Disability in Cultural Context: Providing Social and Emotional Support for Japanese Children with "Developmental Disabilities" at School

Misa Kayama, Ph.D.
University of Illinois at Urbana-Champaign
Urbana-Champaign, IL

Statement of the Research Problem

This dissertation examines, through an ethnographic approach, Japanese cultural beliefs about disability, related educational and socialization practices, and the experiences of elementary school-aged children with disabilities at school. Physical and mental conditions which impair children's functioning occur throughout the world. Yet, how disabling conditions impact children's social and psychological development varies considerably and can be understood as a transaction with culturally shared beliefs and practices (e.g., Banks, 2003). Cultures differ in which physical and mental conditions are considered "disabling," how such conditions are grouped or categorized, societal responses deemed appropriate, and how individuals with disabilities are valued. In the U.S., for instance, about 10% of children in public schools receive special education services (Data Accountability Center, 2012). In contrast, only about 2 % of Japanese children receive special education services (Ministry of Education, Culture, Sports, Science, and Technology, 2011). To interpret such difference between cultures, it is necessary to examine children's experiences at school, as well as cultural beliefs, policies and historical context pertaining to special education and disability. Relatively little sociocultural research on disabilities, however, has focused on non-Western children, which restricts our ability to understand the extent to which and how cultures vary in their responses to disability, and the impact of these differences on the developing child.

Currently, the Japanese education system is in transition, as public schools implement new formal special education services for children with developmental disabilities (e.g., Ministry of Education, Culture, Sports, Science, and Technology, 2007). This transition created an excellent opportunity to examine Japanese beliefs about disability, how they impact children's development, and how adults provide support for children with disabilities. "Developmental disabilities" is a new term used by Japanese educators to refer to various neurologically-based conditions which cause "milder"

difficulties, including learning disabilities, Attention Deficit Hyperactivity Disorders (ADHD), and Asperger's Syndrome (Ministry of Health, Labour and Welfare, 2004). In Japan, children with developmental disabilities traditionally were considered to be among any number of children who were "difficult" or "slow learners," and were socialized within general education classrooms. They received support from their peers and classroom teachers (e.g., Abe, 1998; Mogi, 1992), who have neither specialized training nor resources (Kataoka, van Kraayenoord, & Elkins, 2004). They are now treated as children with disabilities who need special education.

Yet, the practice of providing individualized services to children with developmental disabilities presents a dilemma for Japanese educators and parents. In addition to academic skills, Japanese education has emphasized the spiritual function of education, such as development of personalities and mind, and emotional and social wellbeing (e.g., Ministry of Education, Culture, Sports, Science, and Technology, 2008; Okamoto, 2006). After the implementation of new special education, educators must balance traditional socialization and educational practices of rearing and educating children within peer groups with new requirements to provide formal individualized support for children with developmental disabilities.

Research Background and Questions

By the late 1970s, Japanese scholars had become aware of the presence of children with learning difficulties in general education classrooms (National Institute of Special Needs Education, 1978). It was not until the 1990s, however, that their special needs received wider public attention. In the 1990s, Japanese parents of children with learning disabilities expressed a need for formal support for their children in general education classrooms (e.g., National Association of Parents of Children with Learning Disabilities, 2010). Around this same time, the Japanese government was pressured by a movement across the world to protect children's rights. This movement included the Convention on the Rights of the Child that identified appropriate education as a basic human right (United Nations, 1989), and the Salamanca Statement that called on governments to provide inclusive education (UNESCO, 1994). Yet, how such practices were implemented varied in cultural and social contexts. In Japan, for example, educators were challenged to integrate individualized interventions without disrupting children's membership to their peer groups: a central developmental context for education and socialization into Japanese culture.

The aim of this dissertation research is to explore Japanese cultural beliefs about disability as they impact the experiences of children with developmental disabilities, their parents, and educators; the service delivery system of special education, and policy

analysis regarding how special education has been addressed historically in Japan. The specific research questions are: 1) What are the newly designed social and educational policies pertaining to special education? 2) How do educators and parents understand developmental disabilities? 3) How do educators and parents integrate traditional Japanese socialization and educational practices with the new special education system? 4) What is the experience of children with developmental disabilities, their parents, educators, and peers as they transition into the new special education system?

Methodology

First, I examined the broader sociocultural-historical context in which adults' socialization practices and beliefs and children's development are embedded. Policy analyses involved systematic review of Japanese government documents pertaining to special education. I also reviewed local documents to understand how national laws were translated into practice in particular contexts. These analyses helped to contextualize my field research, which focused on in-depth analyses of children's experiences at Greenleaf Elementary School.

The field research was conducted in 2009-2010, the third and fourth school years during which formal special education services for children with developmental disabilities were being implemented at Greenleaf Elementary School. The methods include participant observation as a teaching assistant and in-depth longitudinal case studies of three children with developmental disabilities, including individual interviews with children, their parents, and 15 educators.

Greenleaf Elementary School meets national standards for public elementary schools in Japan. It is located in a traditional residential and farming community within a large city recognized by Japanese educators as providing high quality special education services. Greenleaf Elementary School enrolls about 200 children from first through sixth grades. During the school years this study was conducted, five to seven children diagnosed with developmental disabilities received services from two teachers in a special education classroom, the "Rainbow Room." In addition, the "Challenge Room," a special support room, was used by children from general education classrooms who needed extra help.

I conducted participant observation as a teaching assistant for children with developmental disabilities in the Rainbow, Challenge and general education classrooms for a total of 16 weeks across two school years. Field notes described children with developmental disabilities during interactions with peers and educators, including how and where they received support. Informal conversations with children, educators, and parents and observations of their interactions were also described in field notes. In addition, three

children with developmental disabilities, their parents and educators participated in semi-structured individual interviews. During the interviews, adults were asked to describe 1) their beliefs about, and reactions to, children's disabilities; 2) experiences in special education; 3) how beliefs about developmental disabilities and societal responses affect the lives of children at home and school; 4) challenges faced by children with developmental disabilities, their educators, and parents; and 5) effective ways to handle these challenges. Individual interviews with the three children with developmental disabilities focused on the services they receive, why they receive them, and how they feel about them. These three children were selected for in-depth, longitudinal case studies. In addition to participant observation and individual interviews, case studies involved review of some school records and informal discussions with peers in general education classrooms.

Recorded interviews were transcribed verbatim. All analyses were conducted in the original language, Japanese. Using analytic induction techniques (Goets & LeCompte, 1981; Lincoln & Guba, 1985), the meanings of participants' experiences and beliefs were interpreted through repeated readings of written materials. Feedback on the adequacy and consistency of the coding and the Japanese-English translation of illustrative excerpts was provided by a Japanese MSW student in the U.S. who had practice experiences as a social worker for individuals with disabilities in Japan. Feedback from some of the participants as well as individuals who have professional and/or academic experiences in the field of school social work or special education in Japan also was obtained to enhance the credibility of my interpretations of participants' experiences and beliefs.

Results

Participant educators and parents were sensitive to children's "differences" that might result in stigma. In summarizing societal responses to these children, a classroom teacher remarked, "This is a society where you are called 'stranger' if you are a little different from others." (Kayama & Haight, 2012, p. 270). Accordingly, educators tended to provide the necessary support for children with developmental disabilities within general education classrooms without stigmatization. They created an environment in which children with disabilities are motivated to learn voluntarily by utilizing resources each child had, including their preferences; special interests and knowledge; and relationships with peers.

Educators created such a context, for example, by publicly remarking on a child's expertise in class, asking peers to create a classroom like "home" in which children with special needs are accepted, and educating children about their peers' difficulties in classroom. Mrs. N shared her experience of teaching first graders about individual

differences by using a metaphor, a "cup of tolerance":

I explained to them that everyone has a different amount that they are able to bear/tolerate (*gaman*). Everyone has a cup [of tolerance], but it's different one by one. Someone has a large cup, but there is someone who has a small cup. We can't change the size of our cups easily. So, there is a person who wants to *gaman* but can't. Last year, it was a child with ADHD in first grade... When the child melted down or got upset, other children said, "His cup has overflowed" (Kayama & Haight, 2012, p. 271).

Children's response, "His cup has overflowed," suggested that this metaphor was meaningful to them.

When children with developmental disabilities have special skills of which they are proud and that are socially valued, their interactions with peers become more positive. Mr. M shared his observation of Dai, who was in his classroom during the previous year:

It makes a difference whether what a child [with a disability] is confident about is valued [by peers]. Last year, Dai was called, "Mr. Fish," by the other children who admired his knowledge of fish. He also told them a story of fish during lunch.

Educators viewed it as part of their responsibilities to identify children's strengths and create opportunities in which children can use their strengths and become more confident. They also used children's needs and misbehaviors as opportunities to learn the necessary skills. The goal is for children to learn interpersonal and academic skills "naturally" and voluntarily through their daily interactions. Children with special needs receive socialization into Japanese culture, as do their typically developing peers who benefit through increased empathy.

Just as educators created a context in which children are able to learn voluntarily, they provided parents with support by establishing trusting relationships and arranging the support in a way that parents can accept their children's special needs "naturally." Mrs. S., a special education coordinator, described how she would initiate contact with parents regarding their children who might need additional support in their general education classrooms.

I would talk to the classroom teacher [of the child] first, and then ask the teacher to talk with parents and suggest that they may want to stop by my office, usually,... but if they decide not to come, I won't keep telling them or chasing or like that. Instead, I'm always trying to be friendly, with an "I care about you!" aura, if I see familiar faces [parents] in the hallway.

Educators carefully observe parents' responses to their children's difficulties, while

providing them with support indirectly. For example, educators created opportunities for parents to observe their children at school, and offered them more intensive support when they were ready to accept their children's need for additional services and support.

Utility for Social Work Practice

Special needs of Japanese children with "developmental disabilities" had not been formally addressed at public schools until recently. The new Japanese special education is a large step towards social and educational justice for individuals with milder disabilities. In the U.S., receiving an appropriate public education is a children's right determined by laws, such as the Individuals with Disabilities Education Act (IDEA). Nevertheless, at the practice level, how the necessary services are provided may depend on availability of resources, including educators' knowledge and skills. The findings of this study provide new perspectives of how educators and school social workers can provide appropriate support and create a context in which children receive such support without stigmatization.

Stigma still exists in the U.S., where individual rights are emphasized and a variety of services and programs are available for children with disabilities. For example, difficulties caused by their disabilities, such as behavioral and interpersonal difficulties, may make children different from others, which can be a source of stigma. Appropriate support, including special education services, can help the children to handle difficulties. Such support, however, may call attention to their differences and contribute to their stigmatization. This dilemma of difference is created by locating problems in individual children with disabilities. One way to solve this dilemma is to relocate problems caused by children's disabilities in relationships within which their differences arise, for example, by involving their peers in solving problems (Minow, 2003). The Japanese case emphasizes the importance of creating a supportive context for children with disabilities within general education classrooms. It is one example of how to deal with the dilemma of difference and to provide equal opportunities for all children, those with and without disabilities, to learn.

Support children's autonomous participation

The Japanese case at Greenleaf Elementary School raises the issue of how adults might support children's understanding and acceptance of support for disabilities (See also Kayama & Haight, in press). Participant children were given opportunities to behave autonomously and to express their preferences, for example, when and where to receive additional support. This allowed children to find their "place" in which they were motivated to handle difficulties. In the U.S., elementary school-aged children with disabilities are not always allowed this degree of autonomy. Their Individualized

Education Programs (IEPs) typically are created by teams of adults. The IDEA and its regulations describe that children also participate in these meetings when "appropriate." Yet, children's participation is only required when a purpose of the meeting is to discuss their post-secondary goals or transition services to reach these goals (Department of Education, 2011). Using a national representative sample, Barnard-Brak and Lechtenberger (2010) found a positive association between children's participation in IEP meetings and their academic achievement at the elementary school level. Involvement of children in the decision making process, for example, through participation in the meetings and incorporation of their preferences and interests in intervention programs, is encouraged, but not yet widely practiced in the U.S.

Create a supportive social ecology

The Japanese case also raises the issue of how adults may unobtrusively facilitate the integration of children with disabilities into peer groups in general education classrooms. Japanese educators used contextual factors, such as peer group membership, as a tool to intervene and facilitate their development. This practice may suggest a strategy to implement classroom based intervention for U.S. general education classroom teachers. After the enactment of the No Child Left Behind Act in 2002 and the reauthorization of the IDEA in 2004, public schools began implementing Response to Intervention, which facilitates classroom based intervention targeting all children in addition to individualized services for children who require more intensive support including special education (e.g., Fuchs, Fuchs, & Stecker, 2010). As a result, classroom teachers' responsibilities to provide intervention programs in general education classrooms have increased, and they are required to gain skills to provide such intervention programs in their classrooms.

For example, cooperative learning groups in which children with diverse abilities work and play together is a recognized strategy used in inclusive classrooms in the U.S. Such environments facilitate social interactions and mutual learning between children with disabilities and their typically-developing peers (e.g., Taylor, Peterson, McMurray-Schwartz, & Guillou, 2002; Zentail, Craig, & Kuester, 2011). Zentail et al. (2011) also found that groups with a member with ADHD were more successful than other groups in completing problem-solving tasks. By involving individuals with whom they have daily interactions at home, school, and other places, educators and school social workers can modify or even create a social ecology for development in which children with disabilities and their peers are motivated to participate and adults can guide them in positive directions.

References

- Abe, Y. (1998). Special education reform in Japan. European Journal of Special Needs Education, 13, 86-97.
- Banks, M. E. (2003). Disability in the family: A life span perspective. *Cultural Diversity and Ethnic Minority Psychology*, *9*, 367-384.
- Barnard-Brak, L., & Lechtenberger, D. (2010). Student IEP participation and academic achievement across time. *Remedial and Special Education*, 31, 343-349.
- Data Accountability Center (2012). Individuals with Disabilities Education Act Data. Retrieved from https://www.ideadata.org/PartBData.asp
- Department of Education (2011). Building the legacy: IDEA 2004. Retrieved from http://idea.ed.gov/explore/home
- Fuchs, D., Fuchs, L. S. & Stecker, P. M. (2010). The "blurring" of special education in a new continuum of general education placements and services. *Exceptional Children*, 76, 301-323.
- Goets, J. P., & LeCompte, M. D. (1981). Ethnographic research and the problem of data reduction. *Anthropology and Education Quarterly*, 12, 51-70.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*, Newbury Park, CA: Sage Publications.
- Kataoka, M., van Kraayenoord, C.E., & Elkins, J. (2004). Principals' and teachers' perceptions of learning disabilities: A study from Nara prefecture, Japan. *Learning Disability Quarterly*, 27, 161-175.
- Kayama, M. & Haight, W. (2012). Cultural sensitivity in the delivery of disability services to children: A case study of Japanese education and socialization. *Children and Youth Services Review, 34*, 266-275.
- Kayama, M. & Haight, W. (in press). The experiences of Japanese elementary-school children living with "developmental disabilities": Navigating peer relationships. *Qualitative Social Work*
- Ministry of Education, Culture, Sports, Science, and Technology (2007). Tsu-chi: Tokubetsu shien kyo-iku no suishin ni tsute [Notice: Implementing special needs education]. Retrieved from http://www.mext.go.jp/b_menu/hakusho/nc/07050101.htm
- Ministry of Education, Culture, Sports, Science and Technology (2008). Sho-gakko gakushu shido yo-ryo [National Curriculum Standard for elementary schools]. Tokyo: Author

- Ministry of Education, Culture, Sports, Science, and Technology (2011). Tokubetsu shien kyo-iku shiryo: Heisei 22 nen-do [Special education statistics: 2010]. Retrieved from http://www.mext.go.jp/a_menu/shotou/tokubetu/material/1309805.htm
- Ministry of Health, Labour and Welfare (2004). Hattatsu sho-gai sha shien ho [Support for Persons with Developmental Disabilities Act]. Retrieved from http://www.mhlw.go.jp/topics/2005/04/tp0412-1b.html
- Minow, M. (1990). *Making all the difference: Inclusion, exclusion, and American Law*. Ithaca, NY: Cornell University Press.
- Mogi, T. (1992). The disabled in society. *Japan Quarterly*, 39, 440-448.
- National Association of Parents of Children with Learning Disabilities (2010). Zenkoku LD oya no kai no ayumi [History of the National Association for Parents of Children with Learning Disabilities]. Retrieved from http://www.jpald.net/ayumi.html
- National Institute of Special Needs Education (1978). Kei-do shin-shin sho-gai ji ni taisuru gakko kyo-iku no ari-kata: Hokoku [School education for children with minor disabilities: Report]. Retrieved from http://www.nise.go.jp/blog/2000/05/b2_s530812_01.html
- Okamoto, K (2006). *Education of the rising sun 21: An introduction to education in Japan* (2nd ed.). Tokyo, Japan: National Federation of Social Education
- Taylor, A., Peterson, C., McMurray-Schwartz, P., & Guillou, T. (2002). Social skills interventions: Not just for children with special needs. *Young Exceptional Children*, *5*, 19-26.
- UNESCO (1994). The Salamanca Statement and framework for action on special needs education. Retrieved from http://www.unesco.org/education/pdf/SALAMA_E.PDF
- United Nations (1989). Convention on the Rights of the Child. Retrieved from http://www2.ohchr.org/english/law/crc.htm
- Zentail, S. S., Craig, B. A., & Kuester, D. A. (2011). Social behavior in cooperative groups: Students at risk for ADHD and their peers. *The Journal of Educational Research*, 104, 28-41.