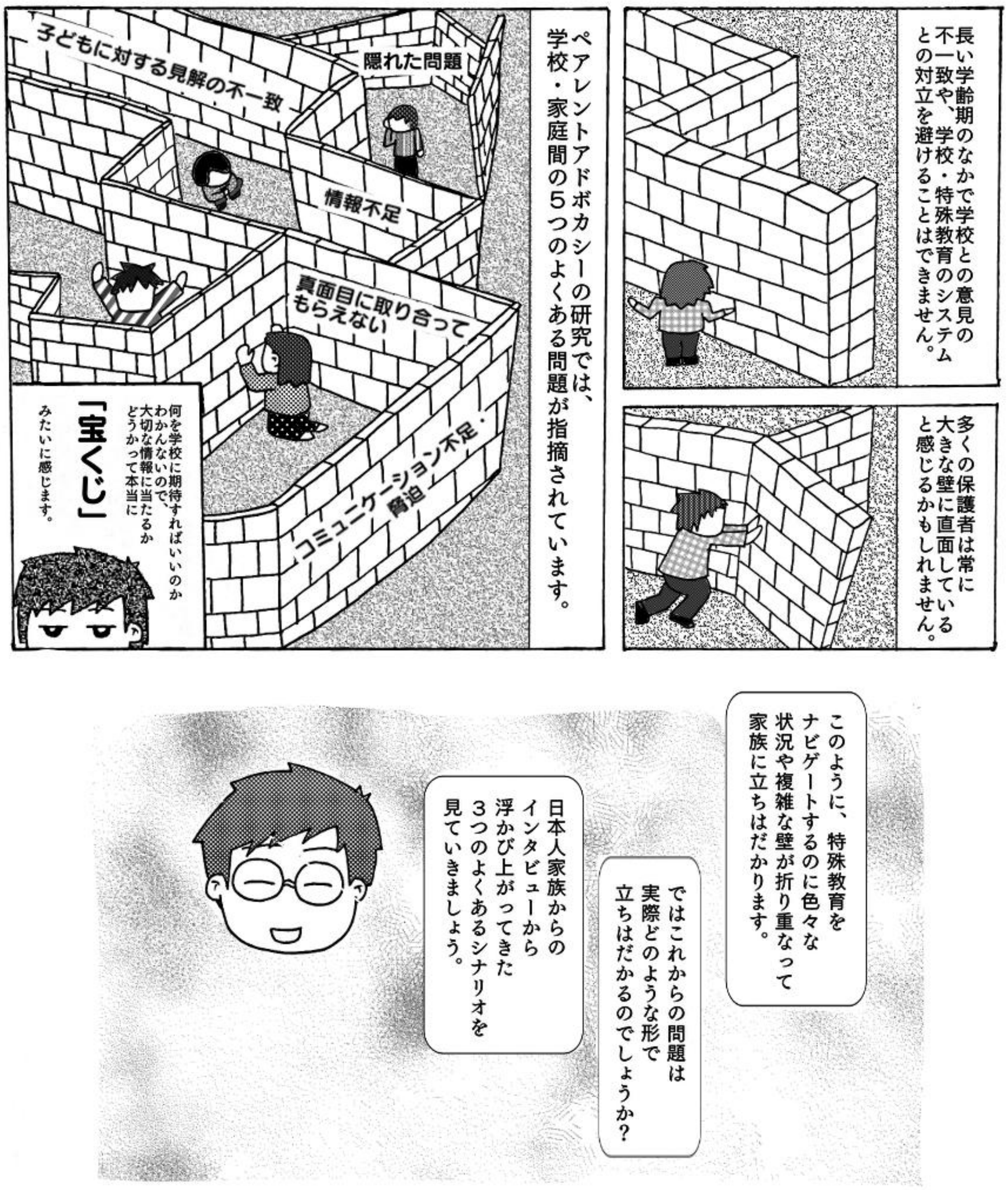
2


このインタビューから、他のCLD家族たちと同じように言葉の壁からくる悩みもある他、「子どものアドボケート」という役割に対する日本人特有の悩みもあることがわかりました。
研究論文では、CLD家族が学校とのやりとりで直面する困難として以下をあげています。
人種差別
言葉の壁
常識・価値観の違い
何を期待すればいいのか
情報の不足
このようにCLD家族の経験は、白人・中流家庭や英語のみ話す家族とは違ったものでした。
アドボカシーという単語を聞いたことがありますか？
聞いたことないですね
障害のある子どもにとって、特殊教育のサービスを受ける際、保護者によるアドボカシーはとても重要です。
しかし、私が日本人の保護者と行ったインタビューでは
どの保護者も法律がどのように自分の子どもの療育、そして自分の役割に関わっているのか知りませんでした。
アメリカには特殊教育に関する法律があるのをご存知ですか？
法律がどのようにご自分のお子さんの療育に関わっているのか考えたことのない方も多いと思います。
しかし、法律と保護者の権利を理解することによって、問題を事前に防いだり、早い段階で解決したりするのに役立ちます。


特殊教育においての「アドボカシー」とは？
保護者は子どもにとって一番身近なアドボケートです。
ADVOCATE（動詞）：～のために主張、弁護，代弁する
「アドボケート」
一番最初の先生
一番大事なロールモデル
誰でもアドボケートになることはできます。
父親・後見人里親・専門家や身近な人達も。
最善の利益を考えてくれる人
幸せをもたらしてくれる人
ADVOCATE（名詞）：主義や主張を擁護する人（例：平等権の擁護者）
英語のアドボケートが権利を主張し行使するのに対し、日本語に直訳すると権利を庇い守るというようにニュアンスが少し違うので違和感があるのも頷けます。
Advo...cate?
ん！辞書で引いてもいまいちよくわからないですね
保護者は子どもの一番の理解者です。
学校で関わる先生たちの多くは学年度によって変わりますが、
SCHOOL
保護者はお子さんの一生を通して関わります。
そのため、法律では保護者に子どもの教育に関する決定権を与えています。
子どもの教育に関する決定を積極的にすることで、保護者はアドボケートとしての役割を担います。
MOMS RULE
PROUD SPECIAL NEEDS MOM
子どもにとって良い教育を与えてあげることは将来にとっても大切なギフトとなります。
4


特殊教育に関する
法律と歴史の概要
*Individuals with Disabilities Education Act (I.D.E.A.)
現在、アメリカにおける特殊教育に関する法律には、個別障害者教育法＊というものがあります。
6つの重要な項目があります。
I.D.E.A.
個別教育プログラム
(IEP)
無償で適切な公共教育
(FAPE)
最も制約の少ない環境
(LRE)
適切な査定
保護者と教師の参加
法的手続きに組み込まれた保護措置
この法律では、障害は人の人生の自然な一部分であり、障害を原因に社会への参加と貢献する権利に影響を与えてはいけないと書かれています。
１９７５年以前は、何万人もの障害のある子どもが公立学校に通学し教育を受けることができませんでした。そして、また適切な診断がない子ども達は、学校で必要なサポートを受けることができませんでした。公立学校に十分な資金がなかったため、時には保護者負担で学校外からのサポートを見つけていました。
１９７５年に＊全障害児教育法が成立して以来、障害のある子どもに無償で適切な公共教育を提供することを義務づけ、障害のある子どもの教育の改善のきっかけを作りました。
EHA
*Education of All Handicapped Children's Act (EHA)
法律制定の狙い
この法律が制定された目的は、
適切な教育によって障害のある人でも市民の一員として社会に貢献する機会をつくることで、
今まで障害者のサポートを全て担っていた家族の負担を減らすことでした。
障害のある人の多くは自力でできることを増やすことによって、
不必要に施設に入れられてしまうことを回避することができました。
１９９０年に、EHAはIDEA法に改定され、障害ではなく個々の生徒に焦点を置いたものになりました。
PUBLIC LAW 101-476
それ以降、様々な裁判例や、政治情勢社会の通念の変化とともにIDEA法は何度か改定され現在の形になりました。
R.I.P.
P.L.
94-142
(EHA)
5


IDEAの信条は、障害のある子どもの教育を改善することによって、障害のある人たちへ平等な機会、完全な参加、そして経済的自立を確保することです。将来成人してなるべく自立し実りの多い生活に向けた準備を学生時代にすることを義務付けています。
IDEAは連邦法です。
連邦法に沿って各州が法令・規則を作成するため、同じ国内でも州により規則が違うことがあります。但し、州の法律が連邦法と矛盾する場合は、連邦法で定められている規定が優先されると憲法で定められています。このように法律のもと、障害のある子どもと保護者の権利が法律で守られているにもかかわらず、学校側には保護者にそれらを説明する義務がありません。その為、保護者が法律を知り、情報を集める必要があります。
アドボケートとしての保護者の二つの大きな目標
学校が子どもに無償で適切な公共教育（FAPE）を提供しているか見定めること。つまり、「個々の子どものニーズに沿った特殊教育および関連サービスを提供し、卒業後の高等教育、就職そして自立に向けた準備をサポートするもの」であるか
(20 U.S.C. 1400(d))
学校とより良い協力関係を築いていくこと…例えば、子どもが成功するために大切なものが学校と家庭双方の利益になるよう 尽力することです。
保護者がより良いアドボケートになるには？
正しい情報を収集する
正確な情報・独自に記録した証拠などを使い、学校との意見の不一致や論争を解決する。
事前に準備をする
地域の学区についての情報や規定などについて調べ、どのように学区全体の物事が決められ、誰によって最終決定されるかを知っておくと良い。
コミュニケーションは文書で行う
基本的にやり取りはメールで行い、コミュニケーションミスがあった場合はきちんと明確にする。ミーティングや協議した内容・大切な出来事などはノートなどに記録をとっておく。もし「言われたこと」が記録されていなかった場合、それは「なかったこと」になる。
わからないことは積極に質問し説明を求める
わからないことがある場合、問題を的確に伝えるために、保護者のために作られたペアレントアドボカシーの資料などから情報を集め具体的に伝わるようにする。
6


長い学齢期のなかで学校との意見の不一致や、学校・特殊教育のシステムとの対立を避けることはできません。
多くの保護者は常に大きな壁に直面しているかもしれません。
ペアレントアドボカシーの研究では、学校・家庭間の５つのよくある問題が指摘されています。
子どもに対する見解の不一致
隠れた問題
情報不足
真面目に取り合ってもらえない
コミュニケーション不足・脅迫
何を学校に期待すればいいのかわかんないので、大切な情報に当たるかどうかって本当に「宝くじ」みたいに感じます。
このように、特殊教育をナビゲートするのに色々な状況や複雑な壁が折り重なって家族に立ちはだかります。
ではこれからの問題は実際どのような形で立ちはだかるのでしょうか？
日本人家族からのインタビューから浮かび上がってきた３つのよくあるシナリオを見ていきましょう。


シナリオ1 ケイコさん
特に大変ってわけじゃないんですけど
毎朝ひろきを小学校に送って行くんですが、
たまに少しモヤモヤする事があるんです。
それは…
担任のミセステイラーとのコミュニケーション。
Good Morning!
グーモーニング
ひろきが何か迷惑掛けてないかなーとか思うんですけど、あまり英語を話すのは苦手です。
ひろきはとてもイイコよ！あっ、でも少し気になることがあった。メールするわね。
BYE
じゃ～
またメール
サンキューミセステイラー
またメールが来るまでドキドキして待たないと…
何かやらかしたのかな。
ドキドキ
ふぅー
でも、結構小さなことだったことが多いです。
帰宅後
16：00
ふ～～～～～っ
ご飯作るか
ダ～


夜十時
ひろきやっと寝たー
メール来てるかな…
ん？消しゴム口に入れる？
OT付けるかどうか見当しよう？
多分私ができないと思ってるから…すぐに後でメールするねって言うし
聞きたい事があったらメールで返してくれるけど
和英辞書
メールが返ってきたらなんか通訳を使ったりとか辞書とか調べたり…私もなんか多分変な文章だけど
ありがとう、これはこう思います
ってゆっくり時間をかければ返信する事ができるので…
普段はそんなに会話しないです。
なんで問題あった時に私に直接言わないでメールで来るんだろう。
送り迎え毎日行ってるのに…
言って欲しいけど、言ってもらっても、ちょっとわからないと思われてるんでしょうね。
これくらい我慢すればいいんでしょうけどね


シナリオ2・ありささん
うちの息子は基本通常学級で 1時間ほど スペシャルエドの サービズを受けてます。
ガサ ガサ
小学校の時は毎日送り迎えで 先生と話す機会があったんですけど、 高校ではまったくありません。
ん？ 学校から？
PROGR REPORT
MATHEMATICS F
English
Biology
エッ？
Fって何これ?!
高校に入ってから、 特に学校から連絡がなかったので 気がつきませんでした。
とか言って、16歳の息子に 「宿題やった?!」 「ちゃんと出した?!」 なんて聞いても煙たがられるので…
ただ、息子の特性として 学校を出たら学校関係のことが すっかり頭から抜けてしまうらしく、
どう対応したら いいのかわからず 見守ってます。


一応合理的配慮として何週間までなら提出しても良いことにはなっているし、
一限だけ特殊学級の先生に見てもらって宿題をやってその場で提出してはいるんですけど、
全科目分一時間では終わらないし。
下手すると三・四週間前のも見つかったりするんですよね。
でもこういうことこそ学校柄から連絡してくれないいんでしょうかね？
最初も息子になんで
特別支援サービスが必要なのとかも説明なかったんですけど
今も、手遅れになる前に連絡くれたらよかったのにとか思います。
この二つのシナリオで浮かび上がってきたこと
ありささんの場合 連絡の責任の所在が不明確 IEPのサポート特殊サービスがよくわからない。
ケイコさんの場合 学校の先生とのコミュニケーション 学校での子供の様子とIEPのゴールの進み具合
シナリオ3 ある日のサポートグループのミーティング
こんにちはー
あ、こんにちはお久しぶりです。
どの保護者も日本語で悩みを相談できることがとても大事だという話になり、
通訳の問題について話題になりました。


本当の通訳の方だったら、多分雇えないんですよ、うちのディストリクトは。
みさと
??
国際結婚して通訳してる方が多くてそういう方って日本語でしゃべる方が得意なんですよね。
私たちのこと聞いて、
英語に直すのはあんまり流暢じゃないっていう方も多いんですよね。
IEPミーティングで会話の内容理解するのとって、先生方や専門家の方の言っていることがわかる人でないと難しいですよね。
こんにちは あの、私もお話加わってもいいですか？
あ、どうぞどうぞ
今ねーちょうどいい
通訳さん見つけるのって大変ですよねって話をしてたところなんです
私の経験では、学区が手配してくれる日本語の通訳さんて、特殊教育とかIEPについて詳しいわけじゃなくって。
なんか ものすごいノート ぱっかりとる通訳さん とか
あの〜？ もしもし？
あ、私は医療通訳専門なんで っていう方とか
そっ??
先生方が長く喋ってたのにほんの少ししか訳してくれない人とか多くて
We are planning to...
and then...
〜です。
短くない?!


うちはラッキーなことに旦那の知り合いにアメリカ人の方で、日本語が上手な方がいて。
その方にずっとお願いしていたんですけど、同時通訳できるしちょっと高いんですよね。
1時間40ドル以上なので、
そうするとディストリクトとしてはちょっと払えないって言われて
自己負担してるんですよね〜
40ドル以上?! しかも自腹?!
大変ですねー
うちの場合主人がアメリカ人なんですけど、
私と彼で家庭で話してる時はわかるのにああいうIEPミーティングだと主人の言ってることもよくわからない感じだったんで。
おそらく使う単語が難しくて私がわからないと思うんですよね。
まゆさんの場合
これ思うんですけど背景知識の問題なのかなぁ
自分が得意分野の事は英語で話されてもわかるんです。
私が一人で参加すると私のレベルに先生が合わせてくれたので、おそらく使う用語とか全然違うと思うんですよね。
IEPについては、日本語でもわからないかも(笑)
そこなんじゃないかなと思います。
日本語でも英語でも、
わかんない世界の事はわかんないですよね。
情報とかもう少し手に入りやすくなればって思いますよね。
早く知ってたらよかったたって後悔したこともありますし。


本当そう思います。
いっつも出遅れてる気分になるんですよね。
Bye!
ミセステイラーとの事どうしたらいいかなぁ
うちの息子のことも、どうにかしたいけど自分一人じゃどう解決したらいいかわからないし
う〜ん
でもこうやってお母さん同士で悩みを相談できて助け合えるのっていいですよね。
いつも何か得られるものがあるし。
シナリオを通して日本人家族が直面する問題についてさらに知ることができたでしょうか？
みさとさんの悩み
的確な言語サポートや質のいい通訳の人材不足。
まゆさんの悩み
学校の先生・IEPチームの使うコミュニケーションスタイルが難しい。特殊教育の専門用語がわからない。

これらのシナリオを踏まえて、

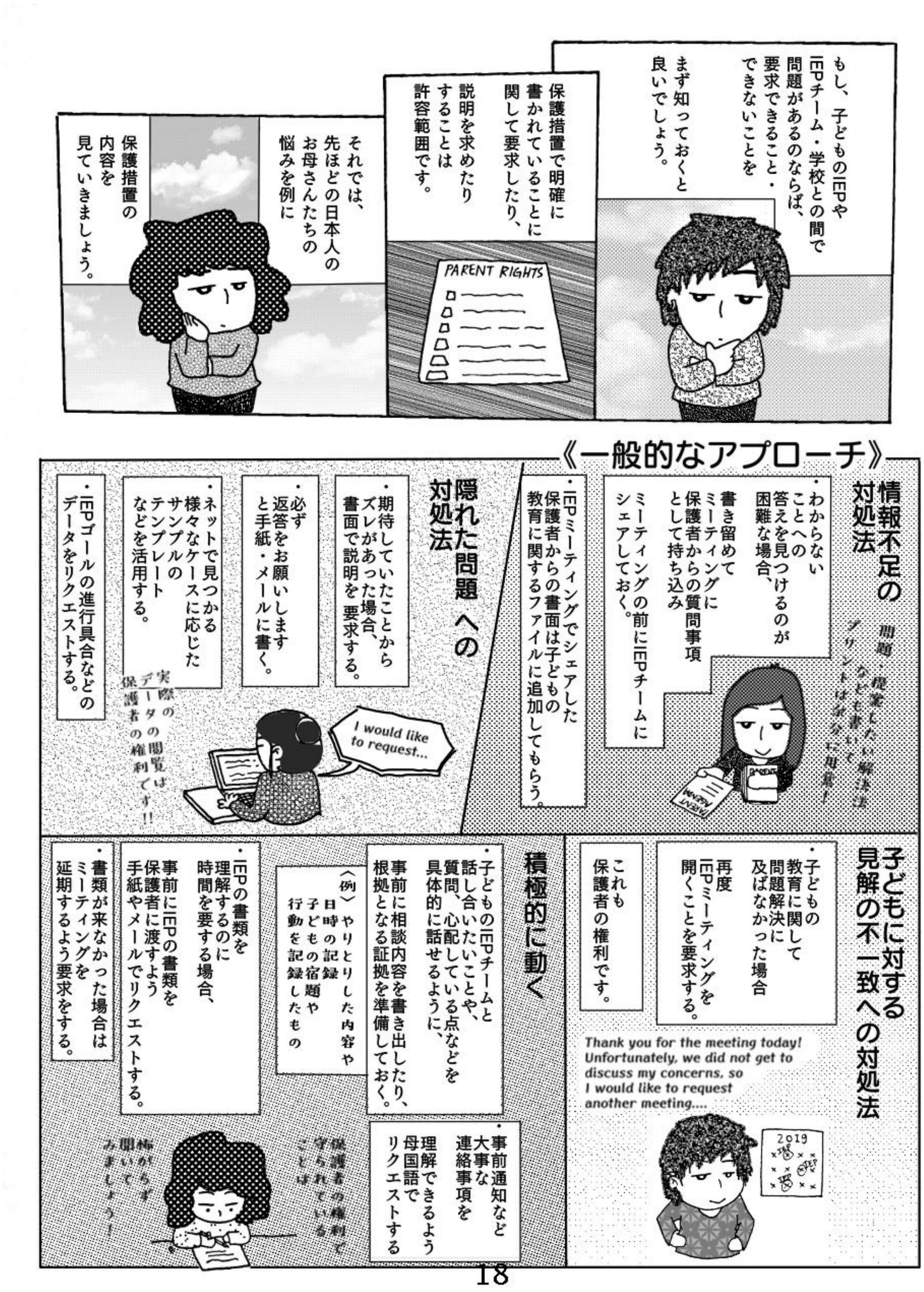
法的手続きに組み込まれた保護措置＊

に書かれている保護者の権利を読み解き、後ほどシナリオの解説をしたいと思います。

＊Procedural Safeguards


法的手続きに組み込まれた保護措置（以下、保護措置）は、唯一学校から保護者に手渡される書面です。
保護措置の意図とは?
子どもの教育に関する記録の開示を、保護者が学校に求める権利を守るため
子どもの診断、査定、そして教育のプレースメントを決定するためのミーティングに保護者が全参加する権利を守るため
学区の査定結果などに疑問・不服がある場合から学区から独立した機関による査定を受ける権利を守るため
子どもの無償で適切な公共の教育FAPEを約束するため
IDEA法は学校と家庭の間で問題が起きた際のガイドラインをこの保護措置で規定しています。
特殊教育では学校・家庭間の問題は様々な方法で解決されます。
＊IEPミーティングでの話し合い
＊州の教育機関に対する苦情
＊調停
＊聴問会
＊裁判所への告訴
ふむふむ
保護措置で守られている保護者の権利
文書による事前通知 (Prior written notice)
学校は子どもの教育に関わる決定事項がある場合、その決定事項が行使される前に文書による事前通知（以下、事前通知文書）を保護者に送付しなければならない
PRIOR WRITTEN NOTICE
学区が何を提案しているのか
提案に対する決定がなぜ採用または不採用にされたかの経緯に対する説明
学校は、保護措置の書かれた文書を以下の時に保護者に提供する義務があります。
最低一年に一度
IEPミーティングでの場合が多い
SEPT.
査定・アセスメントをするとき
子どもが特殊教育を受けるために必要な査定を、保護者または学校が要求した時
苦情申し立て
保護者が初めて障害などへの差別に対して苦情申立書を提出した時
CITIZEN COMPLAINT
聴問会
保護者から学年度に初めて聴問会を要求した時
停学
学校が学年度に障害のある子どもを懲罰として10日以上停学にする決定をした時


日本とは違い、最終決定は学校や先生だけではなく、平等なパートナーである保護者も含めて行います。
そのため、子供の査定やプレースメントの変更、IEPのゴールや決定・提案などに対し
Parent Consent 保護者の同意
PARENT SIGN:
Sign here!
平等な立場で同意をするというのはとても大事です。
IDEA法では、全ての保護者が障害のある子どものために積極的に参加をしアドボケートすることを前提としています。
しかし、多くの日本人の保護者は、学校側に意見することや、対等に関わることに抵抗を感じるかもしれません。
MOMS RULE
けれど、理解が必要なことは説明を求めることで情報を得られるきっかけになります。
何を質問したら良いかわからない場合は、学区に要求できることが書かれている保護措置を**ルールブック**として読んでみるといいと思います。
Consent 同意することについて
What is consent?
PARENTAL CONSENT CFR §300.4
このルールブックは基本的な学校の義務と要求できることなどが書かれており、保護者が学校と協力していくためにあるものです。
冒頭に触れた通り、１９７５年以前は、障害のある子どもの教育に関して学校は一切の責任を持ちませんでした。
現在、様々な権利が保障されていることによって、保護者が子どもの教育と将来のプランに対し意見をだし、IEPチームが提案した案件を承諾または拒否する力があるのです。


もし、子どものIEPやIEPチーム・学校との間で問題があるのならば、要求できること・できないことをまず知っておくと良いでしょう。
保護措置で明確に書かれていることに関して要求したり、説明を求めたりすることは許容範囲です。
PARENT RIGHTS
それでは、先ほどの日本人のお母さんたちの悩みを例に保護措置の内容を見ていきましょう。
《一般的なアプローチ》
情報不足の対処法
・わからないことへの答えを見つけるのが困難な場合、書き留めてミーティングに保護者からの質問事項として持ち込み
ミーティングの前にIEPチームにシェアしておく。
・IEPミーティングでシェアした保護者からの書面は子どもの教育に関するファイルに追加してもらう。
問題・提案したい解決法なども書いて
プリントは余分に用意!
PARENT
PARENT AGENDA
隠れた問題への対処法
・期待していたことからズレがあった場合、書面で説明を要求する。
・必ず返答をお願いしますと手紙・メールに書く。
・ネットで見つかる様々なケースに応じたサンプルのテンプレートなどを活用する。
・IEPゴールの進行具合などのデータをリクエストする。
実際のデータの閲覧は保護者の権利です!!
I would like to request...
子どもに対する見解の不一致への対処法
・子どもの教育に関して問題解決に及ばなかった場合再度IEPミーティングを開くことを要求する。
これも保護者の権利です。
Thank you for the meeting today! Unfortunately, we did not get to discuss my concerns, so I would like to request another meeting....
2019
IEP
積極的に動く
・子どものIEPチームと話し合いたいことや、質問、心配している点などを具体的に話せるように、事前に相談内容を書き出したり、根拠となる証拠を準備しておく。
〈例〉やりとりした内容や日時の記録子どもの宿題や行動を記録したもの
・IEPの書類を理解するのに時間を要する場合、事前にIEPの書類を保護者に渡すよう手紙やメールでリクエストする。
・書類が来なかった場合はミーティングを延期するよう要求をする。
・事前通知など大事な連絡事項を理解できるよう母国語でリクエストする
保護者の権利で守られていることは
怖がらず聞いてみましょう!
18

覚えておきたいこと

子どものアドボケートとしての役割の一部は、子どもの教育やIEPのサポートがうまくいってない場合、IEPメンバーの一員として学校に伝えることです。

みさとさん
～隠れた問題～

メールで通訳のクオリティについて問題があることを伝え（具体例があると良い）、IEPに「平等なパートナー」として参加することが難しいことを伝える 解決策を提示する。

〈例〉学校に違う通訳を見つけてもらう要求をする。
もし不可能な場合、自分で見つけた通訳を学校の負担で連れていく交渉をする。

提案を学校が拒否した場合、どのような経緯で提案を却下したのかの説明を書面で提示するよう求める。

ありささん
～サポートとニーズのずれ～

特別支援の先生とコミュニケーションをとる

宿題の提出に関する問題と、最近の成績に関して心配があることを伝える

一時間ある特別支援の時間でどのようなサポートを受けているのか具体的な説明を求める

IEPゴールの進み具合のわかるデータを要求し、必要に応じてゴールの見直しを要求・協議する準備をしておく

ケイコさん
～情報不足～

ひろきくんのIEPゴールの進み具合について質問・心配事を学校に書面で伝える 先生から問題行動（消しゴムを噛む）の対処としてOTをつける提案についての説明を求めてみる

IEPゴールの進み具合のわかるデータを要求する

フォローアップの質問などの準備もしておく

〈例〉消しゴムを噛見始めたのはいつからか？いつそういう行動に出るのか？どういう時に噛んでいるのか？
噛む理由はわかるか？OTをつけることによってどのようにこの問題行動に対処することになるのか？

など

まゆさん ～情報の不足～

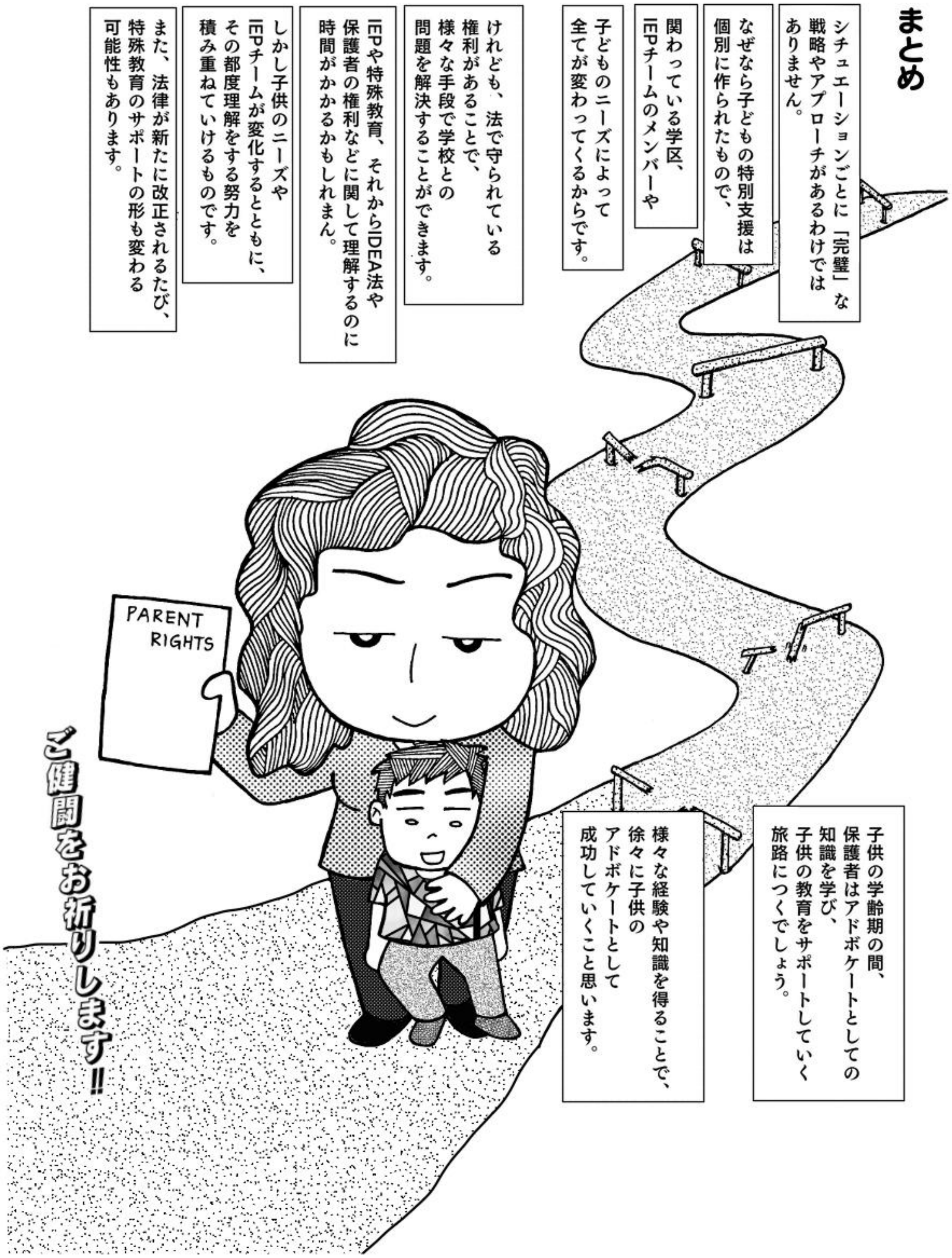
IEPの書類をミーティングの前に送ってもらうよう要求する。

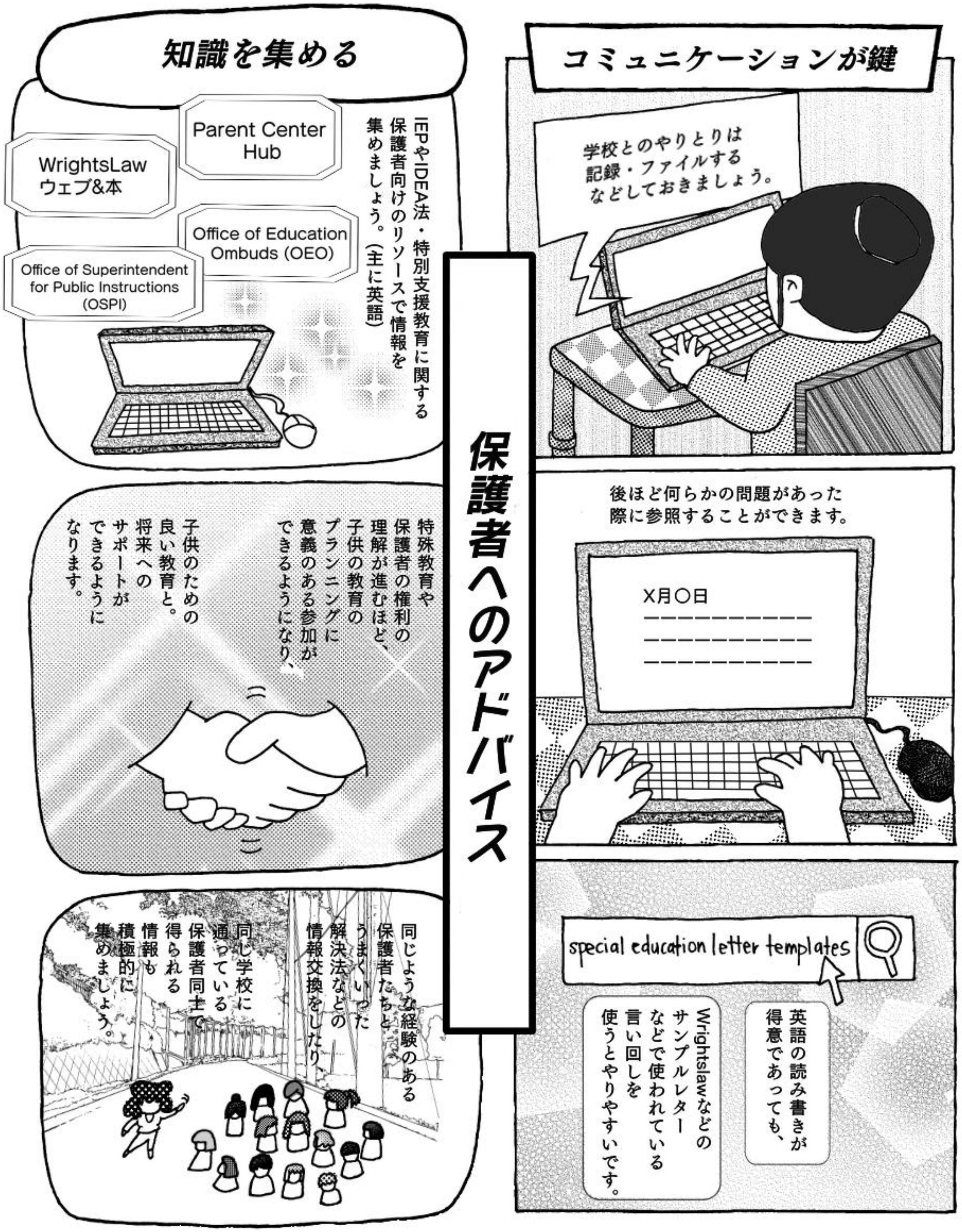
ミーティングの前までに質問事項や保護者視点で心配のあることなどのノートを取っておく。

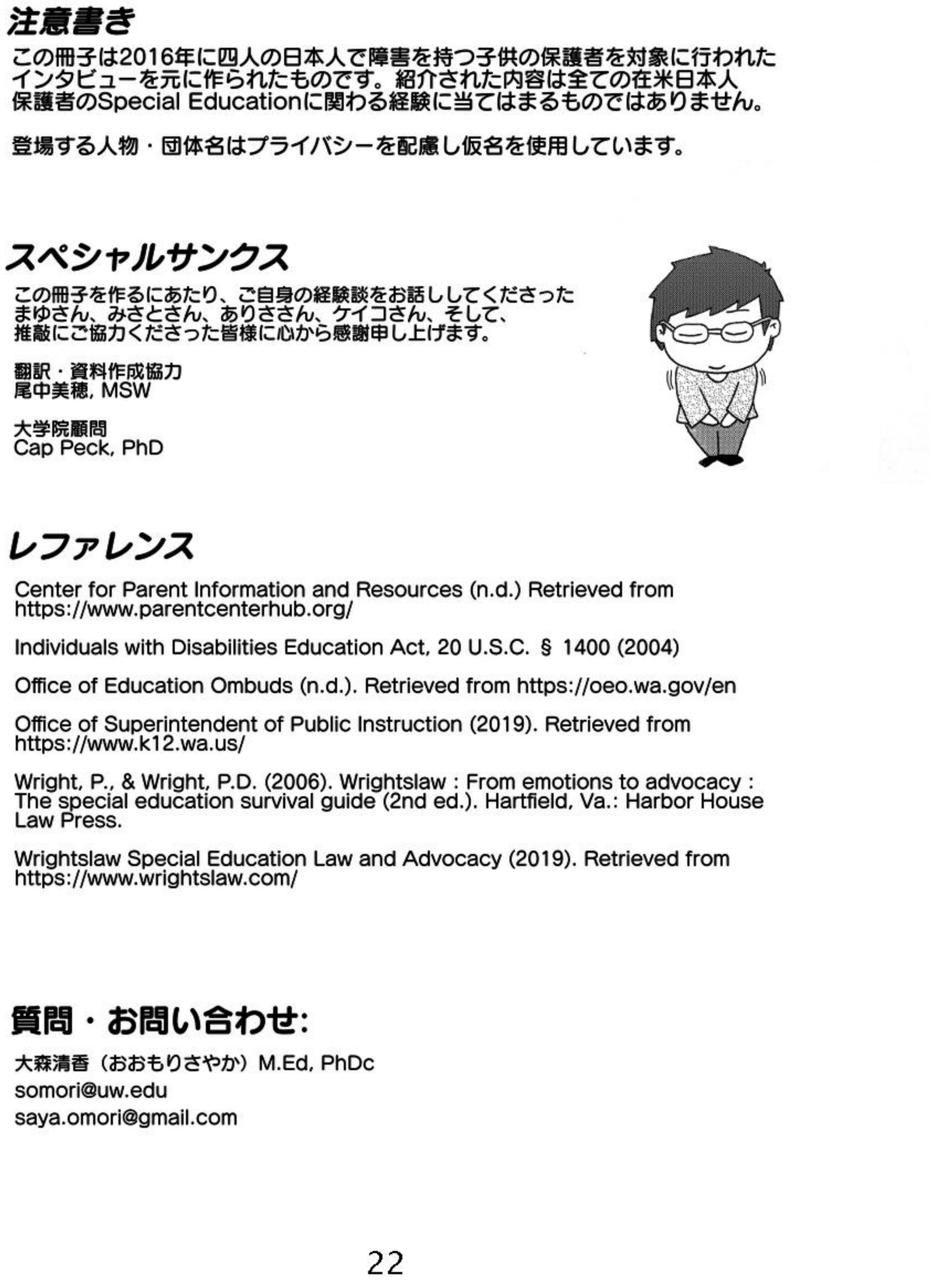
もしミーティングで使われる専門用語がわからない場合、事前にその旨を伝え、ミーティング時のサポートをリクエストする。

〈例〉専門用語などを使う際に書き出してもらい適宜説明を求める。

または、IEPミーティング中はゆっくり話してもらい、決定したことなどを最後に要約してもらう。


まとめ
シチュエーションごとに「完璧」な戦略やアプローチがあるわけではありません。
なぜなら子どもの特別支援は個別に作られたもので、
関わっている学区、IEPチームのメンバーや
子どものニーズによって全てが変わってくるからです。
けれども、法で守られている権利があることで、様々な手段で学校との問題を解決することができます。
IEPや特殊教育、それからIDEA法や保護者の権利などに関して理解するのに時間がかかるかもしれません。
しかし子供のニーズやIEPチームが変化するとともに、その都度理解をする努力を積み重ねていけるものです。
また、法律が新たに改正されるたび、特殊教育のサポートの形も変わる可能性もあります。
PARENT RIGHTS
子供の学齢期の間、保護者はアドボケートとしての知識を学び、子供の教育をサポートしていく旅路につくでしょう。
様々な経験や知識を得ることで、徐々に子供のアドボケートとして成功していくこと思います。
ご健闘をお祈りします!!


保護者へのアドバイス
コミュニケーションが鍵
学校とのやりとりは記録・ファイルするなどしておきましょう。
後ほど何らかの問題があった際に参照することができます。
X月〇日
special education letter templates
英語の読み書きが得意であっても、
Wrightslawなどのサンプルレターなどで使われている言い回しを使うとやりやすいです。
知識を集める
IEPやIDEA法・特別支援教育に関する保護者向けのリソースで情報を集めましょう。（主に英語）
Parent Center Hub
WrightsLaw ウェブ&本
Office of Education Ombuds (OEO)
Office of Superintendent for Public Instructions (OSPI)
特殊教育や保護者の権利の理解が進むほど、子供の教育のプランニングに意義のある参加ができるようになり、
子供のための良い教育と。将来へのサポートができるようになります。
同じような経験のある保護者たちとうまくいった解決法などの情報交換をしたり
同じ学校に通っている保護者同士で得られる情報も積極的に集めましょう。



注意書き

この冊子は2016年に四人の日本人で障害を持つ子供の保護者を対象に行われたインタビューを元に作られたものです。紹介された内容は全ての在米日本人保護者のSpecial Educationに関わる経験に当てはまるものではありません。

登場する人物・団体名はプライバシーを配慮し仮名を使用しています。

スペシャルサンクス

この冊子を作るにあたり、ご自身の経験談をお話ししてくださったまゆさん、みさとさん、ありさん、ケイコさん、そして、推敲にご協力くださった皆様に心から感謝申し上げます。

翻訳・資料作成協力
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レファレンス

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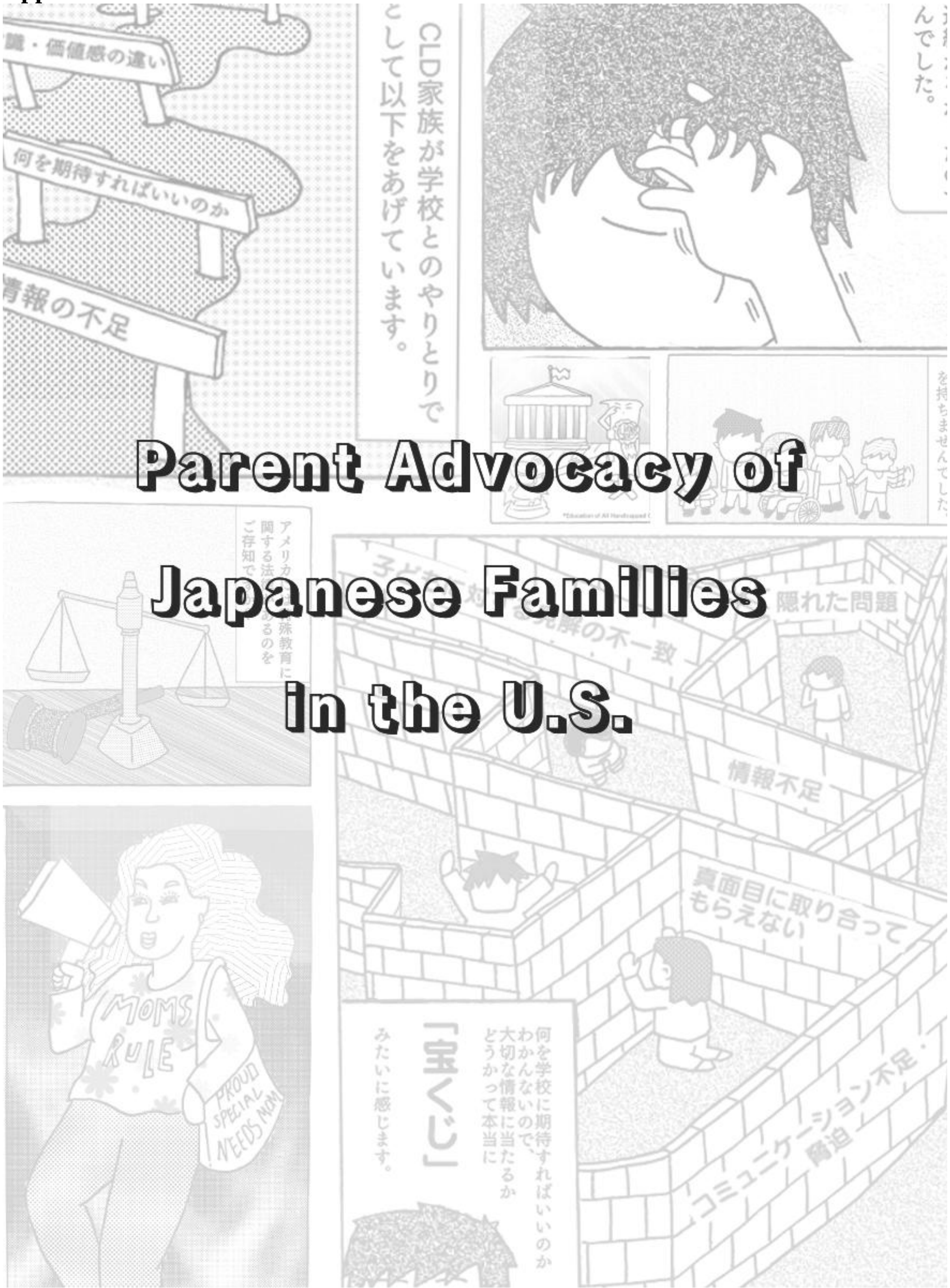
Appendix D


Parent Advocacy of Japanese Families in the U.S.
識・価値感の違い
何を期待すればいいのか
情報の不足
CLD家族が学校とのやりとりでとして以下をあげています。
んでした。
を持ちませんでした
*Education of All Handicapped C
アメリカ
関する法
ご存知で
殊教育に
あるのを
隠れた問題
見解の不一致
情報不足
真面目に取り合ってもらえない
コミュニケーション不足・脅迫
何を学校に期待すればいいのかわかんないので、大切な情報に当たるかどうかって本当に「宝くじ」みたいに感じます。
MOMS RULE
PROUD SPECIAL NEEDS MOM

Japanese Families who were Interviewed for this booklet

Keiko

Has lived in the U.S. for 5 years.
Married to a Japanese husband with 2 children.
Her 7-year old son was diagnosed with PDD-NOS (now Autism Spectrum Disorder) right before moving to the U.S.. The family is planning on moving back to Japan.
Can read and write in English, but is not confident in conversation.

Arisa

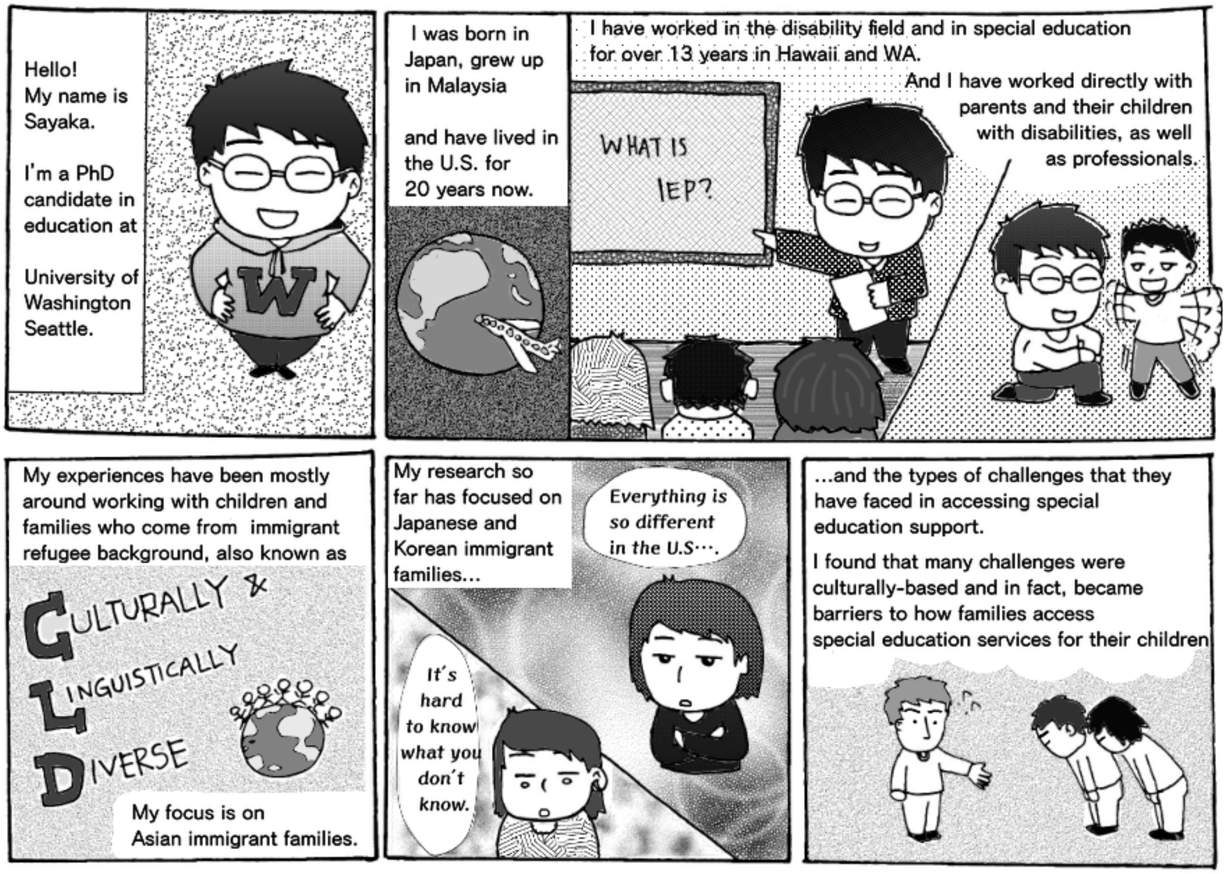
Has lived in the U.S. for 17 years.
Married to an Asian American husband and has a son (16) with a diagnosis of Tic disorder and ASD-like characteristics.
At home, conversations are mainly in English, but Arisa uses both English and Japanese with her son.

Mayu

Has lived in the U.S. for 17 years.
Married to a white American husband and has 2 daughters. Her older daughter (14) was diagnosed with Semantic-Pragramatic Disorder at age 5 in the U.S.
Her daughter has experience receiving Special Education services in different states.

Misato

Has lived in the U.S. for 14 years.
Married with a Japanese husband and 3 sons.
Her oldest son (21) received an autism diagnosis when he was back in Japan, and has experience receiving Special Education services in Japan.
The family speaks Japanese at home.



My prior research findings from interviews with Japanese immigrant families

1. Parents felt the need to be respectful to schools, no matter what.

"It's important in my culture to respect other person.

My approach is not to negate other's opinions, but accept them with respect."

2. Parents with a strong understanding of their child's disability and the needs were more open about their child' s disability.

"I usually tell people from the beginning. It's much easier that way."

"If I don't have a common ground, I probablly won't share much. For example, even if other mom shares 'oh my child has autism.' All I might say is 'oh is that so...' "

3. Connecting with other Japanese families is important.

"Being able to talk in Japanese with other moms with a child who has disabilities is really important.

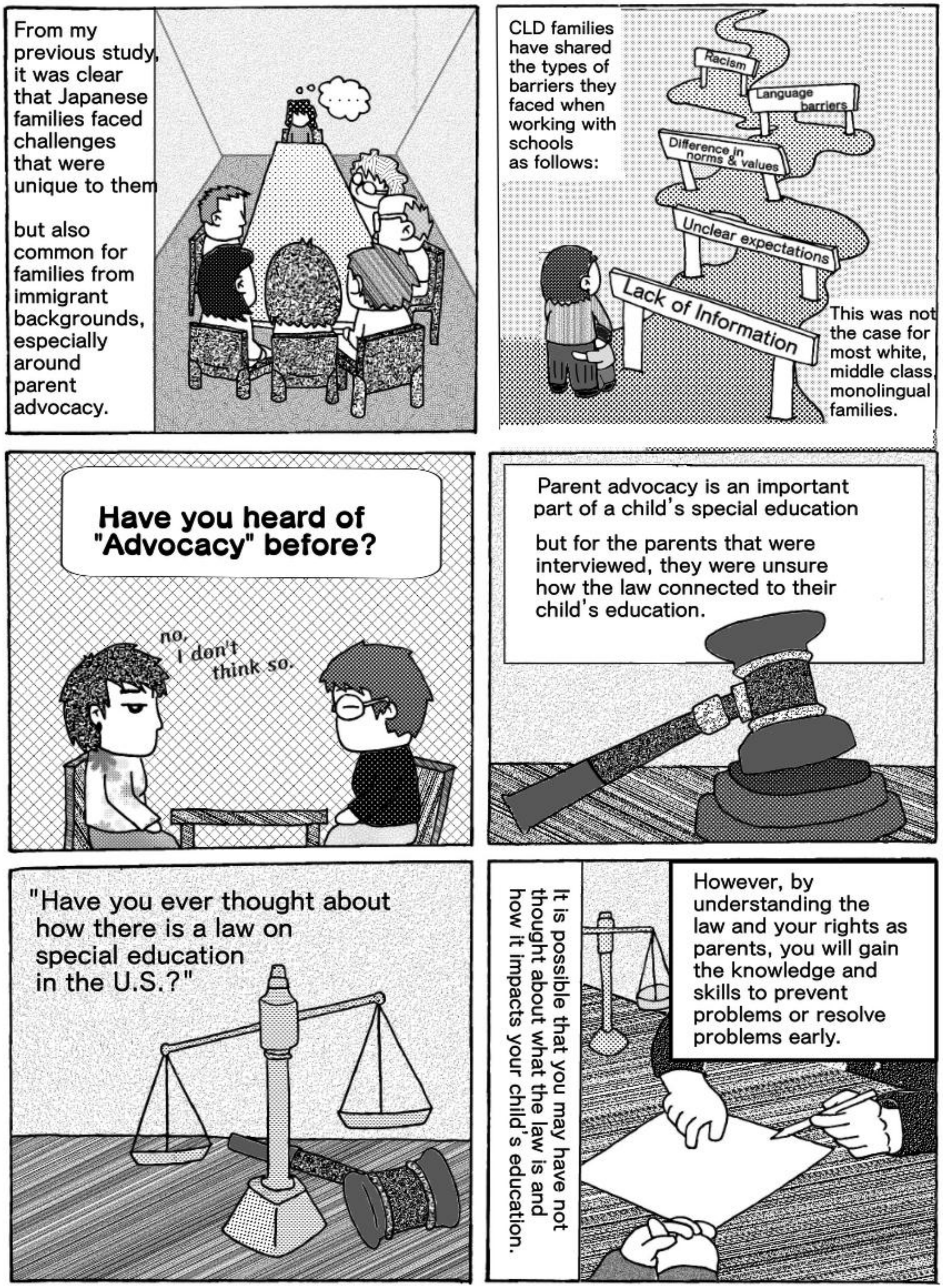
Like casual talk or getting advice/tips.

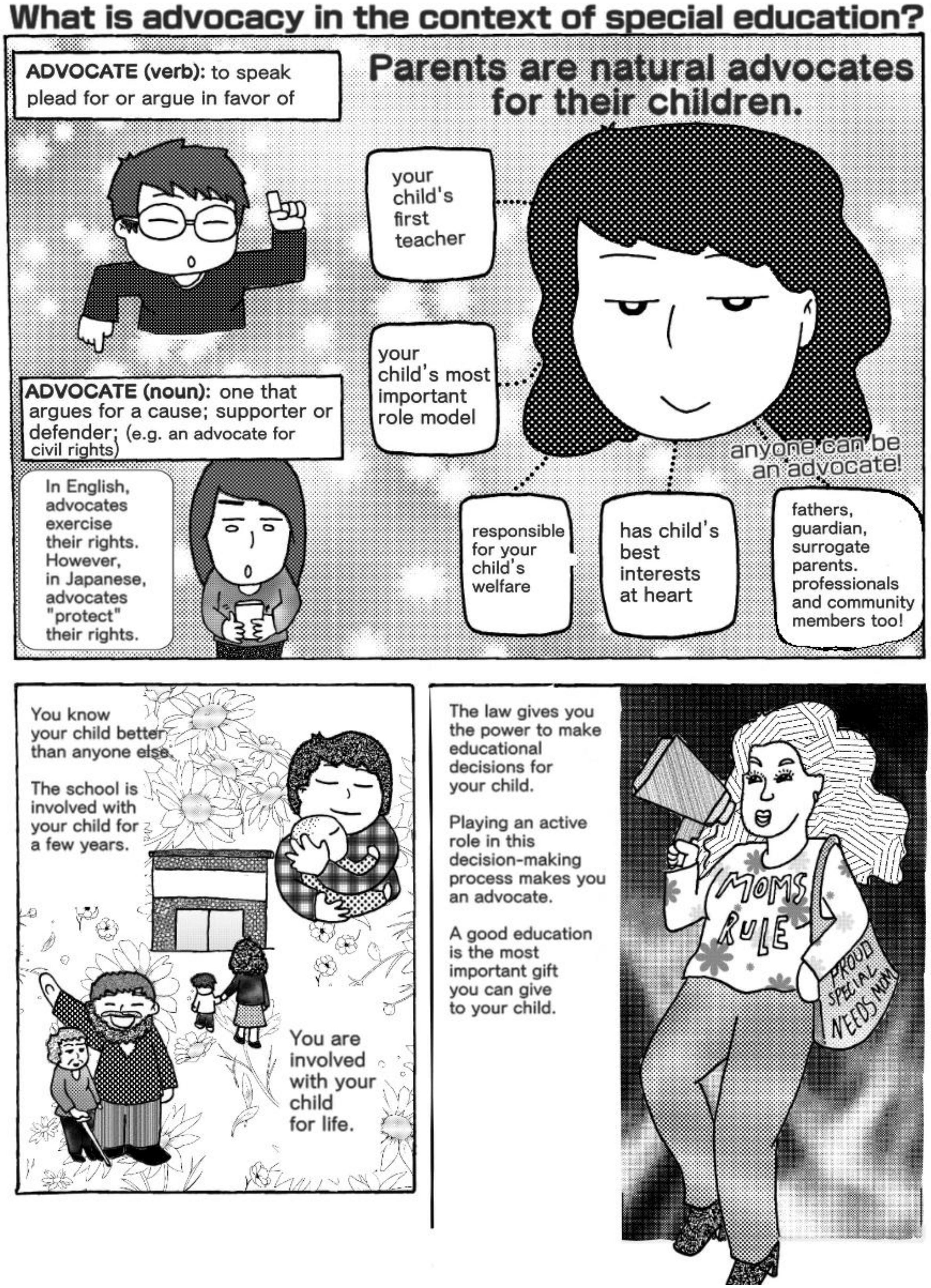
It's possible because we speak the same language and are also in similar situations.

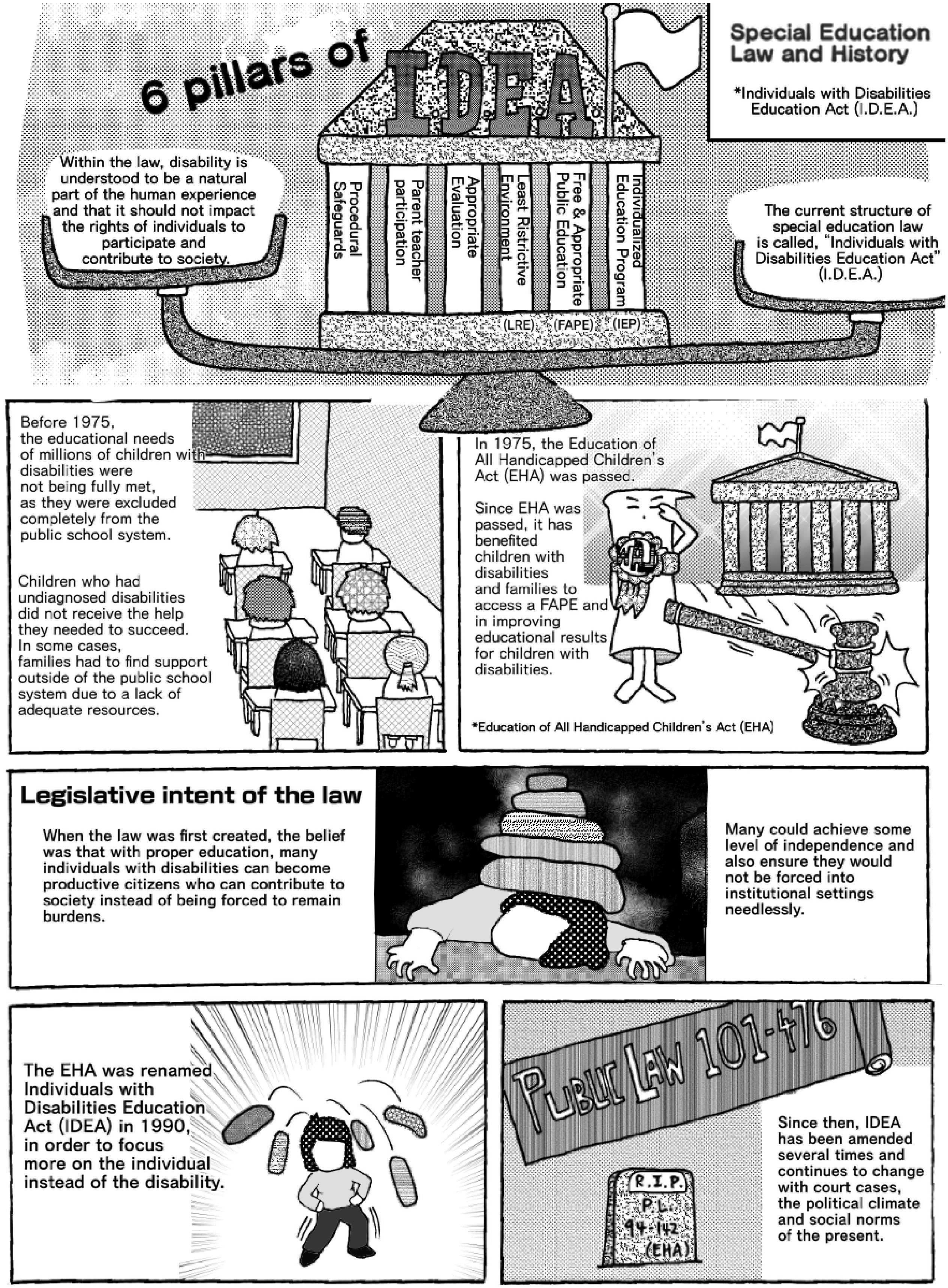
4. Communication with professionals was challenging, especially due to language barriers.

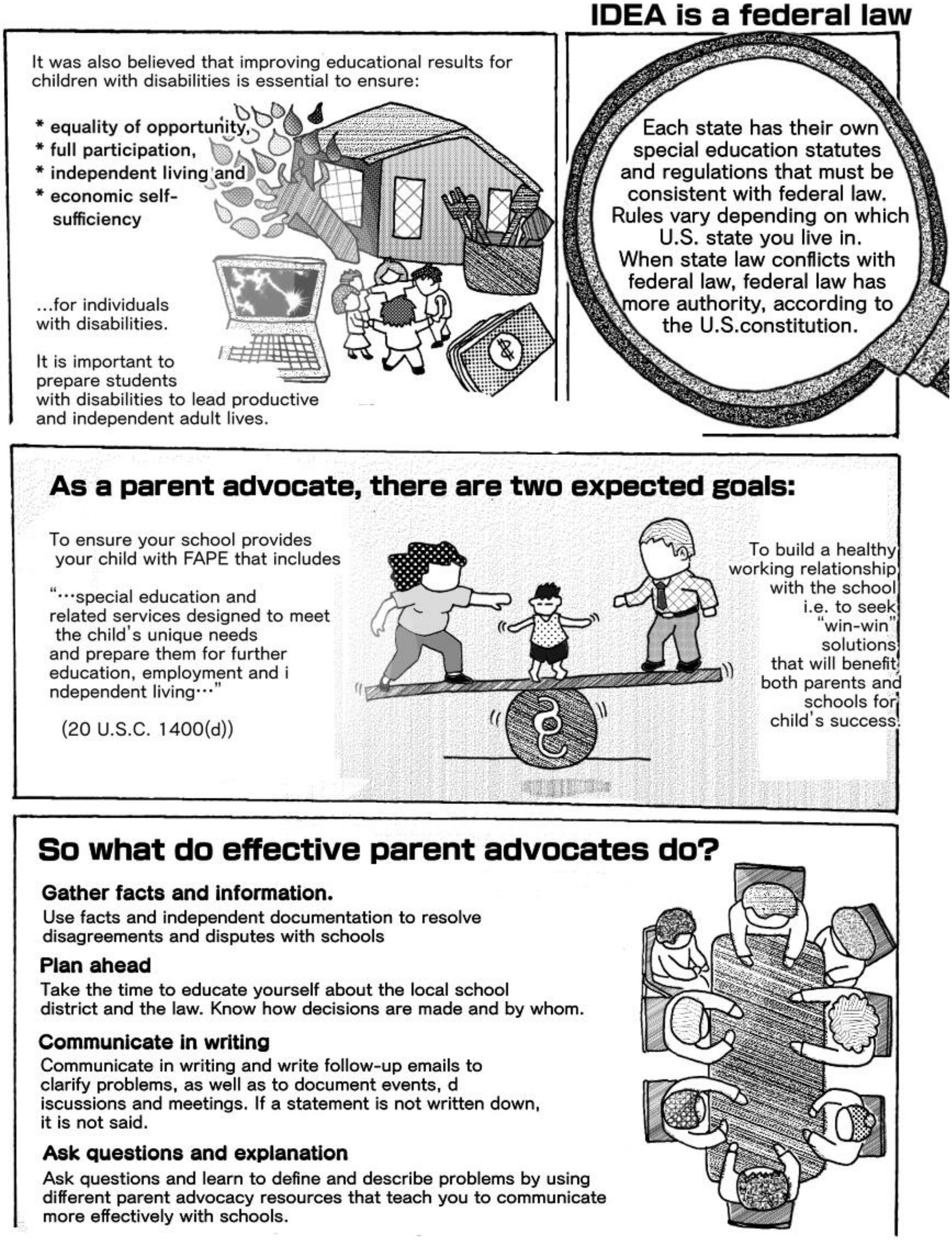
"It's really important for me to be able to meet in-person compared to over-the-phone, I can get more nuances too.

But in reality, it won't happen as often so I find it little disappointing."


From my previous study, it was clear that Japanese families faced challenges that were unique to them
but also common for families from immigrant backgrounds, especially around parent advocacy.
CLD families have shared the types of barriers they faced when working with schools as follows:
Racism
Language barriers
Difference in norms & values
Unclear expectations
Lack of Information
This was not the case for most white, middle class, monolingual families.
Have you heard of "Advocacy" before?
no, I don't think so.
Parent advocacy is an important part of a child's special education
but for the parents that were interviewed, they were unsure how the law connected to their child's education.
"Have you ever thought about how there is a law on special education in the U.S.?"
It is possible that you may have not thought about what the law is and how it impacts your child's education.
However, by understanding the law and your rights as parents, you will gain the knowledge and skills to prevent problems or resolve problems early.


What is advocacy in the context of special education?
ADVOCATE (verb): to speak plead for or argue in favor of
Parents are natural advocates for their children.
your child's first teacher
your child's most important role model
ADVOCATE (noun): one that argues for a cause; supporter or defender; (e.g. an advocate for civil rights)
In English, advocates exercise their rights. However, in Japanese, advocates "protect" their rights.
responsible for your child's welfare
has child's best interests at heart
anyone can be an advocate!
fathers, guardian, surrogate parents. professionals and community members too!
You know your child better than anyone else.
The school is involved with your child for a few years.
You are involved with your child for life.
The law gives you the power to make educational decisions for your child.
Playing an active role in this decision-making process makes you an advocate.
A good education is the most important gift you can give to your child.
MOMS RULE
PROUD SPECIAL NEEDS MOM


Special Education Law and History
*Individuals with Disabilities Education Act (I.D.E.A.)
6 pillars of IDEA
Within the law, disability is understood to be a natural part of the human experience and that it should not impact the rights of individuals to participate and contribute to society.
Procedural Safeguards
Parent teacher participation
Appropriate Evaluation
Least Ristrictive Environment (LRE)
Free & Appropriate Public Education (FAPE)
Individualized Education Program (IEP)
The current structure of special education law is called, "Individuals with Disabilities Education Act" (I.D.E.A.)
Before 1975, the educational needs of millions of children with disabilities were not being fully met, as they were excluded completely from the public school system.
Children who had undiagnosed disabilities did not receive the help they needed to succeed. In some cases, families had to find support outside of the public school system due to a lack of adequate resources.
In 1975, the Education of All Handicapped Children's Act (EHA) was passed.
Since EHA was passed, it has benefited children with disabilities and families to access a FAPE and in improving educational results for children with disabilities.
*Education of All Handicapped Children's Act (EHA)
Legislative intent of the law
When the law was first created, the belief was that with proper education, many individuals with disabilities can become productive citizens who can contribute to society instead of being forced to remain burdens.
Many could achieve some level of independence and also ensure they would not be forced into institutional settings needlessly.
The EHA was renamed Individuals with Disabilities Education Act (IDEA) in 1990, in order to focus more on the individual instead of the disability.
PUBLIC LAW 101-476
Since then, IDEA has been amended several times and continues to change with court cases, the political climate and social norms of the present.
R.I.P.
P.L. 94-142
(EHA)



It was also believed that improving educational results for children with disabilities is essential to ensure:

- equality of opportunity,
- full participation,
- independent living and
- economic self-sufficiency

…for individuals with disabilities.

It is important to prepare students with disabilities to lead productive and independent adult lives.

IDEA is a federal law

Each state has their own special education statutes and regulations that must be consistent with federal law. Rules vary depending on which U.S. state you live in. When state law conflicts with federal law, federal law has more authority, according to the U.S.constitution.

As a parent advocate, there are two expected goals:

To ensure your school provides your child with FAPE that includes

"…special education and related services designed to meet the child's unique needs and prepare them for further education, employment and independent living…"

(20 U.S.C. 1400(d))

To build a healthy working relationship with the school i.e. to seek "win-win" solutions that will benefit both parents and schools for child's success.

So what do effective parent advocates do?

Gather facts and information.

Use facts and independent documentation to resolve disagreements and disputes with schools

Plan ahead

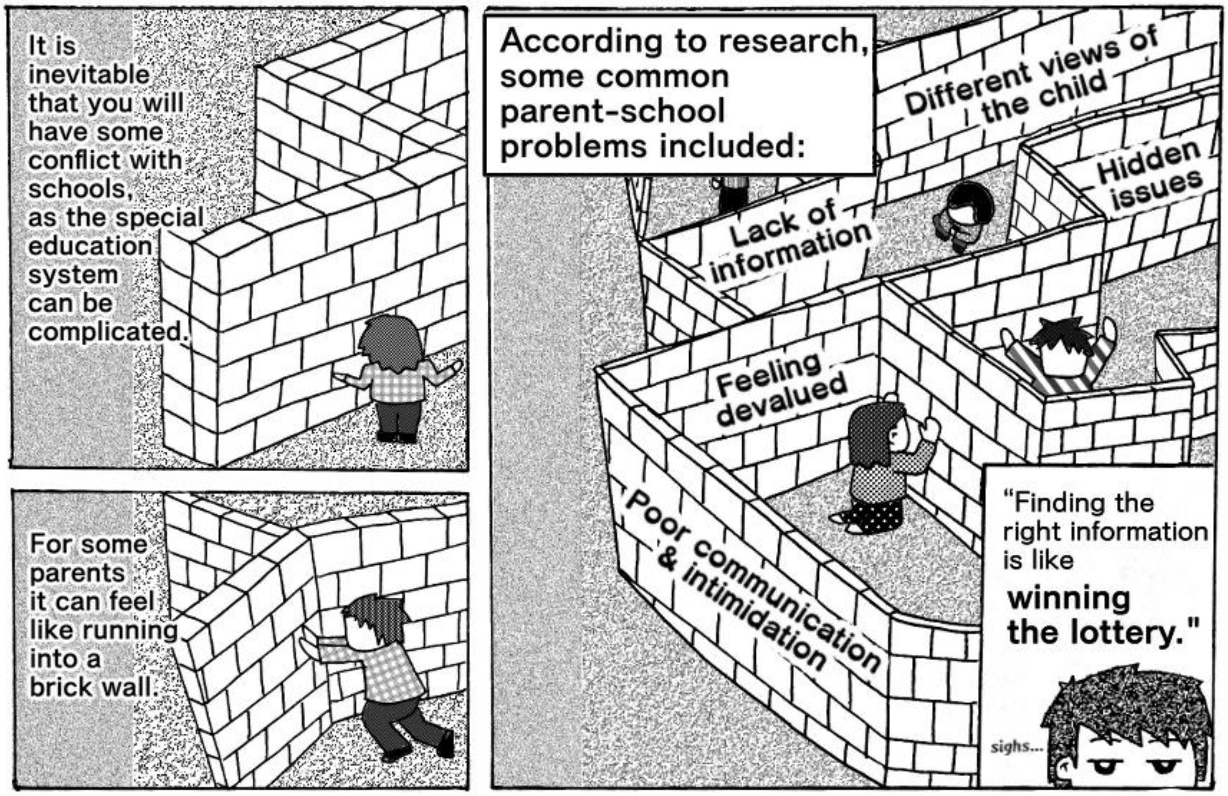
Take the time to educate yourself about the local school district and the law. Know how decisions are made and by whom.

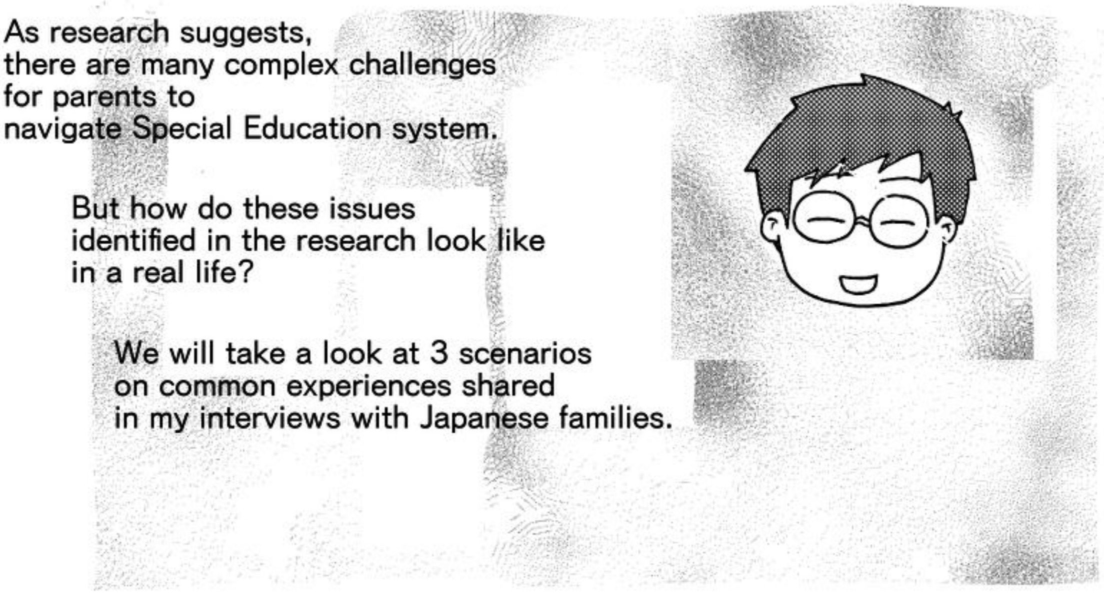
Communicate in writing

Communicate in writing and write follow-up emails to clarify problems, as well as to document events, discussions and meetings. If a statement is not written down, it is not said.

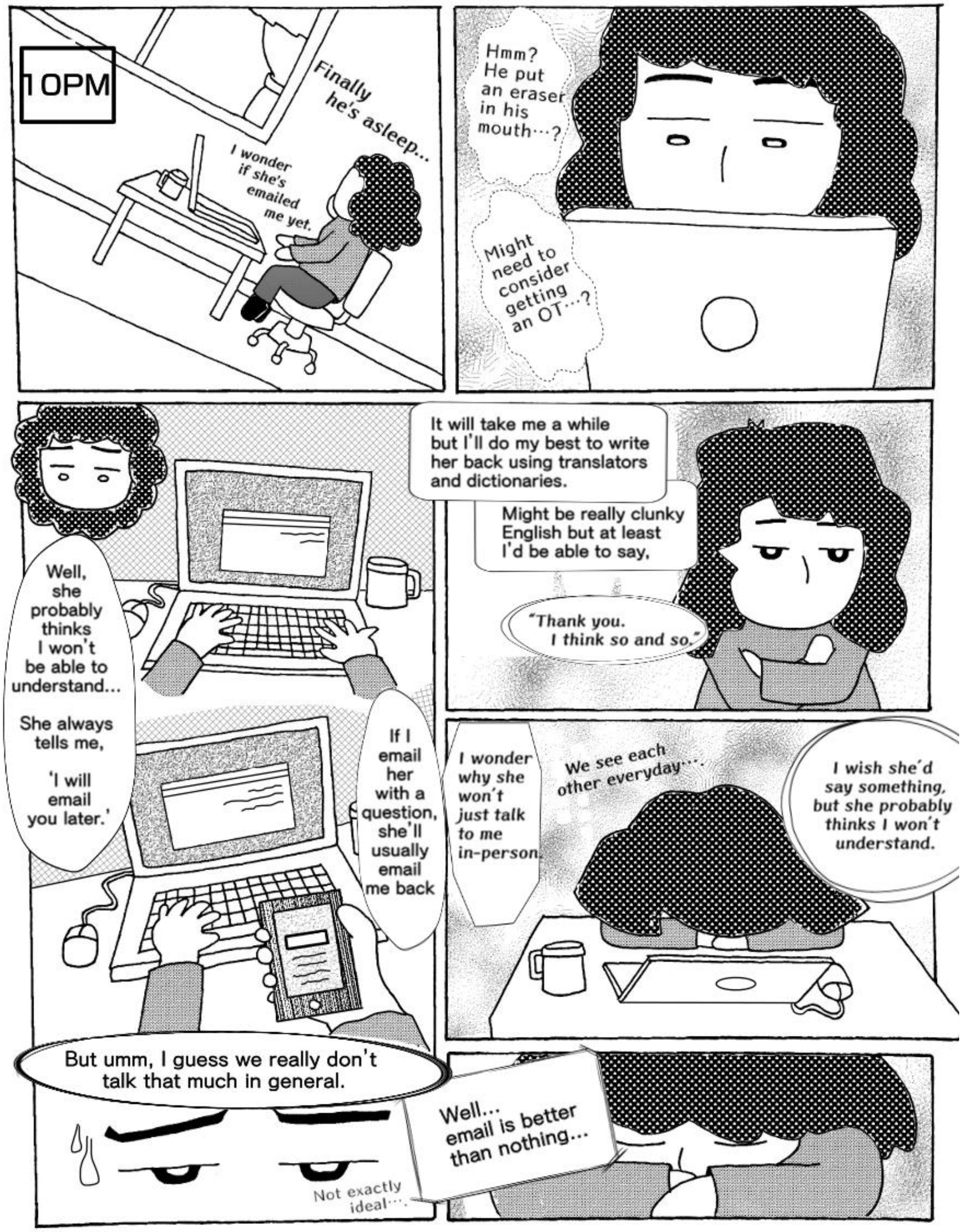
Ask questions and explanation

Ask questions and learn to define and describe problems by using different parent advocacy resources that teach you to communicate more effectively with schools.

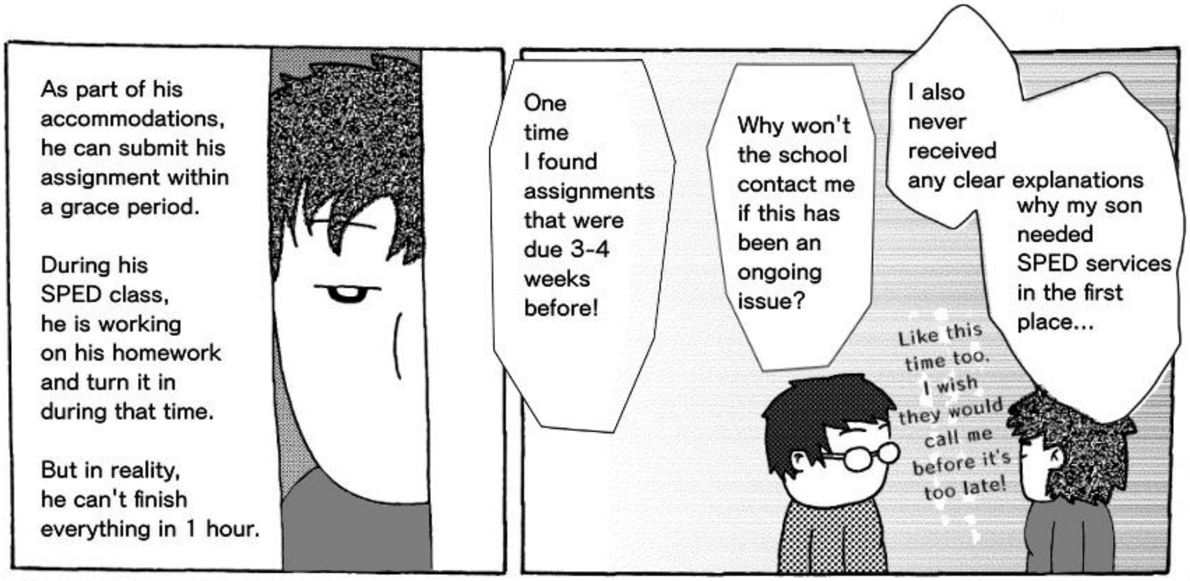

It is inevitable that you will have some conflict with schools, as the special education system can be complicated.
For some parents it can feel like running into a brick wall.
According to research, some common parent-school problems included:
Different views of the child
Hidden issues
Lack of information
Feeling devalued
Poor communication & intimidation
"Finding the right information is like winning the lottery."
sighs...

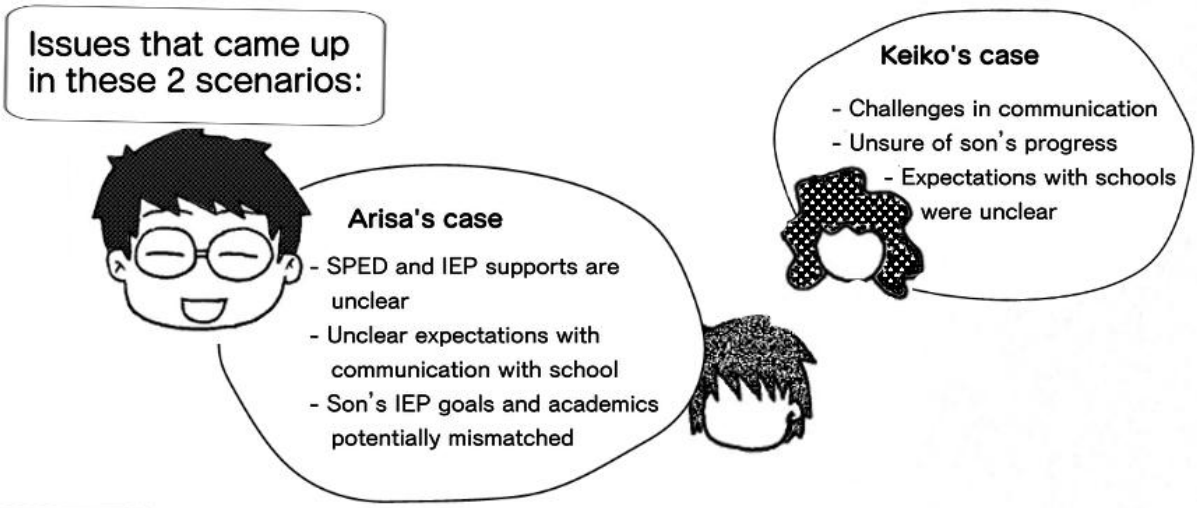

As research suggests, there are many complex challenges for parents to navigate Special Education system.
But how do these issues identified in the research look like in a real life?
We will take a look at 3 scenarios on common experiences shared in my interviews with Japanese families.

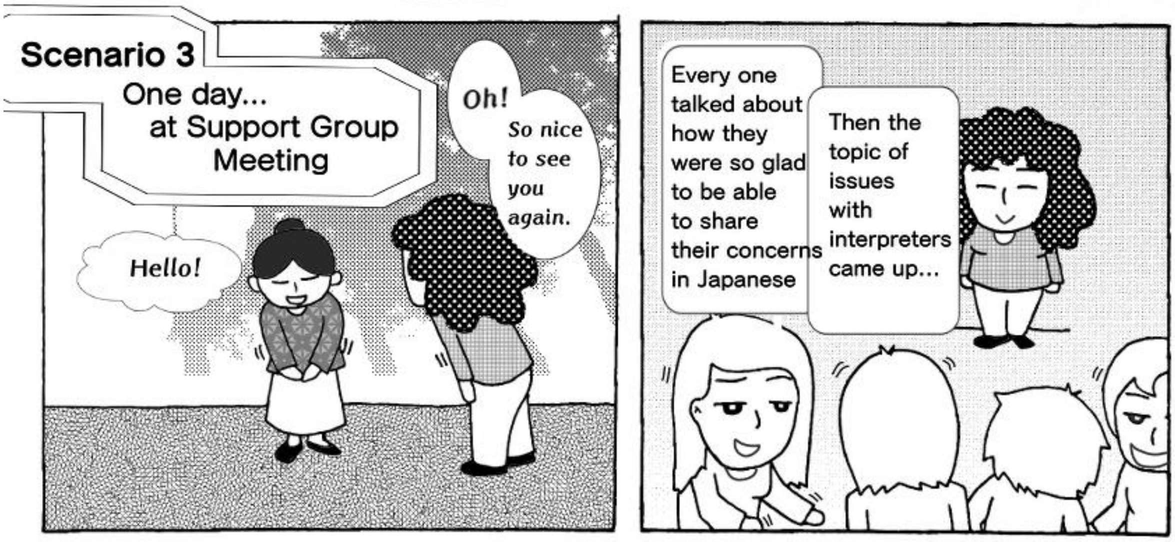

Scenario 1
Keiko
It's not that big of a deal but…
So, I take my son, Hiroki to school every day…
and there's always this feeling that I get when I get closer to school.
And I think it might be…
because of my interactions with Hiroki's teacher, Mrs Taylor.
Good morning!
Good morningu!
"I often wonder what's going on with Hiroki's progress and if he is being a good student.
But it can be a little overwhelming in the moment to ask in English…."
I'll email you later!
Hiroki's great! oh, but there is this one thing though.
email, again?
Uh, thank you, Mrs Taylor!
What could it be this time?
Sighs. Waiting for another email…
But then again, I guess there's been a bunch of little things lately
Later that day...
16:00
Nothing yet... Guess I should start prepping dinner.
Waaaaaaaaah


10PM
Finally he's asleep...
I wonder if she's emailed me yet.
Hmm? He put an eraser in his mouth…?
Might need to consider getting an OT…?
Well, she probably thinks I won't be able to understand...
She always tells me,
'I will email you later.'
If I email her with a question, she'll usually email me back
It will take me a while but I'll do my best to write her back using translators and dictionaries.
Might be really clunky English but at least I'd be able to say,
"Thank you. I think so and so."
I wonder why she won't just talk to me in-person.
We see each other everyday….
I wish she'd say something, but she probably thinks I won't understand.
But umm, I guess we really don't talk that much in general.
Not exactly ideal….
Well... email is better than nothing...


Scenario 2 Arisa
My son goes to general education class and receives 1 hour of SPED services.
Back in elementary, I used to be able to talk to his teachers, but not once since he started high school.
shuffle shuffle
PROGRESS REPORT
MATHEMATICS F
English
Biology
HUH?! Wait, what? He got F?!
Since he started high school, I have so little contact from school that I was not aware of this issue.
But it's not like I can ask my 16-year old
"Have you done your home work?!"
"Did you turn them in?!"
...all the time. It would annoy him.
But part of his challenge is that,
once he leaves school,
he can't seem to recall any school related matters.
All I can do is worry and watch over him...

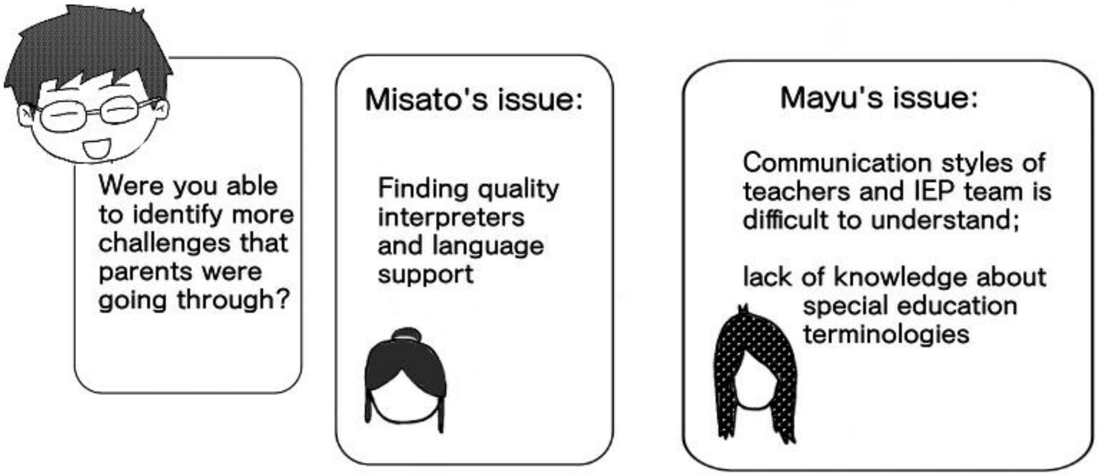

As part of his accommodations, he can submit his assignment within a grace period.
During his SPED class, he is working on his homework and turn it in during that time.
But in reality, he can't finish everything in 1 hour.
One time I found assignments that were due 3-4 weeks before!
Why won't the school contact me if this has been an ongoing issue?
I also never received any clear explanations why my son needed SPED services in the first place...
Like this time too. I wish they would call me before it's too late!


Issues that came up in these 2 scenarios:
Keiko's case
- Challenges in communication
- Unsure of son's progress
- Expectations with schools were unclear
Arisa's case
- SPED and IEP supports are unclear
- Unclear expectations with communication with school
- Son's IEP goals and academics potentially mismatched


Scenario 3
One day... at Support Group Meeting
Hello!
Oh!
So nice to see you again.
Every one talked about how they were so glad to be able to share their concerns in Japanese
Then the topic of issues with interpreters came up...


Misato
You know, I think school districts cannot afford "real" interpreters
The [hired] interpreters are better at speaking Japanese, I think.
But many of them are not fluent when it comes to interpreting what I say into English.
It can be so difficult to understand what's going on at these [IEP] meetings without someone who can keep up with the teachers and professionals.
Hello there. Nice to see everyone. Hope I'm not interrupting.
Oh, not at all.
We were talking about finding good interpreters and how hard it can be
In my experience so far, most Japanese interpreters who are provided by schools don't always know enough about SPED to help Japanese parents in IEP meetings.
Like the interpreter who was writing too many notes and not interpreting much during the meeting.
Or the interpreter who told me the expertise was in the medical field.
We are planning to...
and then...
～です。
Or the interpreter whose interpretations were very short compared to what was said in English.


Luckily for us, my husband and I have a friend who is American and is fluent in Japanese as well
He helped us so much and we were able to communicate better with schools during that time because he could do simultaneous interpretation.
But it became too expensive for us in the end.
We had to pay $40 an hour
$40?!
And the school district wouldn't pay either.
So we had to pay out of our pocket..
I know what you mean. My husband is American as well.
I usually have no problem understanding his English when we're at home. But somehow, during IEP meetings, I have a hard time keeping up with what he's saying.
Mayu's case
When I've attended IEP meetings by myself,
the teachers have always adjusted the way they talk to me.
So I suspect that when they're talking to me, the terms they use are different.
I've been wondering a lot lately if this might be a matter of having expertise or knowledge of the field.
When it comes to IEP's,
I might not be able to understand even if it was all in Japanese.
I just wish there was a better way.
Where is all the info on all this?
How frustrating.



Were you able to identify more challenges that parents were going through?

Misato's issue:

Finding quality interpreters and language support

Mayu's issue:

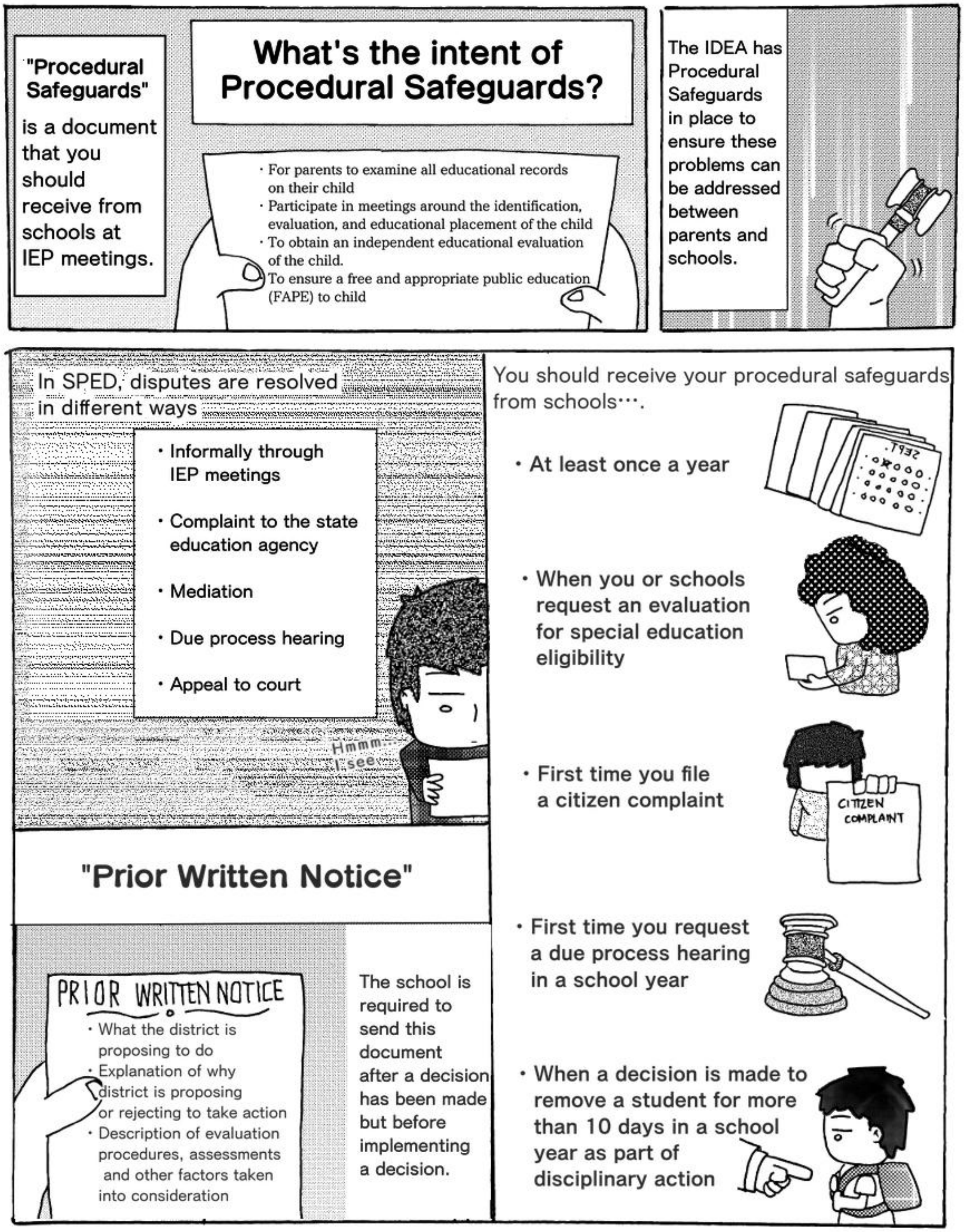
Communication styles of teachers and IEP team is difficult to understand;

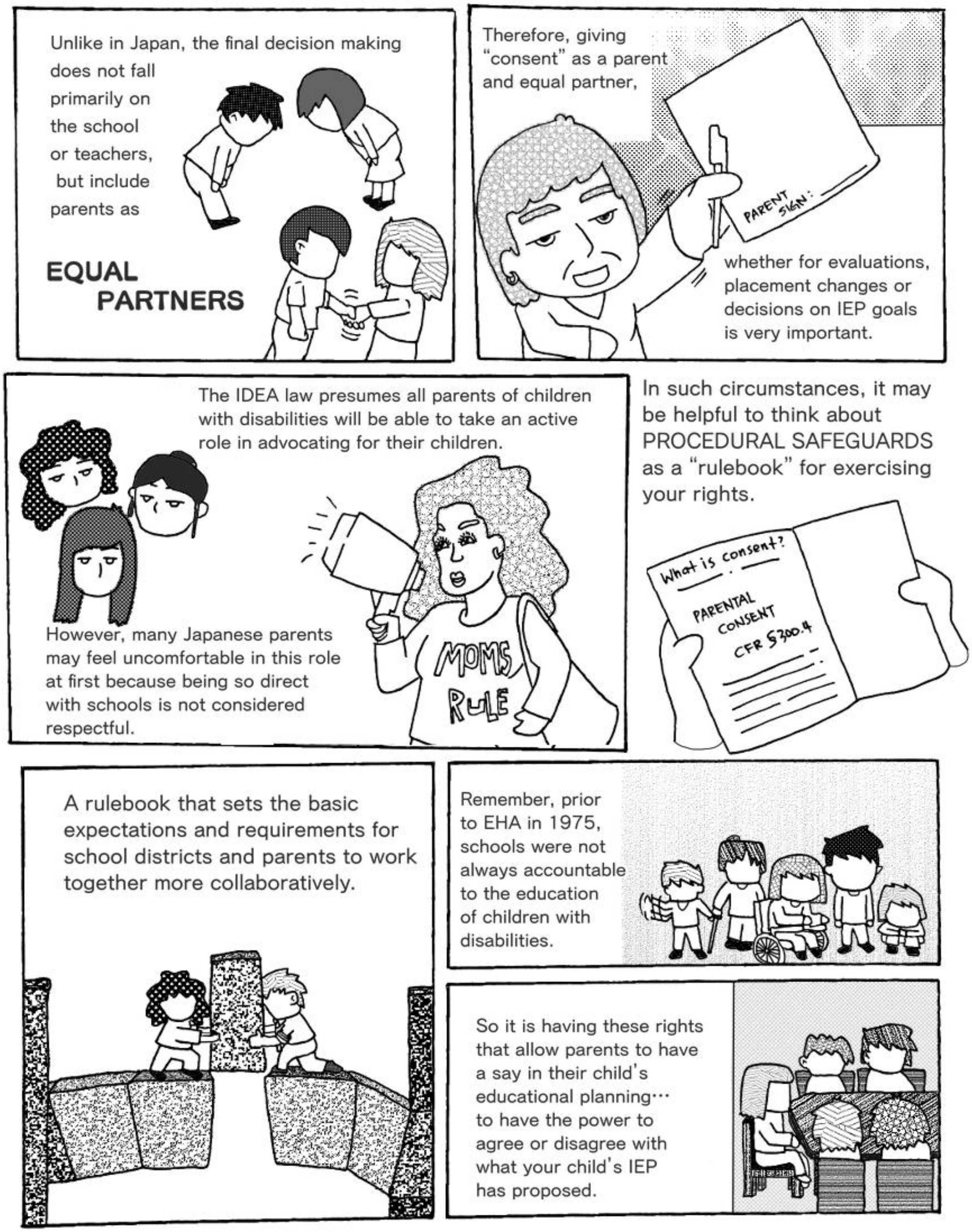
lack of knowledge about special education terminologies

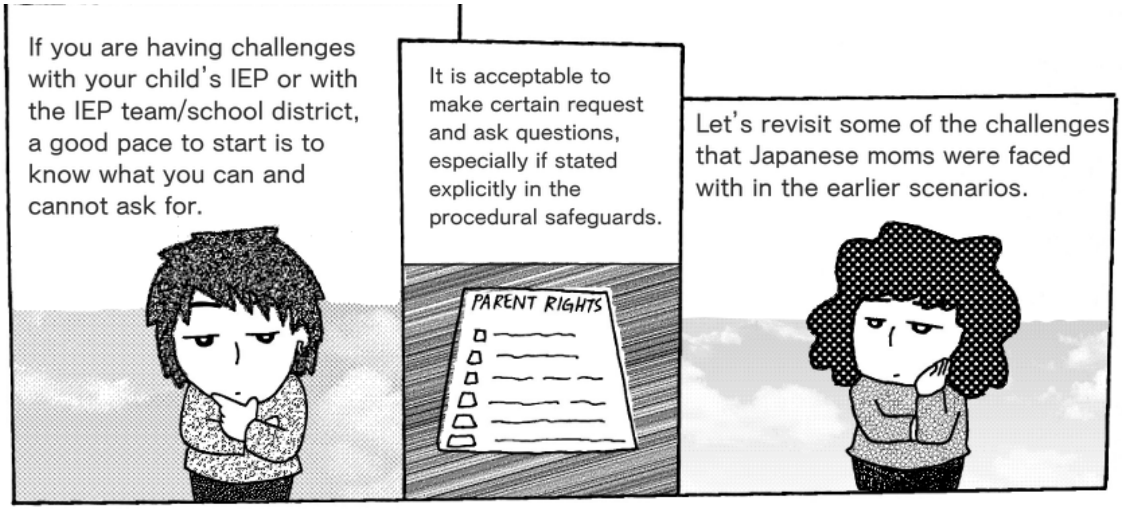
Now that you have read through these scenarios,
let's cover some details about

"Procedural Safeguards"

in this next section before revisiting the parents' issues again.


"Procedural Safeguards" is a document that you should receive from schools at IEP meetings.
What's the intent of Procedural Safeguards?
· For parents to examine all educational records on their child
· Participate in meetings around the identification, evaluation, and educational placement of the child
· To obtain an independent educational evaluation of the child.
To ensure a free and appropriate public education (FAPE) to child
The IDEA has Procedural Safeguards in place to ensure these problems can be addressed between parents and schools.
In SPED, disputes are resolved in different ways
· Informally through IEP meetings
· Complaint to the state education agency
· Mediation
· Due process hearing
· Appeal to court
Hmmm··· I see
"Prior Written Notice"
PRIOR WRITTEN NOTICE
· What the district is proposing to do
· Explanation of why district is proposing or rejecting to take action
· Description of evaluation procedures, assessments and other factors taken into consideration
The school is required to send this document after a decision has been made but before implementing a decision.
You should receive your procedural safeguards from schools···.
· At least once a year
SEPT.
· When you or schools request an evaluation for special education eligibility
· First time you file a citizen complaint
CITIZEN COMPLAINT
· First time you request a due process hearing in a school year
· When a decision is made to remove a student for more than 10 days in a school year as part of disciplinary action


Unlike in Japan, the final decision making does not fall primarily on the school or teachers, but include parents as
EQUAL PARTNERS
Therefore, giving "consent" as a parent and equal partner,
PARENT SIGN:
whether for evaluations, placement changes or decisions on IEP goals is very important.
The IDEA law presumes all parents of children with disabilities will be able to take an active role in advocating for their children.
MOMS RULE
However, many Japanese parents may feel uncomfortable in this role at first because being so direct with schools is not considered respectful.
In such circumstances, it may be helpful to think about PROCEDURAL SAFEGUARDS as a "rulebook" for exercising your rights.
What is consent?
PARENTAL CONSENT
CFR §300.4
A rulebook that sets the basic expectations and requirements for school districts and parents to work together more collaboratively.
Remember, prior to EHA in 1975, schools were not always accountable to the education of children with disabilities.
So it is having these rights that allow parents to have a say in their child's educational planning… to have the power to agree or disagree with what your child's IEP has proposed.



General Approach

Lack of Information

if you have a hard time getting answers to your questions, write a parent agenda for your next meeting. It should include your concerns, problems and proposed solution.

- Share it with the IEP team before the meeting.
- Bring extra copies!
- Your agenda will become part of your child's educational file.

Hidden issues

The simplest strategy when communication and actions are not consistent is to put your request in writing.

- Ask for a response to your request.
- You can use sample letter templates on these types of issues.
- Request data on IEP goals.

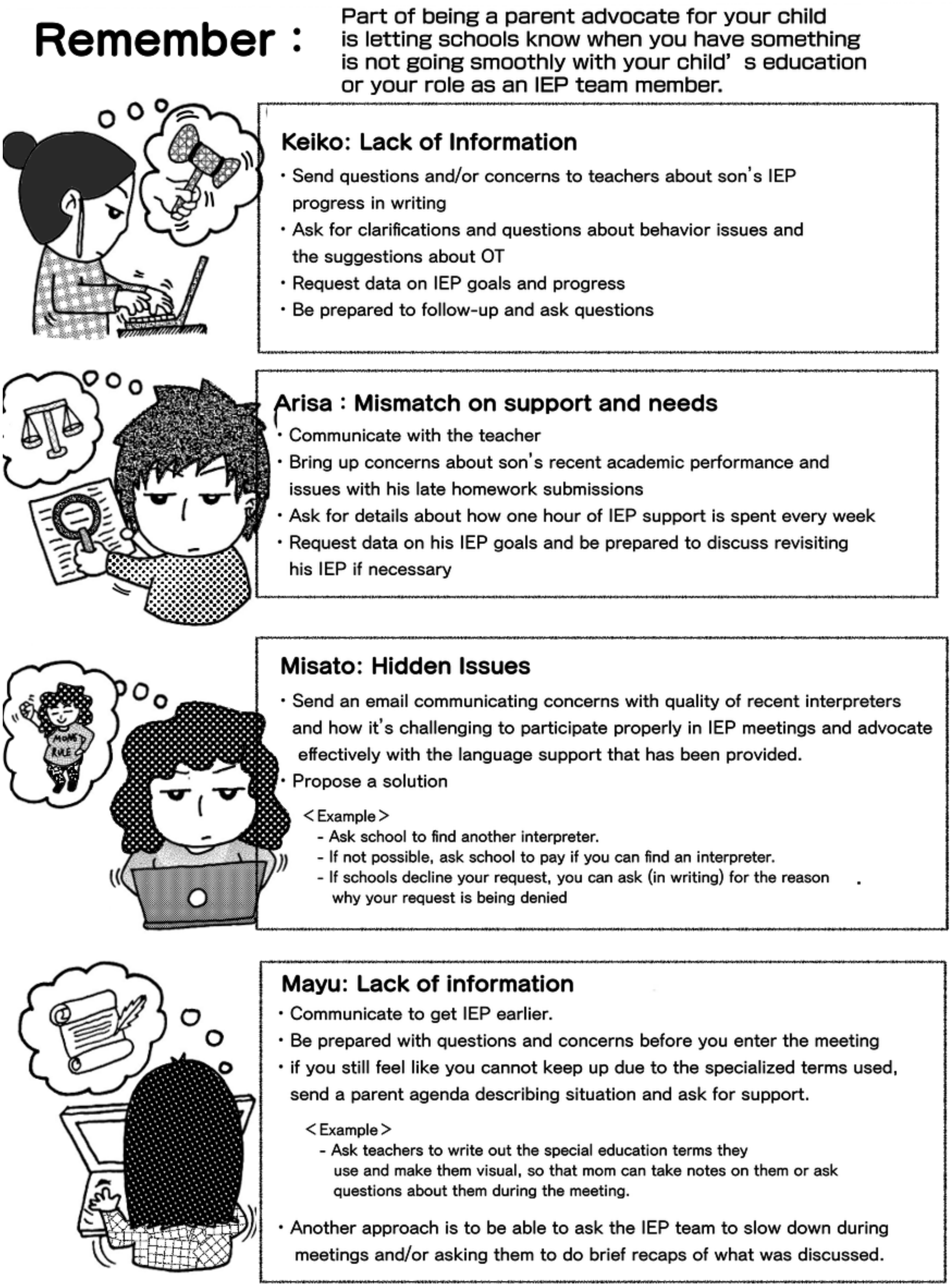
Different views of the child

- Request an IEP meeting as many times as needed in the school year. This is part of your parent rights.

"Thank you for the meeting today! Unfortunately, we did not get to discuss my concerns. so I would like to request another meeting..."

Be proactive

- If you have a hard time understanding the IEP document, put in a request to receive it sooner (e.g. one week or more).
- if document wasn't received on time, you can request to reschedule the meeting.
- Prepare for meetings by making sure you know what questions to ask or concerns to bring up (that is evidence based) about your child's IEP.
- Ask for Prior Written Notice and other important documents in your native language.



Remember： Part of being a parent advocate for your child is letting schools know when you have something is not going smoothly with your child' s education or your role as an IEP team member.

Keiko: Lack of Information

- Send questions and/or concerns to teachers about son's IEP progress in writing
- Ask for clarifications and questions about behavior issues and the suggestions about OT
- Request data on IEP goals and progress
- Be prepared to follow-up and ask questions

Arisa : Mismatch on support and needs

- Communicate with the teacher
- Bring up concerns about son's recent academic performance and issues with his late homework submissions
- Ask for details about how one hour of IEP support is spent every week
- Request data on his IEP goals and be prepared to discuss revisiting his IEP if necessary

Misato: Hidden Issues

- Send an email communicating concerns with quality of recent interpreters and how it's challenging to participate properly in IEP meetings and advocate effectively with the language support that has been provided.
- Propose a solution

  ＜Example＞
  - Ask school to find another interpreter.
  - If not possible, ask school to pay if you can find an interpreter.
  - If schools decline your request, you can ask (in writing) for the reason why your request is being denied

Mayu: Lack of information

- Communicate to get IEP earlier.
- Be prepared with questions and concerns before you enter the meeting
- if you still feel like you cannot keep up due to the specialized terms used, send a parent agenda describing situation and ask for support.

  ＜Example＞
  - Ask teachers to write out the special education terms they use and make them visual, so that mom can take notes on them or ask questions about them during the meeting.
- Another approach is to be able to ask the IEP team to slow down during meetings and/or asking them to do brief recaps of what was discussed.

Summary

There is no one perfect strategy or approach when dealing with uncertain situations. This is because everyone's situation will be slightly different, whether it's you as a parent, your child's needs, the individual school district, or the type of people who are in your child's IEP team.

However, it is important to know that there are different ways to resolve issues you may have with schools. It may take time to learn what you need to know about IEP's and special education, as well as IDEA and parent rights.

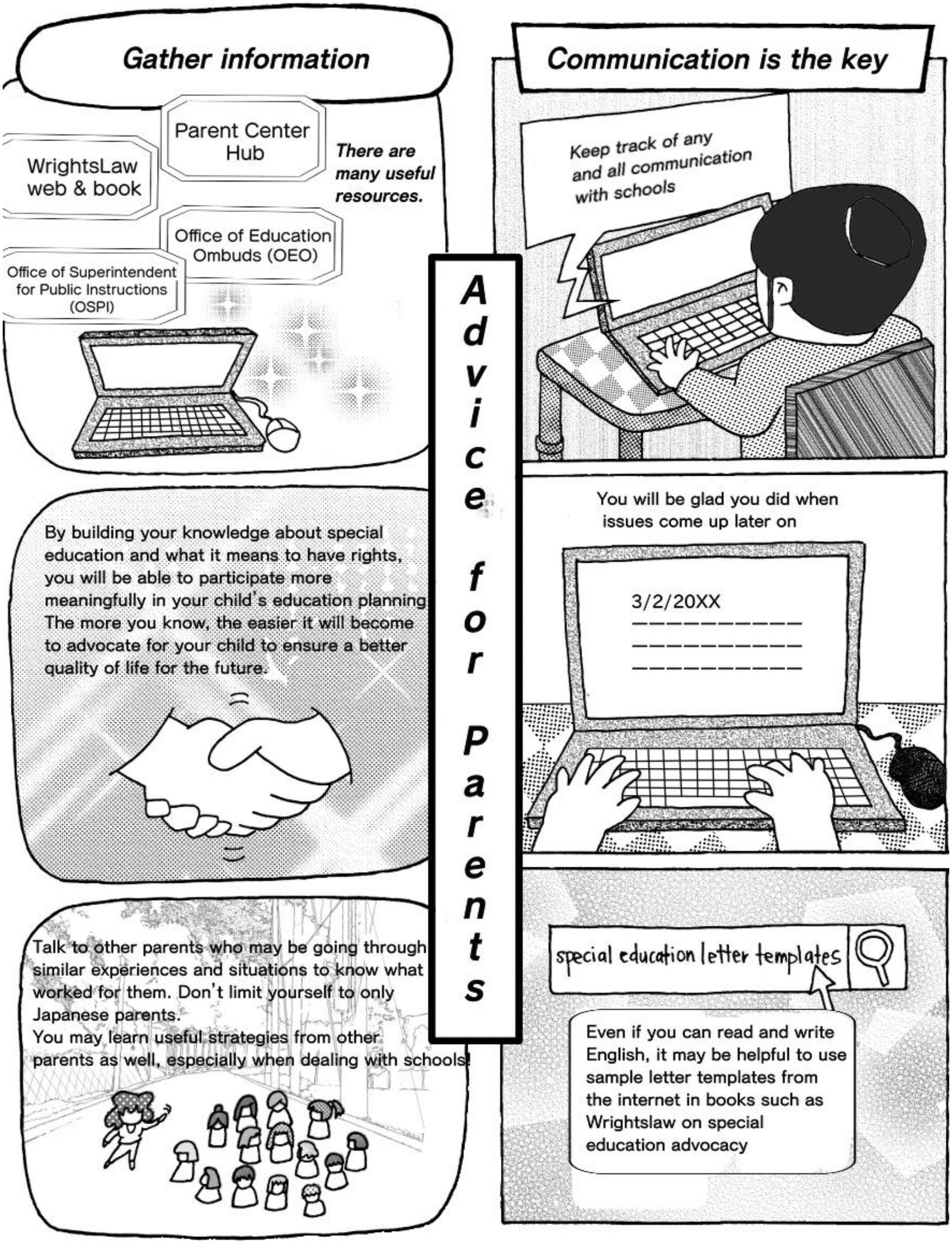
But this learning will be an ongoing process as your child's needs and IEP teams will change over time.

It is also possible that laws may continue to change around how special education support is provided.

You are on this journey to becoming a more knowledgeable parent advocate.

The more you know, the more successful you will be.

If you don't know, find a way to know!


Advice for Parents
Gather information
Parent Center Hub
WrightsLaw web & book
There are many useful resources.
Office of Education Ombuds (OEO)
Office of Superintendent for Public Instructions (OSPI)
By building your knowledge about special education and what it means to have rights, you will be able to participate more meaningfully in your child's education planning. The more you know, the easier it will become to advocate for your child to ensure a better quality of life for the future.
Talk to other parents who may be going through similar experiences and situations to know what worked for them. Don't limit yourself to only Japanese parents.
You may learn useful strategies from other parents as well, especially when dealing with schools!
Communication is the key
Keep track of any and all communication with schools
You will be glad you did when issues come up later on
3/2/20XX
special education letter templates
Even if you can read and write English, it may be helpful to use sample letter templates from the internet in books such as Wrightslaw on special education advocacy

Disclaimer

This resource was developed based on interviews conducted in 2016 with 4 Japanese parents of children with disabilities.

Scenarios based on their experiences may not generalize to all Japanese Immigrant family's experiences with U.S. Special Education.

To ensure the confidentiality of participants, pseudonyms were used for individuals and organizations in the scenarios.

Special Thanks

Special thanks to Mayu, Misato, Arisa, and Keiko, who shared their personal experiences to create this resource. This would not have been possible without their participation & support.

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Appendix E

アメリカ特殊教育における日本人家族の ペアレントアドボカシー

はじめに

こんにちは。ワシントン大学教育心理学専攻の博士課程に所属している大学院生の大森清香です。日本生まれ、マレーシア育ち、そして在米20年になります。

ハワイとワシントン州で13年間障害者支援･特殊教育の現場で障害のある子ども、保護者、そして専門家と働いた経験があります。
その中でも、文化･言語が多様な Culturally and Linguistically Diverse (CLD)と言われる移民･難民系のご家族で、特にアジア系移民のご家族を中心にサポートを行ってきました。

この冊子は、日本･韓国からの移民の家族を対象に、アメリカの特殊教育を受ける中でどんな困難や壁にぶつかったかなどの経験をインタビューして、わかったことをもとに作りました。

インタビューからわかったこと：日本人家族の困りごと

シアトル在住の日本人の保護者にインタビューしてわかったことは、

1. 子どもの障害について知識がある保護者ほど、子どもの障害について他の人にもオープンである
    a. 「共通点がなかったら特にそれ以上は話さないかもしれないですね。例えば、うちの子オーティズムなんですよって言われたとして、あーそうなんですか、で終わっちゃうかもしれないですね。」
    b. 「私は別に普通に話しますよ。話しちゃった方が楽...最初から言っちゃいます。」
- 学校側からの提案を基本的に尊重する
    - 「私のスタンスとしてはあんまり相手を否定することは、多分これは私の文化だと思うんですけど、否定することはしないです。尊重します。」
- 先生や専門家などとのコミュニケーションで言葉の壁を感じる
    - 「翻訳を使ったりとか辞書とか調べたりして、私はそれも理解できるので、私もなんか多分変な文章ですけど、ありがとう、これはこう思いますって、ゆっくり時間を掛ければ、返信することはできるので。」
- 他の日本人で、障害のある子どもを持つ家族との繋がりがとても大切
    - 「同じ環境の障害を持ったお子さんのお母さんたちとお話ししたり、まぁ、相談したり。そういう環境はすごくありがたいなーって。日本語でお話できるのがありがたいな。」

このインタビューから、他の CLD 家族たちと同じように言葉の壁からくる悩みもある他、「子どものアドボケート」という役割に対する日本人特有の悩みもあることがわかりました。

研究論文では、CLD 家族が学校とのやりとりで直面する困難として以下をあげています。

1. 情報の不足
2. 言葉の壁
3. 常識･ 価値感の違い
4. 何を期待すればいいのかわからない
5. 人種差別

このように CLD 家族の経験は、白人産階級や英語を単一言葉とする家族とは違ったものでした。

Q.アドボカシーという単語は聞いたことがありますか？

「*聞いたことないですね。*」

障害のある子どもにとって、特殊教育のサービスを受ける際、保護者によるアドボカシーはとても重要です。しかし、私が日本人の保護者と行ったインタビューではどの保護者も法律がどのように自分の子どもの療育、そして自分の役割に関わっているのか知りませんでした。

アメリカには特殊教育に関する法律があるのをご存知ですか？

法律がどのようにご自分のお子さんの療育に関わっているのか考えたことのない方も多いと思います。しかし、法律と保護者の権利を理解することによって、問題を事前に防いだり、早い段階で解決したりするのに役立ちます。

特殊教育においての「アドボカシー」とは？

保護者は子どもにとって一番みじかなアドボケートです。

保護者は子どもにとって

- 一番最初の先生
- 一番大事なロールモデル
- 幸せをもたらしてくれる人
- 最善の利益を考えてくれる人
- 誰でもアドボケートになることはできます。父親、後見人、里親、専門家や身近な人達も。

アドボケート

（ 動詞）：〜のために主張、弁護, 代弁する

（名詞）：主義や主張を擁護する人**（例：平等権の擁護者）**

『A...D...V...O...C...んー辞書で引いてもいまいちよくわからないですね』

英語の Advocate （アドボケート）が権利を主張し「行使」するのに対し、日本語に直訳すると権利を「庇い守る」というようにニュアンスが少し違うので違和感があるのも頷けます。

保護者は子どもの一番の理解者です。学校で関わる先生たちの多くは学年度によって変わりますが、保護者はお子さんの一生を通して関わります。

そのため、法律では保護者に子どもの教育に関する決定権を与えています。子どもの教育に関する決定を積極的にすることで、保護者は「アドボケート」としての役割を担います。子どもにとって良い教育を与えてあげることは、子どもの将来にとってとても大切なギフトとなります。(WL, 5)

特殊教育に関する法律と歴史の概要

現在、アメリカにおける特殊教育に関する法律には、個別障害者教育法 (Individuals with Disabilities Education Act、I.D.E.A.)というものがあります。

IDEA (2004) は 6 つの重要な項目があります。

1) 個別教育プログラム　(Individualized Education Program (IEP))
2) 無償で適切な公共教育 (Free and appropriate public education (FAPE))
3) 最も制約の少ない環境 (Least restrictive environment (LRE))
4) 適切な査定 (Appropriate evaluation)
5) 保護者と教師の参加 (Parent teacher participation)
6) 法的手続きに組み込まれた保護措置 (Procedural safeguards)

この法律では、障害は人の人生の自然な一部分であり、障害を原因に社会への参加と貢献する権利に影響を与えてはいけないと書かれています。

1975 年以前は、何万人もの障害のある子どもが公立学校に通学し教育を受けることができませんでした。また、適切な診断がない子ども達は、学校で必要なサポートを受けることができませんでした。公立学校に十分な資金がなかったため、時には保護者負担で学校外からのサポートを見つけていました。

1975 年に全障害児教育法(Education of All Handicapped Children's Act (EHA))が成立して以来、障害のある子どもに無償で適切な公共教育を提供することを義務づけ、障害のある子どもの教育の改善のきっかけを作りました。

＊＊法律制定の狙い＊＊

この法律が制定された目的は、適切な教育によって障害のある人でも市民の一員として社会に貢献する機会をつくることで、今まで障害者のサポートを全て担っていた家族の負担を減らすことでした。障害のある人の多くは自力でできることを増やすことによって、不必要に施設に入れられてしまうことを回避することができました。

1990 年に、EHA は IDEA に改定され、障害ではなく個々の生徒に焦点を置いたものになりました。それ以降、様々な裁判例や、政治情勢 、社会通念の変化とともに IDEA は何度か改定され現在の形になりました。

IDEA の信条は、障害のある子どもの教育を改善することによって、障害のある人たちへ平等な機会、完全な参加、そして経済的自立を確保することです。将来成人してなるべく自立し実りの多い生活に向けた準備を学生時代にすることを義務付けています。

そうすることによって、「特殊教育」が障害のある子どもを「送る場所」ではなく、個々に提供される「支援サービス」としての位置付けを保証しています。

ポイント:

IDEA は連邦法です。連邦法に沿って各州が法令･ 規則 を作成するため、同じ国内でも州により規則が違うことがあります。ただし、州の法律が連邦法と矛盾する場合は、連邦法で定められている規定が優先されると憲法で定められています。

このように、法律のもと障害のある子どもと保護者の権利が法律で守られているにもかかわらず、学校側には保護者にそれらを説明する義務がありません。そのため、法律を参照し保護者が情報を集める必要があります。

アドボケートとして、保護者は二つの大きな目標があります:

1) 学校が子どもに無償で適切な公共教育 (FAPE) を提供しているか見定めること。つまり、「個々の子どものニーズに沿った特殊教育および関連サービスを提供し、卒業後の高等教育、就職そして自立に向けた準備をサポートするもの」であるか(20 U.S.C. 1400(d))。
2) 学校とより良い協力関係を築いていくこと。例えば、子どもが成功するために大切なものが学校と家庭の双方の利益になるよう尽力する。

保護者がより良いアドボケートになるには？ (WL, 5)

- 正しい情報を収集する：正確な情報･ 独自に記録した証拠などを使い、学校との意見の不一致や論争を解決する。
- 事前に準備をする：地域の学区についての情報や規定などについて調べ、どのように学区全体の物事が決められ、誰によって最終決定されるかを知っておくと良い。
- コミュニケーションは文書で行う：基本的にやり取りはメールで行い、コミュニケーションミスがあった場合はきちんと明確にする。ミーティングや協議した内容･ 大切な出来事などはノートなどに記録をとっておく。もし「言われたこと」が記録されていなかった場合、それは「なかったこと」になる。

- わからないことは積極的に質問し説明を求める：「わからない」ことがある場合、問題を的確に伝えるために、保護者のために作られた「ペアレントアドボカシー」の資料などから情報を集め具体的に伝わるようにする。

長い学齢期のなかで学校との意見の不一致や、学校・特殊教育のシステムとの対立を避けることはできません。多くの保護者は常に大きな壁に直面していると感じるかもしれません。

ペアレントアドボカシーの研究では、学校と家庭間での５つのよくある問題が指摘されています。

  - *情報の不足*
  - *真面目に取り合ってもらえない*
  - *隠れた問題*
  - *コミュニケーション不足・脅迫*
  - *子どもに対する見解の不一致*

インタビューからの引用：『*何を学校から期待すればいいのかわかんないので、大切な情報に当たるかどうかって本当に宝くじみたいに感じます。*』

清香：
このように、特殊教育をナビゲートするのに様々な状況や複雑な壁が折り重なって家族の前に立ちはだかります。では、これらの問題は実際どのような形で立ちはだかるのでしょうか？日本人家族からのインタビューから浮かび上がってきた３つのよくあるシナリオを見ていきましょう。

<u>登場人物</u>

ケイコさん

米国在住 5 年。日本人の夫と二人の子供の４人家族。長男（７歳）が広汎性発達障害（PDD-NOS、現在の自閉症スペクトラム）の診断をアメリカに移住する前に受ける。駐在のため日本に帰国予定。英語の読み書きはできるけれど会話は苦手。

ありささん

米国在住 17 年。アジア系アメリカ人の夫と長男の 3 人家族。長男(16)はチック症の診断と自閉症スペクトラムの傾向がある。家庭では夫が日本語を話さないため英語と日本語を普段から使っている。

まゆさん

米国在住 17 年。アメリカ人の夫と二人の娘の 4 人家族。長女(14)は 5 歳の時に発達性言語障害（Semantic-Pragmatic Disorder）の診断をアメリカで受ける。療育をフロリダとワシントン州で受けた経験あり。家庭内では英語が飛び交っています。

みさとさん

米国在住 14 年。日本人の夫と 3 人の息子の 5 人家族。成人した長男(21)は幼い頃に日本で自閉症の診断を受け、渡米前は日本で特別支援学級へ通学したことがある。家庭では日本語で会話をする。

シナリオ１：ケイコさん

特に大変ってわけじゃないんですけど、モヤモヤする事はあるんですよね。あまり英語が得意ではないんですけど、毎朝ひろきを送って行くときに担任のミセステイラーと挨拶をするんです。その時、いつもひろきがなにか迷惑かけてないかなーとか心配して様子を聞くんですけれど、「ひろきはとても良い子よ。あっ、でも少し気になる事があったからメールするわね。」っていつも「またメールか」と思いつつ、とりあえずそのまま「サンキュー、ミセステイラー」で終わるんです。メールが来るまでドキドキして待たないといけないんですよね。何かやらかしたのかなーって。でも、結構小さな事だったりが多いんですよ。「消しゴムを口に入れたから OT 付けるかどうか見当しよう。」みたいな「その場で言ってくれたらいいのに」っていうことをメールでくれるんですよね。多分、私が英語ができないと思ってるからでしょうかね。私もなんか多分変な文章ですけど、翻訳を使ったりして、ありがとう、これはこう思いますって、時間をかけて返信するんですけど不便ですね。毎日顔を合わせているんで、問題があったらその時に言って欲しいなと思うんですけど、ちょっと(英語が十分に)わからないと思われてるんですかね。これくらい我慢すればいいんでしょうけどね。

シナリオ２：ありささん

「うちの息子は基本通常学級でサポートを１時間SPEDのサービスを受けてます。小学校の時は、毎日送り迎えで先生と話す機会があったんですけど、高校ではまったく。」

そしたら「えっ？！」ってなったのが、最近きた成績表にFがあったんです。高校に入ってから、特に学校から連絡がなかったので気がつきませんでした。かと言って、１６歳の息子に「宿題やった？！ちゃんと出した？！」なんて聞いても煙たがられるので。一応、学校の先生にメールしても良いらしいんだけど、毎日そんな事でメールするのも迷惑そうで。ただ、息子の特性として「学校」を出たら学校関係のことはすっかり頭から抜けてしまうらしくて、どう対応したらいいのかわからないまま見守ってます。

一応、合理的配慮として何週間までなら提出しても良いことにはなっているし、一限だけ特殊学級の先生に見てもらって宿題をやって、その場で提出してはいるんですけど、全科目分一時間では終わらないし。下手すると３〜４週間前のも見つかったりするんですよね。」

「でも、こういうことこそ学校側から連絡してくれないんでしょうかね？」

「最初も息子になんで特殊サービスが必要なのとかもわかりやすい説明なかったんですけど…今は今で、手遅れになる前に連絡くれたらよかったのに、とか思います。」

清香:　この２つのシナリオで浮かび上がってきたこと：

ケイコ: 学校の先生とのコミュニケーションに関する不満。息子の学校での様子や成長・学校から親に求められていることが不明瞭

ありさ: 特殊教育のサポートやIEPチームからのサポートが明確でない。学校とのコミュニケーション方法が明確でない。息子のサポートのニーズがあっていない

シナリオ３：ひまわり会グループ

ある日のサポートグループのミーティングにて・・・

どの保護者も日本語で悩みを相談できることがとても大事だと話になり、通訳の問題について話題になりました。

みさと「*本当の通訳の方だったら、多分雇えないんですよ、うちのディストリクトは。*

国際結婚して通訳してる方が多くてそういう方って日本語でしゃべる方が得意なんですよね。私たちのこと聞いて、英語に直すのはあんまり流暢じゃないっていう方も多いんで。IEPミーティング

で会話の内容を理解するのって、先生方や専門家の方の言っていることがわかる人でないと難しいですよね。」

ケイコ「あの、私もお話に加わってもいいですか？」

みさと「あ、どうぞどうぞ、今ちょうど、いい通訳さん見つけるのって大変ですよねって話をしてたところなんです。」

「私の経験では、学区が手配してくれる日本語の通訳さんて、特殊教育とかIEPについて詳しいわけじゃなくって。なんかものすごいノートばっかりとったり、「あ、私は医療通訳専門なんで」っていう方とか、先生方が長く喋ってたのにほんの少ししか訳してくれない人とか多くて」

「うちはラッキーなことに旦那の知り合いのアメリカ人の方で、日本語が上手な方がいて。今のところその方にずっとお願いしているんですけど、同時通訳できるしちょっと高いんですよね。1時間40ドル以上なので、そうするとディストリクトとしてはちょっと払えないって言われて自己負担してるんですよね。」

まゆ「それ、わかる。うちの主人もアメリカ人なんですけど、主人も私と家庭で話してる時はわかるのに、ああいうIEPミーティングだと彼の言ってることもよくわからない感じだったんで。だからおそらく使う単語が難しくて私がわからないと思うんですよね。私が一人で参加すると、私のレベルに先生方が合わせてくれるので、だからおそらくその使う用語なんか全然違うと思うんですよね。」

まゆ「私すごく感じるのが、これ背景知識の問題なのかな。だから自分が得意分野の事は英語で話されてもわかるんです。IEPについては、日本語でもわからないかもしれないから。」

「そこなんじゃないかなと思いますおそらく。日本語でも英語でも。わかんない世界の事はわかんないですよね。」

ありさ「こういう情報とかもう少し手に入りやすければなって思いますよね。早く知ってたらよかったって後悔したこともありますし。」

みさと　「本当そう思います、いっつも出遅れてる気分になるんですよね。」

ケイコ　「ミセステイラーとの事どうしたらいいでしょうかね。」

ありさ　「うちの息子のことも、どうにかしたいんだけど自分一人じゃどう解決したらいいのかわからなくて悩みます。」

全員: *でもこうやってお母さん同士で悩みを相談できて助け合えるのっていいですよね。いつも何か得られるものがあるし・・・*

清香: 「シナリオを通して日本人家族が直面する問題についてさらに知ることができたでしょうか?」

みさと: 的確な言語サポートや質のいい通訳の人材不足

まゆ: 学校の先生・IEP チームの使うコミュニケーションスタイルが難しい。特殊教育の専門用語がわからない

これらのシナリオを踏まえて、法的手続きに組み込まれた保護措置(Procedural Safeguards)に書かれている保護者の権利を読み解き、後ほどシナリオの解説をしたいと思います。

法的手続きに組み込まれた保護措置（Procedural Safeguards、以下、保護措置）は、唯一学校から保護者に手渡される書面です。

IDEA は、学校と家庭の間で問題が起きた際のガイドラインをこの保護措置で規定しています。

- 保護措置の意図とは？
    - *子どもの教育に関する記録の開示を、保護者が学校に求める権利を守るため*
    - *子どもの診断、査定、そして教育のプレースメントを決定するためのミーティングに、保護者が全参加する権利を守るため*
    - *学区の査定結果などに疑問・不服がある場合、学区から独立した第三者機関による査定を受ける権利を守るため*
    - *子どもの無償で適切な公共の教育(FAPE)を約束するため*

- 特殊教育では、学校・家庭間の問題は様々な方法で解決されます(WL, 48)
    - *IEP ミーティングでの話し合い*
    - *州の教育機関に対する申し入れ*
    - *調停*
    - *聴問会*
    - *裁判所への告訴*

保護措置で守られている保護者の権利: 文書による事前通知 (Prior Written Notice)

「学校は、子どもの教育に関わる決定事項がある場合、その決定事項が行使される前に文書による事前通知（以下、事前通知文書）を保護者に送付しなければならない」

事前通知文書には、以下の 3 点が含まれています。

- 学区が何を提案しているのか
- 提案に対する決定がなぜ採用または不採用にされたかの経緯の説明
- 決定に至った査定・アセスメントの過程、その他の要因などの詳細

ご存知でしたか？

これらの文書は、保護者の**第一言語**で作成することが限りなく不可能な場合を除き、その言語で書かれた文書を受け取る権利があります。

学校は、保護措置の書かれた文書を以下の時に保護者に提供する義務があります。

- 最低一年に一度（IEP ミーティングでの場合が多い）
- 子どもが特殊教育を受けるために必要な査定を、保護者または学校が要求した時
- 保護者が初めて差別に関する苦情申立書を提出した時

- 保護者が学年度に初めて聴問会を要求した時
- 学校が学年度に障害のある子どもを懲罰として10日以上停学にする決定をした時

日本とは違い、子どもの査定やプレースメントの変更、IEPのゴールや決定･提案などに対する最終決定権は、学校や先生だけではなく平等なパートナーである保護者にもあります。

そのため、意思決定の際には平等な立場で話し合い、承認または拒否をするというのはとても大切です。

IDEA方では、全ての保護者が障害のある子どものために積極的に参加をし、アドボケートすることを前提としています。しかし、多くの日本人の保護者にとって、学校側に意見することや、対等に関わることに抵抗を感じるかもしれません。けれど、理解が必要なことは説明を求めることで情報を得られるきっかけになります。

何を質問したら良いかわからない場合は、学区に要求できることが書かれている保護措置を「ルールブック」としてまずは読んでみるといいと思います。

冒頭に触れた通り、1975年以前は、障害のある子どもの教育に関して学校は一切の責任を持ちませんでした。
現在、様々な権利が保障されていることによって、保護者が子どもの教育と将来のプランに対し意見をだし、IEPチームが提案した案件を承諾または拒否する力があるのです。

もし、子どもの IEP や IEP チーム・学校との間で問題があるのならば、要求できること・できないことをまず知っておくと良いでしょう。保護措置で明確に書かれていることに関して要求したり、説明を求めたりすることは許容範囲です。

一般的なアプローチ

1) **情報不足**: わからないことへの答えを見つけるのが困難な場合、それを書き留めておき「保護者からの質問事項」として IEP ミーティングに持ち込む
    a. 懸念していること・問題・提案したい解決法など含む
    b. ミーティングの前に IEP チームにシェアしておく
    c. プリントは余分に用意！
    d. IEP ミーティングでシェアした保護者からの書面は子どもの教育に関するファイルに追加されていく
2) **隠れた問題**:
    a. もし、コミュニケーションした内容と実際に取られたアクションが違った場合、一番簡単な方策は書面で説明を要求することです
    b. 必ず「返答をお願いします」と手紙・メールに書きましょう
    c. 様々なケースに応じたサンプルの手紙などがネットでも見つけられるので有効活用しましょう
3) IEP ゴールの進行具合などの**データをリクエスト**しましょう。実際のデータの閲覧は保護者の権利です。
4) もし、子どもの教育に関して問題があったり、解決に及ばなかったりした場合、**再度 IEP ミーティングを開くこと**を要求しましょう。これも保護者の権利です。
5) もし、**IEP の書類**を確認・理解するのに時間が必要な場合、事前にその書類を送ってもらうよう手紙やメールで**リクエスト**しましょう（例：１週間前など。もし返事が来なかった場合、ミーティングを延期するようリクエストしても良いです。）
    a. 事前通知など大事な連絡事項を保護者の第一言語で理解できるようリクエストしても良いです。
6) **積極的に動く**
    a. 子どもの IEP チームと話し合いたいことや、質問、心配している点などを具体的に話せるように、事前に相談内容を書き出したり、根拠となる証拠（例：宿題などの取り組んでいるゴールが困難な証拠）を準備しておく

それでは、先ほどの日本人のお母さんたちの悩みを例に保護措置の内容を見ていきましょう。.

ケイコさんの悩み：
学校の先生とのコミュニケーションに関する不満。息子の学校での様子や成長･学校から親に求められていることが不明瞭。

ありささんの悩み：
特殊教育のサポートや IEP チームからのサポートが明確でない。学校とのコミュニケーション方法が明確でない。息子のサポートのニーズがあっていない。

みさとさんの悩み：
積極的に IEP に参加するための通訳がいない･通訳者を自己負担している。

まゆさんの悩み：
特殊教育に関する知識･専門用語がわからない。

覚えておきたいこと：子どものアドボケートとしての役割の一部は、子どもの教育やIEPのサポートがうまくいってない場合、IEPメンバーの一員として学校に伝えることです。

ケイコ:

情報不足

- ひろきくんのIEPゴールの進み具合について質問･心配事を学校に書面で伝える
- 先生から問題行動（消しゴムを噛む）の対処としてOTをつける提案についての説明を求めてみる
    - 例：消しゴムを噛見始めたのはいつからか？どういう時に噛んでいるのか？噛む理由はわかるか？OTをつけることによってどのようにこの問題行動に対処することになるのか？など
- IEPゴールの進み具合のわかるデータを要求する
- フォローアップの質問などの準備もしておく

ありさ:

IEPゴールの進み具合について質問する

- 特別支援の先生とコミュニケーションをとる
    - 宿題の提出に関する問題と、最近の成績に関して心配があることを伝える
    - 特別支援の1時間でどのようなサポートを受けているのか具体的な説明を求める
    - IEPゴールの進み具合のわかるデータを要求し、必要に応じてゴールの見直しを要求･協議する準備をしておく

みさと:

隠れた問題

- メールで通訳のクオリティについて問題があることを伝え（具体例があると良い）、IEPに「平等なパートナー」として参加することが難しいことを伝える
- 解決策を提示する。例：学校に違う通訳を見つけてもらう要求をする。もし不可能な場合、自分で見つけた通訳を学校の負担で連れていく交渉をする。提案を学校が拒否した場合、どのような経緯で提案を却下したのかの説明を書面で提示するよう求める

まゆ:

情報の不足

- IEPの書類をミーティングの前に送ってもらうよう要求する
- ミーティングの前までに質問事項や保護者視点で心配のあることなどのノートを取っておく
- もしミーティングで使われる専門用語がわからない場合、事前にその旨を伝え、ミーティング時のサポートをリクエストする。例：専門用語などを使う際に書き出してもらい適宜説明を求める。または、IEPミーティング中はゆっくり話してもらい、決定したことなどを最後に要約してもらう。

まとめ：

シチュエーションごとに「完璧」な戦略やアプローチがあるわけではありません。なぜなら子どもの特別支援は個別に作られたもので、関わっている学区· IEPチームのメンバーや子どものニーズによって全てが変わってくるからです。

けれども、法で守られている権利があることで、様々な手段で学校との問題を解決することができます。

IEPや特殊教育、それからIDEA法や保護者の権利などに関して理解するのに時間がかかるかもしれません。

しかし子供のニーズやIEPチームが変化するとともに、その都度理解をする努力を積み重ねていけるものです。

また、法律が新たに改正されるたび、特殊教育のサポートの形も変わる可能性もあります。子供の学齢期の間、保護者はアドボケートとしての知識を学び、子供の教育をサポートしていく旅路につくでしょう。

様々な経験や知識を得ることで、徐々に子供のアドボケートとして成功していくこと思います。

保護者へのアドバイス

1) コミュニケーションが鍵

- 学校とのやりとりは記録·ファイルするなどしておく（後ほど何らかの問題があった際に参照することができます。）
- 英語の読み書きが得意であっても、Wrightslaw などのサンプルレターなどで使われている言い回しを使うとやりやすい

2) 知識を集める

- IEP や IDEA·特別支援教育に関する保護者向けのリソースで情報を集める(主に英語)。
    - *Wrightslaw「ライツロー」本とウェブサイト [https://www.wrightslaw.com/]*
    - *Office of Education Ombuds (OEO) [https://oeo.wa.gov/]*
    - *Parent Center Hub [https://www.parentcenterhub.org/]*
    - *OSPI [https://www.k12.wa.us/]*

- 特殊教育や保護者の権利の理解が進むほど、子供の教育のプランニングに意義のある参加ができるようになり、子供のための良い教育と将来へのサポートができるようになります。
- 同じような経験のある保護者たちとうまくいった解決法などの情報交換をしたり、同じ学校に通っている保護者同士で得られる情報も積極的に集めましょう。

注意書き

この冊子は 2016 年に四人の日本人で障害を持つ子供の保護者を対象に行われたインタビューを元に作られたものです。紹介された内容は全ての在米日本人保護者の Special Education に関わる経験に当てはまるものではありません。登場する人物・ 団体名はプライバシーを配慮し仮名を使用しています。

スペシャルサンクス

この冊子を作るにあたり、ご自身の経験談をお話ししてくださったまゆさん、みさとさん、ありささん、ケイコさん、そして、推敲にご協力くださった皆様に心から感謝申し上げます。

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