

**Japan's new minority: Persons with hattatsu shōgai (developmental disability)**

by

Junko Teruyama

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Doctoral committee:

Professor Jennifer E. Robertson, Chair  
Associate Professor Junko Kitanaka, Keio University  
Lecturer IV Holly Peters-Golden  
Professor Elisha P. Renne  
Associate Professor Kiyoteru Tsutsui

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## **LIST OF ABBREVIATIONS**

**MEXT**

Ministry of Education, Culture, Sports, Science and Technology

**MHLW**

Ministry of Health, Labour and Welfare

**SSE**

Special Support Education

**SST**

Social Skills Training

## CHAPTER I: INTRODUCTION

On March 11<sup>th</sup>, 2011, a large earthquake of magnitude 9.0 struck the Tohoku area, the northern regions of Japan. The earthquake was one of the largest in Japanese history, and more than 15,000 persons were killed and thousands more were injured and displaced. The shake was followed by a mega-tsunami that hit the Pacific coast of the region, not only washing out the homes of many but also causing the meltdown of the nuclear power plant in Fukushima Prefecture. Day after day, the newspapers told stories of shifting radiation levels, evacuation procedures, and the shortage of power in Tokyo and its vicinities. Amidst this chaos, *Asahi Shimbun*, one of the largest newspapers in the nation, published a half-page story on March 22<sup>nd</sup> about a family that was affected by the disaster. The Ota family has a 10-year-old boy who goes to the local special support school for children with disabilities. He panics when surrounded by strangers and is afraid of loud noises, such as that of an ambulance siren. The boy tends to express stress by banging his hands against the wall while repeating phrases he has heard in TV. Although the family had evacuated from their home, the boy's parents were hesitant to bring him into the temporary evacuation center for fear that his stress-induced behaviors may not be readily accepted among the 300 local residents who are staying at the designated local school gym, sleeping and eating side by side. The Otas parked their car outside the gym and spent the first week living in the

tiny space of the car. Friends brought food that was distributed from the center to their car. It was snowing every night, and the boy's grandfather would wake up in the middle of the night to turn the engine on for a moment to get some heat. But gas was running low in all regions throughout Tohoku, and at times they stayed up all night, wondering how long all this was going to last. The subheading of the story read: "Desperate family, at the evacuation center." (*Asahi* 2011a).

Approximately one month later, the same newspaper reported that a family in Ehime Prefecture, in the southern part of Japan, decided to host the Otas at their home, 600 miles away from Iwate Prefecture. The story featured a photo of the family and their eight-year-old son, who has the same disability as the Ota family's son. The picture showed the hosting son holding out a large drawing paper reading, "Uchi ni oideyo (come to our house)" (*Asahi* 2011b). The mother explained: "I was able to relate to their situation. Thinking about how our son would react under those circumstances, I probably would have made the same choice to stay in the car." The two mothers had exchanged letters after the publication of the first article and eventually had gotten to know each other through the correspondence. Consequently, the Otas had decided to relocate. Although this was but one of the numerous stories of personal tragedy, suffering, and hope published during the aftermaths of the earthquake, it was among only a handful of stories covering the difficulties that those with disabilities and their families had faced under the dire situation. It is an alternative story in that sense, but it also serves to make evident the increasing visibility of those with disabilities, including the way in which they are recognized – and are recognizing each other – as a minority group. This aspect of the coverage becomes particularly poignant when compared



to coverage of the Great Hanshin Earthquake in 1995, where there was almost no revelation of such families and their struggles until months later.

The Ota's boy is autistic, as is their host family's son. Autism came to be broadly acknowledged in Japan over the past decade, through the prevalence of the term "*hattatsu shōgai*." *Hattatsu shōgai*, translated literally as "developmental disability," is a generic term for congenital disabilities that do not entail intellectual disability (ie. can score over 70 in the IQ test); the condition is believed to be caused by brain disorders that are, to some extent, genetically inherited. The three major disabilities that *hattatsu shōgai* encompasses are Learning Disability (LD), Attention Deficit Hyperactivity Disorder (ADHD), and Autism Spectrum Disorder (ASD). The term *hattatsu shōgai* is not a diagnostic category in itself. Rather, it is a term in general usage – used by both lay-persons and psychiatrists – to refer to any of these disabilities, alone or in combination. One of the primary reasons why this term has a stronger foothold than the other, more specific diagnostic labels that it includes, is because it has been instrumental in categorizing a specific group of individuals who fall between the cracks of the Japanese welfare system that acknowledges only three categories of disability: physical, intellectual and mental. In other words, the term *hattatsu shōgai* refers to those who did not qualify for special education or the disability quota in employment, and who did not qualify for social welfare services based on their disability status. This situation has improved significantly over the duration of my fieldwork; today, as I write this, an increasing number of organizations and institutions, both private and public, are beginning to provide services accommodating individuals with *hattatsu shōgai*. The categorization of *hattatsu shōgai*, therefore, is based not so much on the similarities among the specific

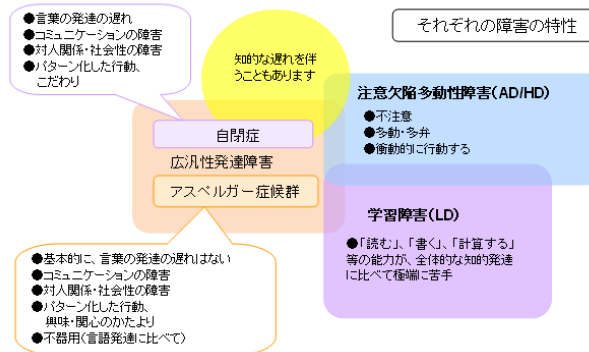
disabilities that it encompasses than on the social imperative to give a name to those who have conditions that require special accommodations but were not acknowledged as such by the public welfare system. I will be using the Japanese term *hattatsu shōgai* throughout this dissertation, for there is not a parallel term in English that categorizes these disabilities in a manner equivalent. This is not to say that the conditions coined as *hattatsu shōgai* do not exist outside of Japan. LD, ADHD, and ASD all appear in the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association; and Japanese psychiatrists refer to this manual in diagnosing *hattatsu shōgai*. The clinical pictures of the patients do not differ greatly between the US and Japanese contexts, either. In fact, there is a significant amount of data and information cited from American sources that are being circulated in Japan, not only in the psychiatric community but also among parents. However, when I use the term *hattatsu shōgai* in international conferences, I am invariably asked the question of why dyslexia and autism, for example, are categorized under a single name, suggesting that this is counterintuitive to those who are familiar with the English-language literatures of the field. Since this specific categorization speaks for the social context by which these disabilities became popularized, I will stick to the Japanese term, *hattatsu shōgai*.

### **The definition of *hattatsu shōgai* and notes on the use of terms**

The following figure is a conceptual diagram describing *hattatsu shōgai*, published by the Ministry of Health, Labour and Welfare (MHLW). It lists the characteristics of each disability as follows:

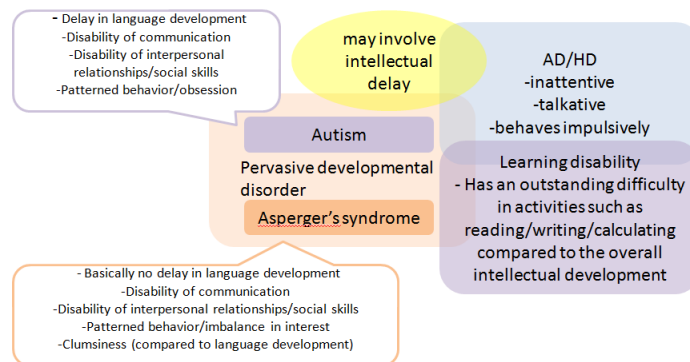
Gakushū shōgai (LD) (The purple section at the bottom right)

- Has an outstanding difficulty in activities such as “reading,” “writing,” “calculating,” etc. compared to the overall intellectual development.



Chū kekkan tadōsei shōgai (AD/HD) (The blue section at the top right)

- Inattentive
- Active/talkative
- Behaves impulsively



Jiheishō (autism) (The light purple section within the orange section)

- Delay in language development
- Disability of communication
- Disability of interpersonal relationships/social skills
- Patterned behavior, obsession

Fig.1. Conceptual diagram of hattatsu shōgai  
(<http://www.mhlw.go.jp/seisaku/17.html>)

Asuperugā shōkōgun (Asperger's Syndrome) (The light orange section within the orange section)

- Basically has no delay in language development
- Disability of communication
- Disability of interpersonal relationships/social skills
- Patterned behavior, imbalance in interest
- Clumsiness (compared to language development)

While this image represents the “official” outline of hattatsu shōgai, there has been some debate regarding the definition of the terms and transitions over time. To avoid confusion, I will briefly go over some of these earlier discussions in order to clarify my choices and intentions behind the use of the various key terms referenced throughout this dissertation.

First, there was a point when hattatsu shōgai was more commonly referred to as keido hattatsu shōgai (mild developmental disability). The word keido (mild) was used to note the lack of intellectual disability. Eventually, however, this term came to be criticized for its connotation suggesting that the suffering and the level of challenge faced by those with hattatsu shōgai is “mild” (i.e. not severe).<sup>1</sup> In this dissertation, I will not use keido hattatsu shōgai other than in citing an external source that uses the term.

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<sup>1</sup> MHLW has issued a document stating that this term is not defined in ICD-10 or in DSM-VI, and points out that its source is obscure. (MHLW 2007) MEXT has also issued a document stating that it will refrain from using the term. (MEXT 2007)

Second, the term hattatsu shōgai in itself is not a new lexicon. It was previously used in a more general sense to refer to all disabilities that take shape during the developmental stages of childhood (including intellectual disability). Thus it once corresponded more closely to the English term “developmental disability,” although it was rarely used outside the professional medical community. Even to date it is sometimes pointed out that hattatsu shōgai does include intellectual disability, although such references are quite scarce. Aligning to the more dominant discourse, I use hattatsu shōgai as a term that excludes intellectual disability, by the definition just discussed. This is also to say that the focus of my research is limited to those who fit this definition. Those with intellectual disability – be it caused by developmental delay or not, be it associated with autistic tendencies or not – constitute an entirely different minority group, one with its own history and idiosyncratic position within the disability rights movement in Japan. My research focuses on the newly emerging minority group that has not been accounted for by the existing frame of Japanese social and welfare systems.

Third, in referring to those with autistic tendencies, the terms “high-functioning autism (kōkinō jiheishō),” “Asperger’s Syndrome (asuperugā shōkōgun),” and “autism spectrum disorder (ASD/jiheishō supekutoramu shōgai)” are often used interchangeably. The difference between high-functioning autism and Asperger’s Syndrome lies primarily in the degree of language delay during the early years of childhood. But the clinical pictures of the two are actually very similar and there has been an ongoing debate about whether the distinction between the two is feasible and/or useful. When DSM was revised in 2013, it officially eliminated the category of Asperger’s Syndrome and incorporated it into the category of autism spectrum disorder, under the claim that there was no consensus or

consistency in the way Asperger's Syndrome was being diagnosed. Consequently, it is presumed that the use of the term Asperger's Syndrome will become obsolete with time. In this dissertation, I use both high-functioning autism and Asperger's Syndrome when referring to specific diagnoses that individuals have received, while using autism spectrum disorder in a more general sense.

### **The scope of my research and its significance**

Hattatsu shōgai is a relatively new concept in Japan. Although there seems to be some mention in academic journals published during the 80s, it was only in the 1990s that the term gained currency in the popular media. In 2002, the Ministry of Education, Culture, Sports, Science and Technology (MEXT) organized a research committee that conducted a nation-wide survey to estimate the number of school-aged children with special needs. The results – along with the significant pressure from the public that followed publication of those results – led to the 2007 landmark educational reform program requiring public schools nation-wide to accommodate children with disabilities through differentiated instruction and extensive utilization of special education resources.

In the US, as in the United Kingdom, autism, LD, and ADHD have been known and studied for decades, and the clinical practice and public engagement in those nations helped form the bases by which the new policy was instituted in Japan. Japanese disability activist organizations consider themselves to be but one chapter of a global movement towards the liberation of disabled people, and they tell their story as a celebrated achievement by which a marginalized and stigmatized minority group won public recognition and asserted the

affirmation of diversity from an otherwise ignorant and conservative government. The rationale for the Japanese government to adopt the new policy was premised on the adherence to the 1994 Salamanca Statement and Framework for Action on Special Needs Education of UNESCO and The Convention on the Rights of Persons with Disabilities, which was negotiated at the UN since 2002. The new policy was contextualized and legitimized in terms of a global trend towards acknowledging and engaging in disability rights activism.

Despite all the reference to external factors that triggered the adoption of the new policy, my fieldwork observation of the local movement in Japan revealed the domestic context of a story that is more complicated and nuanced than a generalized global picture of disability activism might suggest. Hattatsu shōgai came to be initially and widely known through popular media, which associated the disability to juvenile crime. The quickly growing movement that then developed in this context, evolving to account for and accommodate children with the disability, caused much bewilderment among teachers in the public schools. The increasing visibility of the disability led to the creation of a large-scale industry around the care and support of children with hattatsu shōgai, while also giving a voice to a group of adults who began to identify with the category. Stories of struggle and suffering emerged in the public sphere, intricately shaping discourses around what it means to live with hattatsu shōgai, as well as establishing various vocabularies demarcating the political stakes associated with the condition. Questions of “difference” regarding those with the disability became the discursive terrain on which notions of individuality, diversity, tolerance, and inclusion are tested. My research takes a close reading of the process by which hattatsu shōgai quickly gained currency in Japan over the past decade. This work is

meant less to be a contribution to the grand narrative of the global disability rights movement by providing a local chapter to it, than to be an examination of the transition within Japanese society triggered by the formation of a new minority group.

Despite the popular belief that anthropological knowledge is universal and “culture-blind,” previous scholarship in the field of medical anthropology has rigorously examined how medical/scientific knowledge is conceptualized, interpreted, and practiced in different ways across cultures and societies (Lock and Kaufert 1998; Young 1983; Scheper-Hughes 1987). Disability provides an especially illuminating perspective in this discussion, because of its investment in the globally institutionalized human rights activism, which universalizes the meaning of “liberation” (Ingstad et al. 2007), also the existence of international classification systems that influence the epistemological grounds in which local movements are formed (Petryna 2002; Nakamura 2006), and, finally, the fact that disability is less often an immediately life-threatening condition than it is manifest in the long-term experience of social suffering, endurance, negotiation and reconciliation within the specific sociocultural context (Kleinman 1995). To locate disability in both global and local context is, therefore, to consider the body as an “artifact of social and political control” (Scheper-Hughes 1987), and to reveal an ideology of medical knowledge that is embedded, not only in objective indexes, but also in everyday practices that are culturally and historically grounded (Lock et al. 1998; Young 1983; Kleinman 1995).

Anthropological studies on illness and disability in Japan have contributed to this literature by problematizing the essentialized political identity of disability such as in the global Deaf culture (Nakamura 2006), examining the processes by which the legitimacy of



certain medical knowledge is put into question as in the examples of brain-death, menopause (Lock 1997; Lock 1993) and depression (Kitanaka 2011), analyzing the linguistic practice which mediates discrimination and segregation (Gottlieb 2001), and reframing the politics of morality among care-takers based on the cultural notions of aging and family (Traphagan 2007). I hope to situate my work in this genealogy of literatures as an examination of the politics by which certain individuals are “qualified” for disablement through larger systems of signification, thus bearing forms of stigmatization and marginalization that are specific to the context of Japan’s powerful myth of homogeneity (Davis 2002; Goffman 1963; Daniel 1997; Befu 2001).

### **The early years: media review**

My preliminary fieldwork took place during the summers of 2005-2007 and I conducted intensive fieldwork during 2008-2010; the ethnographic material presented in the subsequent chapters is from this period. To supplement my ethnographic data, and to provide a cultural context to my ethnography, I will take a brief look at earlier representations of hattatsu shōgai, particularly as represented in the popular media during the early 2000s when the term was first introduced. In the following section, I will examine some of the salient themes in the early story coverage, which I see as representative of the tone by which hattatsu shōgai came to be acknowledged, contextualized, and understood.

### **Defining hattatsu shōgai**

The earlier mentions of hattatsu shōgai in the newspapers are usually accompanied with a general definition of the term. I would first like to look at how hattatsu shōgai has been defined or, more specifically, how it has been differentiated from other existing categories of disability. This discussion allows me to then examine how the trope of the “cultural Other” has been deployed to describe those with hattatsu shōgai.

Many of the earlier articles enumerate the various salient symptoms characterizing hattatsu shōgai. For example, children with the disability are described as “able to calculate but does not understand the ‘story problems’ in math,” “does well in reading and writing but does not grasp the idea of fractional numbers,” “can understand information when the material is read to them, but not when they read them to themselves” and “achieves high standard in mechanical information processing such as memorization, but has difficulty understanding others' feelings and emotions.” What we see here is a frequent juxtaposition of what one can do next to what one cannot. In other words, achievement in a certain field is contrasted to the failure in another. This discrepancy becomes a defining marker of hattatsu shōgai – the condition is not characterized by the general lack of ability, but by the gap between what one is capable of and what one is not. This method of describing hattatsu shōgai seems to be employed as a means to distinguish its characteristics from those of intellectual disability. In Japan, intellectual disability is defined as having an IQ below 70 (in a distribution where 100 is the average), where those above 70 are considered to be within the “normal” range. Those with hattatsu shōgai, on the other hand, are within the “normal” range by the measure of IQ, but experience difficulties in certain limited areas. The definitions of hattatsu shōgai used in these articles highlight the selectivity of the inability on

very specific, focused areas of academic work, distinguishing the disability from the already widely known category of intellectual disability. This juxtaposition of capability and incapability in describing the disability has had profound implications in establishing an uncanny position for hattatsu shōgai vis-a-vis existing categories of disability. Marked not by generalized incapability but by the unexpected gap between what one can and cannot do, hattatsu shōgai has been explicitly demarcated from other disabilities, thus gaining something analogous to “honorary white” status along the scale of normalcy and disability.

Another salient aspect of the tone and language used in defining hattatsu shōgai is its association to the cultural Otherness. Certain behaviors of children with hattatsu shōgai are often described with an undertone almost resonating that of articulating a different culture. “People with autism spectrum disorder sometimes become self-abusive when they cannot communicate well. Some even hit their faces so hard that they lose their vision,” writes a reporter of *Yomiuri Shimbun* (*Yomiuri* 2001b). Statements such as this focus on the outward manifestation of a “strange behavior,” leave unexplained the rationale behind such apparently self-destructive actions. Do they hit themselves out of frustration? Is it an act of self-punishment? In another article, a typical person with Asperger's syndrome is characterized as “able to speak in a grammatically correct way but does not understand subtle sarcasm or jokes and cannot differentiate 'tatemae' (formalized expression) and 'honne' (true intention)” (*Yomiuri* 2001b). This statement strangely reminds us of literature in the anthropology of Japan that articulates the 'tatemae'/'honne' distinction, and the communicative practices of

shifting along these two poles, as *the* practice through which the Japanese self is identified<sup>2</sup> (Doi 1973, 1986). In this statement, the mode of literacy described by “grammatical correctness” is positioned in stark contrast to a more culturally specific, nuanced function of literacy and language. To claim that people with Asperger's Syndrome lack the ability to communicate using the latter mode of language – implying a failure to gain an appropriate *cultural* literacy – seems to allude to the Otherness of those people, almost as if questioning their Japaneseness<sup>3</sup>. Many of the articles that I encountered describing interactions with children with Asperger's Syndrome recount the experience with the connotation of an “inter-cultural exchange.” To cite an example, in a 2004 article from *Yomiuri Shimbun*, a teacher of an educational support class humorously describes a conversation with her first-grade student, Kazu, who has Asperger's Syndrome.

Trying to get Kazu's attention, I said, “Listen to me.” But then, Kazu immediately looked away from me. I got mad and didn't say a word. Kazu, raising his eyebrows, turned back to face me. I repeated, “Listen to me.” Again, he looked away. Is he making a fool of me? “If you're going to behave like that, I'm not going to talk to you any more!” Seeing my angry face, Kazu looked like he was going to cry. “But you told me to listen....” Surprisingly, it turned out that

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<sup>2</sup> Doi's works are seen as the foundational texts on 'tatemae' and 'honne', but numerous literatures on Japan (both within and outside the discipline of anthropology) have inherited Doi's framework that the concepts have become a canonical theme in referring to Japanese culture and personhood. For example, Gottlieb (2012).

<sup>3</sup> The presence of this discourse of associating autism with cultural Otherness is not exclusive to Japan. For example, see Silverman (2011).

Kazu wasn't exactly looking away from me, but he was trying to turn his ear to me so that he could listen better. "When you listen to people, you should look at the person's face." I told him. So he started staring at my face. Suddenly, he made a remark "you have big eyes." Unexpectedly flattered, I couldn't help but smile. "But if you stare at me like that, it's difficult for me to talk. You don't have to keep your eyes on me all the time. Also, I'd rather if you looked at me around here (pointing to chin) than in my eyes." So he started staring my mouth and his next words were, "your bottom teeth are lined up in a weird way." I didn't know what to reply, knowing that he wasn't aware of the distinction between flattering comments and slandering remarks (*Yomiuri* 2004:34).

Although the two interlocutors in this dialog are purportedly engaged in a conversation, both of them are having difficulties grasping the intention of the other. While the teacher does not understand Kazu's gesture of "turning his ear to listen," Kazu is not quite aware of his teacher's feelings when he makes various comments about her face. The crisscrossing of the conversation becomes amusing, almost as if we are following a dialog of people coming from two distinct cultures. The difficulty in understanding the mode of thought of individuals with hattatsu shōgai forms an underlying theme in early representations of the disability. The dynamic also informs – and is mutually informed by – the mediation of certain pivotal hattatsu shōgai juvenile crime cases, which I will be discussing below.

## **Referencing the US**

A good number of articles discuss hattatsu shōgai through references to the condition in the US context. Special education and legal support systems in America are

described as the ideal model to be emulated. In the readers' column of *Asahi Shimbun*, from July 1997, a woman in her forties writes about her conversation with an American schoolteacher for which she became an exchange host:

[the schoolteacher] said that her daughter has learning disability. "What is learning disability?" I asked, and she told me that her daughter had severe difficulty in reading and did poorly on exams. But now, that daughter studies marine biology at the University of California. I asked her how she passed the entrance exam, and to my surprise, she told me that she had the exam in oral form because she can understand it when it was read to her, although not when she had to read it herself. She also mentioned that another student, who couldn't spell and did disastrously in language education, now studies at Stanford University. The schoolteacher said that some students may have difficulty in spelling but they should have some other talents or areas that they enjoy, and that it is the teachers' responsibility to come up with a way to make the best out of each student's potential. Thinking of the poor education in Japan that only measures students' ability in terms of standardized knowledge, I was deeply struck by the great tolerance and understanding in U.S education. [*Asahi* 1997:5]

Not only is the reference to the US and UK limited to the examination of the "model" educational systems from a distance, but it also appears in a more personal level through the narratives of students who went abroad to experience the system first-hand. An *Asahi* article from 1994 describes a "returnee" student who first accompanied his father for a job assignment in the United States (*Asahi* 1994). The student was in second grade then, and he enrolled in an elementary school in America where he was diagnosed as dyslexic. He received individualized education at the school. Upon returning to Japan as a middle school

student, when he continuously failed in classes and was labeled as “lazy” and “disrespectful to the teachers,” he started expressing a desire to return to the United States. During the summer of his senior year in high school, he participated in a summer program in Massachusetts for dyslexic students and returned “iki-iki-toshite” (refreshed, lively and energetic). That same year, he decided to enroll in a high school in the United States. He eventually graduated and started college in the US. The reporter writes: “They provide him extensions for exams, oral tests in place of written ones, and they even have audio-taped text books. They provide the necessary learning environment for dyslexic students.”

In March of 2002, *Asahi* did a series on how ADHD is being treated in public schools in the US (*Asahi* 2002a). The series highlights the stark contrast between the incapability of Japanese schools to accommodate for students with hattatsu shōgai and the strong support provided by the American schools. Before 12-year-old Keita moved to the US with his family on his father's job assignment, he was frequently missing school and was bullied by his classmates. His mother tried to talk with the school officials but she was not understood and nothing was done to help improve his relationship to his peers. When he moved to the United States and enrolled in his new school, the teacher tried to help him more in making friends than in making him keep up with the work. He was assigned to a counselor who taught him the necessary social skills, and the assistant English teacher placed a priority on teaching English for social interactions. Keita's mother was pleased with the approach to her son's educational instruction: “Here, students' individual needs are taken seriously. It's not about the label of disability.”

There are several themes shared by all three of these stories: the comparative perspective between Japan and the United States, criticism against Japanese education, a high respect for the American education, and an implicit message that Japan should follow the steps of American education. In one somewhat ambivalent response to this pattern of holding up the American model for inclusive education, a former schoolteacher comments:

I'm skeptical about blindly following America and bringing in everything that they do into the Japanese context. People say that we should ban special education programs in Japan and advocate inclusion like American schools do, but assigning teachers' assistants to specific students, a practice widely adopted in the U.S. schools, is also an alternative form of special education. Things are not all that simple." [*Asahi* 2002:33]

The assignment of aides to specific students was actually one of the new practices that the Japanese schools began with the implementation of Special Support Education in 2007, as I will discuss in more detail in Chapter Two of this dissertation. In many ways, MEXT has been benchmarking the American system of special/individualized education and the media has gone along with this. But this particular comment by a reader questions this tendency to uncritically follow the American model. Furthermore, it is worth pointing out that the discourses praising American education are obviously turning a blind eye to certain problems in America. The US system is one that is highly unequal; the quality of public education varies greatly according to one's zipcode, as academic standards tend to be highly localized.

Nevertheless, the repeated reference to the US is important to examine from a larger context. Considering how criticism of the Japanese education is almost always accompanied by some form of allusion to the American (or sometimes British) system, it seems that the practices in America provide for a framework in which one can talk about



hattatsu shōgai. It functions as a model, at least a provisional one, that serves as an outline to what students with disability should be entitled, how they should be cared for in the schools, and to what extent the parents can voice those demands. For a new disability that lacks historical context, American education seems to be a substantial point of reference in shaping a consensus on what hattatsu shōgai stands for. The reverence for American education is a theme that also came up numerous times while I was conducting fieldwork, and there were moments when I ended up arguing with my informants, pointing out the flaws of the American system and the dangers of making a simplistic and optimistic comparison. However, the belief in the American model was deep-rooted, and it was clear that that belief was instrumental in bringing about actual improvements to the educational policies. In a way, the discourse of treating the American education as an exemplary model was used strategically to criticize the “backwardness” and “inflexibility” of Japanese education.

### **Unexplainable motives, arbitrary targets: portrayal of the “new” criminals**

Across Japan of the late 90s, a series of brutal crimes, many of them committed by teenagers, made front-page news, thus triggering tremendous social anxiety. An incident occurring in the city of Kobe in 1997 initiated the series. On May 24th, an 11-year-old boy was kidnapped and killed on his way to visit his grandfather. His headless body was discovered, severely disfigured; three days later, his head was found placed on top of the gatepost of the local school; a statement signed by the criminal was stuffed in its mouth.

When a middle-school student of age 14 was arrested for committing this unimaginably atrocious crime, the case created a huge national uproar, triggering heated debates about “the problems of Japanese children.” The media revealed that the perpetrator had been previously diagnosed with ADHD.<sup>4</sup> Coined “the Sakakibara case” (after the pseudonym that he used when signing the statement), the incident contributed greatly to the emergence of hattatsu shōgai within the public imagination, thereby contributing to the function of the term as an explanatory schema for the mediation of violence and criminal activity among Japanese youth. The characteristics of the crimes seemed to demarcate a new paradigm of juvenile delinquency, because they were not motivated by poverty, discrimination or personal hatred, as were more conventional cases. In most cases criminal motives were unclear and the targets were arbitrary, thus hattatsu shōgai seemed to provide an easy answer to the causality of these crimes. Furthermore, the “Otherness” of the people with hattatsu shōgai – the apparent “foreignness” of their mode of thought and use of language, as discussed above – seems to have rendered the disability particularly vulnerable to exploitation in this context. Hattatsu shōgai quickly became the scapegoat by which to explain the unexplainable, acquiring the blame for this apparently unprecedented pattern of juvenile crime.

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4 The psychiatric evaluation ordered to be conducted in court stated that he has behavioral disorder combined with sadistic tendencies, and did not mention the term “hattatsu shōgai.” However, the fact that his mother had taken him to a counselor prior to the incident and had received the diagnosis of ADHD was publicized widely.

The Sakakibara case was followed by other cases that became instrumental in publicizing hattatsu shōgai. In April 2001, a female college student in Tokyo was stabbed to death by a 29-year-old man named Makoto Yamaguchi. Media coverage of this incident vividly depicted the “strangeness” of the suspect. Before he was even arrested, newspapers reported on the details of his attire, which, despite the warm spring weather, included a fur coat and a stuffed-animal-like hat (the latter taking the ironically appealing form of a lesser panda). After his arrest, it was reported that Yamaguchi chose his victim at random; he told the police that he “didn't care who it was, as long as it was a good-looking woman.” When he was interrogated with questions that he could not answer, he responded by saying, “my mother would know.” It was later revealed that his mother had passed away when he was a teenager. At the time of the incident, the perpetrator had been walking behind the victim, reportedly with the intention of molesting her. When the victim unexpectedly turned around, Yamaguchi felt insulted by what he thought was a disdainful glance, and he took out his cooking knife and stabbed her. Six months after this incident, Yamaguchi's lawyers attested in the trial that he has autism spectrum disorder and therefore cannot be held responsible for his actions. After numerous clinical examinations and prolonged trials, the Tokyo district court ruled in 2004 that Yamaguchi is responsible for the crime and sentenced him to life in prison.

Although not a juvenile crime, this case was significant in that it spurred much debate – represented in popular media as well as in specialized publications for medical and legal professionals – around the question of the legal responsibility for crimes committed by individuals with hattatsu shōgai (Sato 2005). Heated discussions were raised regarding

whether hattatsu shōgai should be treated in similar ways as intellectual disability, potentially modifying the conditions of criminal liability. At the same time, and far more problematically, ramifications of such cases led to a widespread discursive association between hattatsu shōgai and criminal behavior. Much of the public attention paid to the case centered on the suspected perpetrator's strange attire and on his apparently delusional responses in the interrogation process. Here again, the fact that he was diagnosed with autism spectrum disorder seemed to explain the reason why a grown-up man could be wearing a lesser-panda hat and talking about a mother who had passed away. Such a presentation, making the claim for a simple causal relationship between the disability and Yamaguchi's inability to conform to society (thus making him a "delinquent" or a "crazy person"), forms the implicitly suggested but strongly influential theme running through many of the articles.

In July 2003, another similar case followed, this time committed by a 12-year old boy who killed a 4-year old boy named Shun Tanemoto. The suspect kidnapped Shun at an electronics store in Nagasaki city; the two did not know each other. With the intention of assault, the suspected perpetrator brought Shun to a parking structure and abused him with a pair of scissors. When he noticed the security camera installed in the building, he panicked and tried to escape. In a hurry, and realizing that he couldn't bring Shun with him, he killed the boy by pushing him over the edge of the structure, from a height of 65 feet. The family court, where the 12-year-old was put on trial, disclosed the fact that he has hattatsu shōgai, and claimed that he lacked the social skills to understand others' feelings. He had just started junior high school, where he had experienced a difficult time adapting, and there was

constant tension within his family. When interrogated by the police about the day that he committed the crime, he stated that he was in a hurry to get home, as he was anxious that his mother would scold him for being late. In the articles, he was represented as demonstrating an unusual level of fear of his mother, a situation he had experienced since elementary school. The court ruled that he be sent to juvenile reformatory institution to work closely under the observation of psychiatrists, having considered it unlikely that his parents would be cooperative in the process of his reeducation.

The media's attention to the boy's upbringing and his relationship to his family – which is unusual for juvenile crime cases – elicited powerful responses to this case and its coverage. As it was pointed out that the upbringing of the boy was strikingly similar to the previously mentioned Sakakibara case, some called for promoting government intervention on family issues as a means to alleviate social anxiety around increasing juvenile crime (*Yomiuri* 2003b). Others responded critically to the fact that the boy's disability was given so much attention by the media, which had gone so far as to report a high rate of juvenile crime within the hattatsu shōgai population as compared to the general population, a piece of “information” cited from anonymous statistical data (*Yomiuri* 2003a). Noting a problematic discursive trend, the president of Autism Society Japan (ASJ) drew attention to “the dangers of simplistically associating hattatsu shōgai to the potentiality of delinquency,” and stated that ASJ will strive to correct social misconceptions (*Yomiuri* 2003c). On a similar note, Tsujii Masatsugu of Chukyo University wrote that, “it is commendable for the court to disclose as much information as possible to the family of the victim,” but simultaneously expressed some reservation regarding the extensive association of hattatsu shōgai with

deviant behavior. Referring to a similar case that took place in Aichi prefecture in 2000, where a 17-year-old with Asperger's Syndrome was taken in by the police for killing an older woman. Tsujii writes:

That case raised a lot of misconceptions to the general public. Some parents told their children not to make friends with those with disability. There were also cases where parents of children with disability were confronted by other parents at school meetings. [...] It wouldn't be an exaggeration to say that these people are the victims of a new discrimination." [Asahi 2003:14]

Tsujii is calling attention to the powerful and often problematic role of the media in perpetuating specific – particularly negative – images of the people with disability. His account of the parents eloquently describes how discrimination can manifest through discourses provided by the popular media. The newspaper articles had set the tone for people to talk about hattatsu shōgai in a very specific way, condemning their potential criminal status.

I would now like to turn to the voices of the mothers, which constitute a powerful counter-narrative to this highly stigmatizing discourse.

### **Suffering the blame: the stories of motherhood**

Mothers of children with hattatsu shōgai are most often the primary caretakers of their children, and they are seen to be responsible for raising them “properly.” Should they fail to comply with those expectations, they would be in a socially stigmatized position for being unable to fulfill “the mother's role”. A letter by a 38-year old housewife introduced

in the “Opinions” section of *Asahi Shimbun* describes the experience of raising her daughter (who she now thinks is learning disabled but without diagnosis):

My daughter was very slow in learning to talk. No matter how simply I phrased things, she wouldn't understand. When she was about three or four, I had her tested for hearing impairment but they didn't find anything wrong with her. They actually thought that the problem was about me (in the way that I was raising her). I started to think that maybe I hadn't spoken to her enough when she was younger, or that maybe I had been cooking the wrong kinds of food. I started to feel that it was all my fault, because I was inadequate as a mother. My own mother also blamed it on me, saying “child-raising is always difficult, but everyone manages.” My husband, the only person I could rely on, was busy working and wouldn't come home till late. [*Asahi* 2001:10]

The sense of being isolated at home to take care of the child puts a lot of pressure on the mothers. When they find something out of ordinary about the child, the frustration can be overwhelming. The implicit themes raised by this testimony come into focus with the mother's words, “everyone manages.” “Everyone” is referring to “every mother,” suggesting a universality of experience – that is, mothers supposedly facing the same struggles to attain the same goal of successful child rearing. The comment sounds less like advice or consolation from a mother to a daughter than a peer criticism lodged from one mother at another. The lack of presence on the part of the husband also seems to weaken the significance of family ties in this context, leaving “collective motherhood” as the only source of identification for the writer. Thus, problems with child raising pose critical questions about motherliness and membership to the community of mothers, often leading to self-blame and to the degeneration of self-esteem. This is the context in which mothers of

children with hattatsu shōgai have become one of the most vocal and active proponents of public awareness and the correction of widely held misconceptions.

The “Kiryu (air current)” section of the *Yomiuri Shimbun* is a space allotted to letters from readers. Most of the letters describe an episode from the writer’s daily life with an undertone of criticism towards the status quo of various social problems and current issues. Beginning at around 2002, letters on the topic of hattatsu shōgai started to appear in this section, mostly written by the mothers of children with the disability. These letters provide insight into the ways in which the mothers construct their agency and entitle themselves to tell their own stories, speaking from the position of “co-sufferer” of the disability experience.

A letter that appeared in October 2003 in the “Kiryu” section was from a 41-year-old housewife living in Thailand (*Yomiuri* 2003d). Responding to the case of the 12-year-old boy held responsible for killing a young child in Nagasaki prefecture, the letter argues that the mother of the suspect should not be blamed for raising the child to become a criminal: “The boy was diagnosed with hattatsu shōgai, but I believe it is extremely difficult at present to identify this disability and make early interventions through appropriate care.” She also mentions that many of her Japanese acquaintances, having noticed that their children were “somewhat unusual,” contacted medical professionals only to field hopeless responses like “children with this condition never get any better.” The writer sympathizes with “the desperate mothers who feel driven into a corner, not only by the social stigma but by professionals as well.” Another writer, on the following day, also voiced her concerns about criticizing the mother of the boy (*Yomiuri* 2003e): “He was probably somewhat different from the other children, but I’m sure that the mother put in her best effort in raising the boy.



I have nothing to argue against the gravity of the crime that he committed, but the depressing part of this incident is to see all the condemnation being focused on the mother's child-raising.”

As we can see in these comments, it is in the language of motherhood that these writers voice their concerns and criticisms against the media and public discourses, while also expressing sympathy to their peers who have been wrongly blamed for their painstaking effort to raise their children with disability. It is also important to note that this communication is taking place in the Opinion section of the newspapers. The Op-Ed sections have historically been the medium by which Japanese housewives have exchanged ideas, raised voices and realized common political goals. During the early 1950s, political consciousness among housewives came to a peak, with many women raising their voices in these columns, advocating for issues pertaining to children's safety, opposing the revival of the “family system” under the post-war constitution and supporting the anti-nuclear campaigns in the Bikini Islands. As Shimizu has written, it was a time in which “the hands that mixed miso (bean paste) were now grabbing pencils to express their opinions, especially their hopes for peace in the post-war period” (Shimizu 1955). In the 1950s, the Op-Ed sections of newspapers were the primary medium for these women to exchange ideas, as most were basically confined to their homes to take care of their husbands and children. However, today, many mothers raising children with hattatsu shōgai use the internet as the primary medium to exchange information, share personal experiences and provide mutual support. Therefore, opting to write to the Op-Ed sections has a different significance today; they are making a public statement to contribute to the lay understanding of the disability, to be read by the general population. In other words, it is with the hope of shaping a particular

kind of lay discourse on hattatsu shōgai that they are contributing their comments to the major newspapers.

### **Disability as *kosei***

In the “Kiryu” section of *Yomiuri Shimbun*, a 33-year-old mother writes about her second-grade son, who had constantly been labeled by his teachers with various conditions of hattatsu shōgai: “ADHD,” because he couldn't sit still in class, “autistic,” because he caused so much trouble, and “Asperger’s,” because he was doing relatively well in academics despite these other conditions. Although he was finally seen by a doctor who concluded that he has none of those disabilities, the mother writes, “even if my son did have any of that, I think it should be considered as his *kosei*. If the teachers and the other children would tolerate it as *kosei*, they would eventually learn to care for others and to help one another” (*Yomiuri* 2002a:13). In another “readers’ column” of *Yomiuri*, a 39-year old mother writes, “the word ‘hattatsu shōgai’ is being used increasingly these days, but I wish we could use the word ‘hattatsu *kosei*’ instead. My husband and I think of our 7-year-old son as possessing a wonderful *kosei*” (*Yomiuri* 2005:23).

“Kosei” literally means “personal quality/character.” This is not a phrase coined by the mothers themselves, but it originates from the earlier disability rights movement in 1970s, when “Aoi shiba no kai” (Green Grass Organization), a socializing group for people with cerebral palsy, came up with the slogan as a means to promote self-empowerment and disability pride (Brown 2006; Mori 1999). Very simply put, the idea of disability being a

kosei promotes a discourse of liberation; it celebrates disability as a personal quality, rather than framing it as a deficiency or lack of capability. However, in the three decades since the times of the Aoi shiba no kai, the term “kosei” has become much more loaded. As Cave describes, the educational reforms taking place in Japan during the 1980s and 1990s had adopted “stress on individuality” (kosei jūshi) as a slogan that was “purportedly aimed at encouraging creativity by introducing more freedom and choice into the education system” (Cave 2001). The call for kosei-centered education in the public sphere has led to the re-appropriation of the term to embody the criticism against the rigid and standardized educational system. In other words, the mothers who wrote the above letters to the newspaper are implicitly criticizing the failure of the schools to view the children’s disabilities as a matter of individuality. In the following section, I will further discuss the ways in which public school education is being addressed in the media articles.

### **Challenging the educational system**

Both implicitly and explicitly, the newspaper articles identify the “rigid and overly-standardized system” of Japanese education as the crucial deterrent to the exploration of alternative methods of instruction for the students who are falling behind. The academic struggles and failures of students with hattatsu shōgai are seen not as a result of the impairment per se, but as a negative consequence resulting from the inability of the schools to accommodate those students. It is immediately apparent that such discourses stand as the inheritance of the social model of disability activism, which claims that disability is not a “natural” consequence of the impairment but is created by the environment that is

planned/designed/built in the ways that may be inaccessible to certain groups of people (Fougeyrollas et al. 2001).

A 1995 article from *Asahi Shimbun* describes a private school in Aichi Prefecture, which was founded by parents to provide an alternative education for students with hattatsu shōgai in grades 7-12 (*Asahi* 1995). Miyako Kito, one of the organizers of the school says: “We don't give repetitive exercises. We don't use textbooks either. This is a place to have the children learn that studying is fun, and to cultivate a sense of trust among them.” The reporter then describes sitting in at an English class for middle school students:

There are three students and one teacher, Ms. Nakagawa, who is a housewife living in the local district. Instead of using textbooks, Ms. Nakagawa responds to the students' ideas and makes suggestions. On this day, they used an English board game. The students would move their pieces and practice English by answering the English questions written on the space that they land. If they cannot answer, Ms. Nakagawa or the other students may help them. In the other classes, the students were learning to sew and to do plant dyeing. Some are very involved while some others wouldn't show any interest and spend time reading comic books, but the teachers wouldn't scold them. [*Asahi* 1995:2]

The educational experience provided in this school seems to be very different from the conventional schools. The use of games in class, the local community outreach, the informal relationship between the teacher and the students, the generally non-competitive atmosphere, and the advocacy of “fun learning” and “hands-on experience,” are all very apparent from this article. Many of these features seem to be a result of carefully avoiding the practices in public schools that have been condemned by the parents of children with hattatsu shōgai (i.e. rote memorization, standardized curricula, harsh competition, and learning experience heavily focused on reading).

While the usefulness of alternative education and teaching styles has been pointed out in many other articles, there are also articles that describe the individual practices of trial and error by public school teachers to extend a helping hand to children with hattatsu shōgai. *Yomiuri Shimbun* carried a series of short essays written by a teacher working at an individualized special education class for children with hattatsu shōgai.

I asked Itsuko what she wanted to do. She held up a chair and said, “I want to throw this.” So I said, “why don't you throw this, instead?” and gave her a stuffed animal. She took it out on it. Then she wandered around the classroom and eventually sat down to draw. [...] Itsuko then said, “I'm going to study a bit” and wrote “ $1+1=2$ ” and “ $1+2=3$ ” on a piece of paper and asked me to give flowered circles, so I did. [*Flowered circles are marks that schoolteachers give to excellent answers.*] She then asked, “Was I good today?” I was struck by that question. I know that her parents and teachers are trying to give her extra attention, but what if that's making her feel like she is a problem child? The more she pressures herself to ‘be good,’ the more she'll accumulate stress. I want to take the time to show her that she's good. The first step would be to accept and understand these children. [*Yomiuri 2002b:28*]

While the aim of this class is apparently to help the children keep up with the schoolwork, the teacher seems to be seeing it differently. She lets Itsuko do as she wishes, noticing that the child craves the opportunity to release some stress. Although there are conversations and interactions between the teacher and Itsuko, the teacher never disagrees with the student. The attitude of the teacher seems to communicate an understanding that living with hattatsu shōgai is, in itself, a difficult and emotionally straining experience; she give the students a place to unwind and be themselves, which is prioritized above having them strive to “keep up” with the work.

These stories – describing the day-to-day interaction with children with hattatsu shōgai and noting the discoveries and disappointments, the effective and failed measures – became increasingly professionalized as time progressed. Similar columns can still be seen in newspapers today, but they are usually written by trained psychologists or counselors, and their writings are interspersed with academic concepts and names of institutionalized/commercialized treatment programs. Their practices have come to be widely known as ryōiku, which I will discuss in more detail in the next chapter.

Thus far, I have provided an overview of the early representations of hattatsu shōgai in the public media. My intention has been to show the process by which hattatsu shōgai came to be defined as a category. Of particular importance is the fact that the public acknowledgement of the disability was not prompted or promoted by the medical community; rather, public awareness was raised by the engagement of the judicial and educational professions. It was through their efforts that the need for a broad social accounting for individuals with this new disability emerged as a critical issue. Consequently, hattatsu shōgai has never been a politically neutral and culturally blind category of biomedicine. From the outset, the ways in which the condition's boundaries are demarcated – how its symptoms are described and its treatments are discussed – speak to the processes whereby the Japanese public has strived to define and contain this new category of disability, along with the new minority population that it circumscribes.

The following chapters take a closer look at how the concept of hattatsu shōgai evolved and took shape in the years that followed. Chapter Two is based on my

ethnographic work in the school setting, discussing the impact of the new policy to accommodate for children with the disability through the perspective of a classroom aide. In Chapter Three, I focus on intervention programs for children with hattatsu shōgai and discuss the philosophies and goals behind various treatment practices. In Chapter Four, I turn my attention to adults with hattatsu shōgai and examine their personal stories of “discovering” their disability and identifying with the label. Finally, in Chapter five, I will take a step back to examine the discourse regarding the increasing rate of hattatsu shōgai diagnosis and the various confounding debates to which this increase has given rise.

## CHAPTER II: SPECIAL SUPPORT EDUCATION

On an early spring day in 2009, I was sitting in a small meeting room with four other women, three of whom I was meeting for the first time. We took turns briefly introducing ourselves. The fourth woman, a leader of a local non-profit organization, led the rest of the meeting, describing the two boys we were assigned to look after in the coming months. The Japanese school year started in April, and we were going to be aides at an urban public elementary school in Tokyo to help two incoming first grade students adapt to the school regimen. “Ryo has difficulty sitting still and following instructions. He’s also short-sighted and wears glasses; not a major problem, but he may have a hard time seeing the blackboard if he’s seated at the back of the room. He knows how to write, but has difficulty shaping the letters. Here’s a sample of what he wrote in preschool.” All of us leaned forward to take a glance at the worksheet, which was completed with handwriting that looked more like carefully designed geometric patterns than legible letters. There seemed to be an inconsistency in pen pressure as well. “Daisuke, the other boy, is very intelligent and can complete assignments beyond his grade level but he has a strong predisposition to maintain rules and order in certain things. He’d spend half an hour changing the order of crayons according to color, for example. He won’t be able to finish up a task according to the teacher’s instructions.” We all took notes as the organizer went



on to describe the two boys' family and educational backgrounds, results of intelligence tests, and an account of school's expectations. Only one of us had previous experience as an aide at another school, but all of us had completed a short course on hattatsu shōgai at the non-profit organization, which was commissioned by the local board of education to provide trained aides to the elementary and junior high schools of the district. At the end of the meeting, we filled out some paperwork, discussed our working shifts, and made plans to meet at the school on our first day.

Beginning with this meeting, I spent a period of eight months as a classroom aide for these two boys in first grade. Prior to this period, I had been involved in a research project affording me the opportunity to interview teachers and parents regarding their experiences with classroom aides in elementary and middle schools in Tokyo. I was also able to observe the classes, noting the students' interaction with their peers, aides and teachers. However, I felt very nervous about embarking on this new phase of my fieldwork, which meant participation in the school activities. Most of my fieldwork until this point had focused on parents' organizations and advocacy groups, and all I had heard about schools were negative sentiments and criticisms. One man with a learning disability, who I had previously met in a self-help group, once confided to me with bitterness: "It was in elementary and middle schools that I was made aware of how incapable I was, and I lost confidence in myself. It was the worst of times." Educational reform was at the core of lobbying activities operated by advocacy organizations, and a vast majority of the informants that I had met up to this point had spoken of "the school" as the ultimate problem; it was the battlefield in which children with hattatsu shōgai apparently encountered unreasonably

difficult academic challenges, including unduly severe discipline, which had deprived them of their sense of self-worth. Their sentiments sounded plausible.

Previous anthropological studies on Japanese formal education include those that examine the psychological aspects of discipline and socialization (Lewis 1995; Tobin et al. 1991), those that focus on the school as an institution and explore its bureaucratic and administrative processes (Singleton 1967), and those that implicitly or explicitly contextualize the educational experience in terms of the imperatives imposed by the larger society, namely, to become efficient and productive members of the highly technocratic society that forged the country's economic power in the 1980s (White 1987; Cummings 1989). However, there is very little anthropological research done on how "difference" is being dealt with in Japanese schools. Rohlen (1983) has examined the various academic goals and orientations among several high schools, and White (1988) and Goodman (1990) have studied returnee students as minority students in the classroom. But ethnographic work addressing how individual difference is being experienced, managed and dealt with on a day-to-day basis in the school setting has been very limited. The negative comments that I had heard at the advocacy organizations fueled my interest in this field, and I entered the field hoping to explore the dynamics by which student "difference" is being treated in the classroom.

## Special Support Education (SSE)

The emergence of the notion of hattatsu shōgai, and the necessity to account for the special needs of children with the disability, posed a big challenge to the Japanese public education system. It was in 2002 that MEXT (Ministry of Education, Culture, Sports, Science and Technology) conducted a nationwide survey to estimate the number of students with hattatsu shōgai in elementary and junior high schools; MEXT concluded that approximately 6.3% of the students enrolled in regular classrooms (tsūjō gakkū) were suspected of having the disability<sup>5</sup> (MEXT 2002). Although this figure was met with reservation, because it was based on the reporting by teachers and thus was strictly observational, it was nevertheless considered to be an unsettling result, given that the special education system in place at that time (including special education schools and classes) was designed to accommodate for only 1.4% of all school-aged children (MEXT 2005). In other words, the survey brought to light the existence of a vast population of students with special needs – nearly five times the number of those who were previously receiving appropriate support – struggling in the regular classroom, unidentified and left without help. The official MEXT report of this survey became a monumental document toward the advocacy for educational reform, and the survey's figure of 6.3% was quoted in numerous sources that pushed the government to take action and provide adequate support for those students. It

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<sup>5</sup>The survey was designed based on LDDI (Learning Disabilities Diagnostic Inventory), ADHD-RS (ADHD Rating Scale) and ASSQ (Autism Spectrum Screening Questionnaire), which are diagnostic tools developed in the U.S and Sweden, and the results were found to be comparable to figures reported in DSM-IV and IDEA (Individuals with Disabilities Education Act) papers. A follow-up survey was conducted in 2012, a decade after the first survey, and the rate was updated to 6.5%. (MEXT 2012)

was in this context that MEXT designed the framework for Special Support Education (tokubetsu shien kyōiku) which was put into effect in April of 2007. The implementation of the Special Support Education (the official English term for tokubetsu shien kyōiku; hereafter referred to as SSE) was the largest reform of the educational system for disabled children since 1979, when elementary and junior high school education was made compulsory for all disabled children. The newly implemented SSE is most often characterized in the language of a “spectrum,” which emphasizes the blurry boundary between disability and able-bodied-ness, thus avowing a refusal to slot students into the existing either/or categories but to account for – and to provide for the unique needs of – each individual student in every shade of the gray zone (Ishikawa 2007).

The introduction of classroom aides was one of many improvements made possible by the implementation of SSE. As of 2009, approximately 26,000 aides have been placed in 32,000 public elementary and middle schools nationwide<sup>6</sup> (MEXT 2009). In Tokyo, aides are recruited through advertisements in public notice papers, local bulletin boards and websites of municipal governments. A large portion of the applicants are housewives, many of whom are mothers themselves, but there is also a significant number of former schoolteachers and retired people, as well as undergraduate and graduate students majoring in relevant disciplines. Many local governments and boards of education provide short courses to train the applicants for a period of time ranging from a few days to several months.

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<sup>6</sup>It must be noted that since SSE encompasses all types of disability, the number of aides listed in this data includes not only those who are assigned to students with hattatsu shōgai, but also those who are assigned to students with physical, cognitive, and other disabilities.

In the particular district in Tokyo, where I worked, this training course took about ten days; the training involved lectures on hattatsu shōgai and various methods of intervention, as well as talks by older students with hattatsu shōgai and discussions with experienced aides. Upon completion of the course, the new aides were placed in local elementary and junior high schools, usually working on contract by semester. Aides' working hours vary by the amount of help that the assigned student requires, and they receive hourly pay at a rate comparable to other part-time jobs in the service industry.

The implementation of SSE involved various other administrative changes, including the appointment of a “special needs coordinator<sup>7</sup>” in each school, the practice of drafting Individual Education Plans (IEPs) to track the performance of each special needs student, and opportunities for schoolteachers to improve their knowledge and skills regarding diverse disabilities and individualized education through training courses. Among the many procedures that SSE mandated, one of the highlights was the drafting of an IEP for each student requiring special support. Every semester, teachers, parents, school psychologists, and special support coordinators are asked to hold a meeting to draft an updated IEP. IEPs chart the progress of each student, addressing specific challenges, setting short-term and long-term goals of instruction, and proposing plans for action. Administratively, this procedure adds an additional layer of burden to the teachers and thus,

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<sup>7</sup>Each school is to appoint a “special needs coordinator” among its teachers, who will then be responsible for establishing liaison with local hospitals, welfare offices and neighboring schools/preschools, while also overseeing the administrative work of allocating resources to all special needs students enrolled in the school.

in the period I witnessed, it led to a rather strong resistance from the schools. MEXT decided to enforce it nevertheless, claiming it to be a critical part of SSE.

The new policy also changed the names of all public special education schools to “tokubetsu shien gakkō (special needs school)” instead of the former designations of schools for deaf/blind and other disabilities (rōgakkō, mōgakkō and yōgo gakkō, respectively), thereby dismantling the categorization by disability type. At the heart of this large-scale reform was the imperative to make a significant shift from the notoriously segregationist enrollment policy and to respond to the international pressure to promote inclusion in the educational setting. In the section that follows, I will briefly discuss the historical background of Japanese special education to provide a context for this reform.

### **History of special education in Japan**

The history of special education in Japan dates back to the Edo period (1603-1867). Japanese society during the Edo period was characterized by its stringent feudal system and agriculture-based economy, particularly in its early years. With the exception of those who were born into the small upper-class, there were limited opportunities for children’s education; most were expected, from an early age, to contribute to the household through labor<sup>8</sup>. For lack of a national policy on disabled individuals, those who could not work were

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<sup>8</sup> <sup>8</sup> The Bakufu and each “han” (feudal domain) had established schools for the children of the warrior class (bushi), the leading class during the Edo period, and there was a limited number of schools for the children of the merchant class as well. The Shingaku movement founded by Ishida Baigan also became a

left to the discretion of the family and the local community, and were largely considered to be the black sheep. One exception was the blind, many of which were involved in the occupation of massage and acupuncture and were thus incorporated into a highly organized occupational community, called “tōdōza,” that secured their livelihoods. Some among the blind population were also involved in religious occupations or became traveling musicians. Although tōdōza was discontinued with the Meiji Restoration of 1868, the traditional association of the blind with the occupations of massage and acupuncture continues to the present day, as the school of the blind employs professionals in these fields as part of its career development program for students. During the latter half of the 18<sup>th</sup> century, a market economy began to develop at a national scale, increasing the migration from rural regions to urban areas and accelerating the stratification of social classes. Private schools called “terakoya” became prevalent, providing education for children of the middle class. The education of children with disabilities was then taken up by some of these terakoya in response to the demand of parents in the urban areas, but the details of these educational practices have not been made clear. It was also during the late Edo period and early Meiji period that people who were sent abroad to learn from Western European and American societies brought home notions of welfare and charity as well as practical knowledge of special education and the operation of institutions for the disabled. These findings slowly

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foundational educational tenet for the merchant class, articulating the “ways of merchants” (chōnindō). For details on the overview of the educational system during the Edo period, see Dore (1956), and for details on Shingaku, see Robertson (1979).

came to be shared among the intelligentsia, leading to the modernization of the educational system with the Meiji Restoration.

The Meiji Restoration marks the end of Japan's long history national isolation and the beginning of its modernizing nation-building campaign under a constitutional monarchy. The new government implemented a nationwide school district system modelled after the European societies and launched a highly centralized and systematic public education system which mandated primary education to its entire citizenry. It was in the early draft of this policy (kyōikurei) that the necessity to establish schools for the deaf and blind was first articulated. The plan, however, never took off. The policy, finalized in 1879, included no provision for schools for the disabled; it was, in fact, only through the personal efforts of religious institutions and local magnates that several privately owned schools for the deaf and blind (rōain) were founded. As of 1906, there were 31 such schools in the country, two of which were run by the national government. In the meantime, the implementation of compulsory primary education was being met with a lot of resistance, especially in regions where children were viewed as important providers of labor in agriculture and commerce. As a countermeasure, the government mandated compulsory education, in the Meiji Constitution, as a principle of allegiance to the nationstate, thus obliging all loyal citizens to send their children to school. In doing so, the government then had to clarify provisions for waivers from the education requirement. The legislation of 1890 noted that families with children who have severe illnesses or disabilities, alongside those in conditions of extreme poverty, may be exempt from the responsibility of enrolling their children to the public education system. This legislation, called "shūgaku yūyo/menjo kitei," was effective until



1979. Although initially put into effect as a waiver for the enrollment policy, by the time it was revised, in 1979, the legislation had become notorious for providing the grounds for shutting out disabled children from the public school system.

The Taishō period (1912-1926) which followed was characterized by a heightened interest in democracy, which had a further impact in the field of special education. Institutions for those with severe intellectual disability were established, special education classes for those who were falling behind the standardized curricula were opened, and many private schools for the deaf and blind were made public, leading to the improvement of their educational quality.

Unfortunately, however, education based on the new democratic ideology was short-lived. Beginning in the early years of Showa period (1926-1989) militarism proceeded apace. Japan invaded China in 1931 and bombed Pearl Harbor a decade later. By the time Japan entered the Pacific War, the country quickly shifted to a highly militaristic state that embraced a rigidly standardized curriculum, one designed to produce a disciplined and obedient citizenry ready to serve the nation. The ill, the disabled, and the weak were at once seen as second-class citizens, worthless and incapable of contributing to the militaristic national regime (Yamaguchi 2004).

The Postwar Japanese Constitution, promulgated in 1947, immediately after the country's defeat in the war, marked a new start for public special education. Public education became a constitutional right of Japanese citizens, as opposed to a duty, which entailed legal provisions to secure educational opportunities for children with disabilities. In 1952, the Ministry of Education set up a department for special education, which issued a

set of guidelines to categorize students based on their educational needs and the type and degree of their disability. The Ministry of Education went on to conduct surveys on each of those categories in the following years. The resultant study represented the first epidemiological research on various disabilities, revealing the fact that a vast percentage of identified students were not enrolled in schools. Based on this finding, the Central Education Council (Chuō Kyōiku Shingikai) provided financial support to families with disabled children in order to help increase student enrollment rate while allocating funds to found special education schools. Such schools were not part of the public compulsory education at this point, and therefore the Ministry of Education had to make various special provisions to provide funds to build schools, distribute textbooks, and subsidize lunch services. Throughout the 1950s and 60s, the number of special education schools and classes slowly but steadily increased and educational opportunities for disabled children improved dramatically throughout the country. The establishment of parents' organizations and disability rights advocacy groups came hand-in-hand with this transition. With this added pressure, an agenda emerged in the early 70s that prioritized making special education compulsory within the public education system, culminating in the passing of landmark legislation of 1979.

The shift to compulsory special education (yōgo gakkō kyōiku gimusei) made public education available to all children regardless of disability type and degree. Prior to 1979, those who were living in regions without special education schools had typically applied for waivers (shūgaku yūyo/menjo kitei) and stayed at home or were sent to live in institutions for the disabled. Very few students with disabilities were enrolled in the regular schools, and

those that were had likely achieved enrollment after aggressive lobbying by parents and local advocacy organizations. Thus the legislation was a turning point in the history of Japanese education in that it provided equal rights to education for all. However, this legislation was in fact met with mixed responses from the public. Some welcomed it as a long-awaited change, while others saw it as a discriminatory policy that slotted disabled children into “special” schools, segregating them from the mainstream education. At the heart of this dispute was a controversy around the ideal behind – and the practical meaning of – the concept of *equality*. This question continues to linger to present, constituting the debate over the positioning of special education vis-à-vis regular education.

Postwar Japanese education is founded upon two contradictory ideologies regarding equality (Sawada 1979). One of these is based on a principle that assumes the same potential in all children and argues, on that basis, for equality of opportunity; the ideal is to provide the same opportunity to each and every child, so that every child has the same chance to make the most of their potential. In other words, this principle presupposes that every child is entering the school system with the same level of innate ability. This ideology constitutes the basis for Japan’s highly standardized and centralized curricula, which ensures equality of opportunity to each student enrolled in every public school nationwide while minimizing attention to individual difference and deflecting attention from the various social, economic and cultural inequalities that exist outside of the school system. On the other hand, beginning in the 1960s, a new ideology, termed “hattatsu hoshōron”, emerged as a basis to critique the aforementioned ideology as punitively meritocratic and thus instrumental in fostering unnecessarily harsh competition among students (The Association of Japanese

Clinical Psychology 1980). “Hattatsu hoshōron,” literally translatable as “security of development theory,” was crucially different from the “equality of ability” idea in that it assumed that children are born with different abilities. In this model, it is the role of education to scaffold the development of each child in order to support the best of the child’s individual potential. While the “equality of ability” theory became the mainstream ideology underlying the public education system as a whole, “hattatsu hoshōron” was quickly adopted and embraced by a smaller group of teachers and scholars, particularly those in the field of special education, for it provided a strong argument for individualized instruction to students who were considered to be incapable of adapting to the regular classroom. The Japan Teachers’ Union (JTU), the labor union for public school teachers, was one of the most fervent supporters of “hattatsu hoshōron” and was also the most powerful advocate for the legislation of 1979 that mandated public education to all disabled children.

Although “hattatsu hoshōron” and its ideological basis are rarely referenced in recent years, debates regarding difference in ability remain relevant. For example, Koyama (2011) compares SSE to the legislation of 1979 and argues that, while the latter policy focused on “equal opportunity to education” and “guarantee of school enrollment,” the focus of SSE is on the “guarantee of education that is appropriate for each student” and thus marks a “shift of educational quality.” Providing the backdrop to this transition was the Ad Hoc Council on Education (Rinji Kyōiku Shingikai) (1985-1987), which advocated for the shift from a highly standardized and centralized curriculum to a more flexible and diversified educational system, one that identifies outstanding abilities and gifts in children and provides differentiated instruction. Koyama claims, however, that this new paradigm has simply

reinstated, using the plausible expression of “individuality,” (kosei) the notion that difference in abilities is fixed and insurmountable.

In essence, the criticism against SSE points out that the reform betrays the premise of “equal opportunity” by naturalizing the diverse potential of children entering the school system and unproblematically slotting them into ability-based groups. The critique has been echoed by other stakeholders, those who likewise raise questions regarding SSE’s process of identifying and labeling certain children who may have trouble adapting to the school system. What lies behind this criticism is the decades-old controversy regarding how to account for different abilities in children.

Despite such debates, however, MEXT pushed forth with the policy, partly because the existing special education system was becoming outdated and incapable of responding to the increasing number of students with disabilities and their diversifying needs. In particular, MEXT has pointed out the increasing number of children with overlapping disabilities who, therefore, do not fit neatly into the existing categorization systems premised in the organization of the existing special education system. External pressure represented a second trigger leading to the policy changes: Japan had signed the UN Convention on the Rights of Persons with Disabilities in 2007, but the nation’s segregationist education policy was seen as one of the major stumbling blocks in ratifying legislation, thus hindering the shift to a more inclusive society.<sup>9</sup> On top of this, Tokyo had been running for the Olympic Games bid since 2009 and the government was striving to make a positive impression to

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<sup>9</sup>Japan ratified the convention on January 20, 2014.

international community.<sup>10</sup> It was due to these issues that the shift to SSE was strongly advocated for within the Japanese government. In the following sections, I will look more closely at how the policy was implemented in the everyday interactions within the school setting, with the backdrop of the confounding debates regarding ability, equality and special needs.

### **Politics of difference**

MEXT was careful not to designate SSE as a program specifically directed to hattatsu shōgai, but kept it open-ended as a program to accommodate children with diverse needs. The implication here is that SSE accommodates all at-risk children and youth regardless of whether their troubles are caused by hattatsu shōgai or not. In fact, students are not even required to submit their medical record/diagnoses in order to qualify for SSE; the observable difficulty that they are experiencing in the classroom, or comments from preschool teachers that hint at their “difference,” are considered to be sufficient bases for their qualification. In part, it makes sense to provide support for students based on the practicality of their difficulty rather than on any medical conditions that may or may not become overt obstacles in the classroom. On the other hand, however, framing SSE as a program that accommodates students with diverse needs – needs largely represented by, but not limited to, those of hattatsu shōgai students – enables MEXT to strategically showcase

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<sup>10</sup> In September 2013, Tokyo was selected as the venue of the 2020 Olympics.

its commitment to “individualized education” while circumventing the criticism that SSE is simply another special education program for yet another category of disabled students. In other words, SSE was carefully designed to be a policy that places “individuality” at its forefront, rather than “disability.”

This discourse of individualism was well received by the parents’ organizations, the prime advocates of the SSE. The following image shows a booklet published by EDGE, an organization promoting awareness for dyslexia and other learning disabilities

(Figure 2). Titled “the reasons why we are all so special,” this booklet opens up with the question, “what if Japan were a village of 100 children?” To answer that question, the booklet

explains: there will be 31 children who like to cook, 27 who like to play soccer,

20 who wear classes, one who has difficulty in interpersonal relationships (alluding to ASD), five who have difficulty in reading and writing (alluding to LD), three who move around too much (alluding to ADHD), and two who cannot go to school. The image explicitly avoids the use of the word “disability,” depicting hattatsu shōgai as one of the many individual traits that may be juxtaposed to cooking or playing soccer. The lack of any mention of physical or intellectual disabilities or mental disorders becomes a compelling aspect of this representation, setting hattatsu shōgai apart from those existing categories while embracing

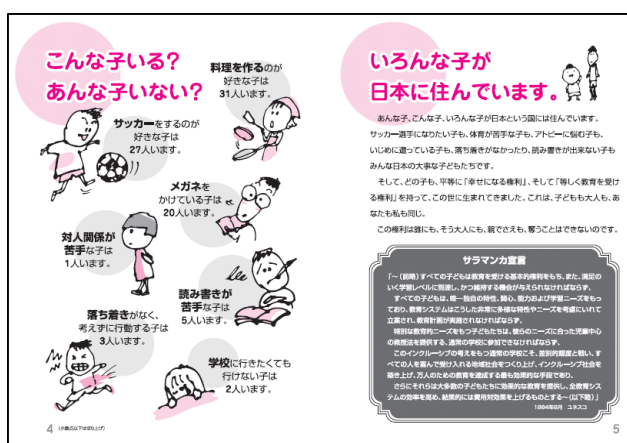


Figure. 2. What if Japan were a village of 100 children?

the idea that characteristics of hattatsu shōgai are personal qualities of the individual (*kosei*). The specific picture of inclusion and diversity that the activists chose to promote seems to resonate with MEXT's philosophy of SSE, which aims to provide individualized instruction to students with various needs.

In theory, therefore, SSE is applicable to all students who have difficulty conforming to classroom instruction. However, in practice, the general understanding among the teachers and school psychologists with whom I worked was that the program is designed for children who expressed, at the very least, a high probability of having hattatsu shōgai. In the school where I worked, there were a handful of students who constantly got into trouble. One boy's defiant behavior was rationalized by the fact that his parents had recently immigrated to the country from the Middle East. Another boy, whose mother was American, was the target of teasing by his classmates because of his awkward Japanese accent. Unable to articulate his feelings, he sometimes acted out with violent responses. One girl, who too often forgot her textbooks and notebooks at home, was explained as coming from a single-parent home and, for that reason, we were asked to be tolerant of her forgetfulness. Another boy, who always seemed to be somewhat out of mind and lacking concentration, came from a complicated family background and had spent a significant amount of time living in a foster home prior to rejoining his family. Being in the classroom with these students, we aides often intervened when their behaviors became too disruptive or when they got into tense fights with their classmates. However, apart from a brief, light-hearted comment interjected by the classroom sub (who remarked that the boy whose parents immigrated to Japan may need his own aide), no references were ever made about their



qualification for SSE. In certain instances, some of the students needed more help than did Ryo or Daisuke, but no questions were ever asked about whether they should receive specialized instruction in the resource room, for example, or if an IEP should be drafted to track their progress. It seemed that the rationale for Ryo and Daisuke as SSE students rested entirely on the supposition of hattatsu shōgai. Although neither of them had a hattatsu shōgai diagnosis, there was no other apparent factor to account for their “different” behavior. Both of them were from relatively well-to-do, upper-middle-class Japanese families; if not for hattatsu shōgai, why would they have so much trouble? Working closely with the two, we aides spotted various signs that we thought were symptomatic of hattatsu shōgai, but, as mentioned previously, we were equally able to spot such tendencies in other students. “When I try hard enough to see signs of hattatsu shōgai in any of them, it seems like it’s everywhere, in everyone one of them, and I don’t know what to do,” said one of my fellow aides with a concerned tone. With what little training we received about the disability, we were feeling uneasy about the fact that our very presence in the classroom was demarcating a boundary that distinguished Ryo and Daisuke from others. “I sometimes wonder what’s so special about them, and what’s so normal (*futsū*) about the other kids,” said another aide. The line between being normal (*futsū*) and being special – or between exhibiting a strong character (*koseiteki*) and being impermissibly discordant – often seemed arbitrarily drawn.

There is one incident that remains vivid in my memory and that I recall whenever this discussion about being “*futsū*” comes up. During the course that I attended to train prospective classroom aides, an instructor explained that some children with hattatsu shōgai have difficulty in coordination and tend to be clumsy. In order to gain hands-on experience

of what it feels like to have limited dexterity, we tried making origami cranes while wearing thick gloves. Even folding the paper in half was a sweat, and none of us finished it in time. Seeing that, the instructor said, “if the child has serious coordination issues, perhaps you could help him/her make something different. It doesn’t have to be a crane. It could be something simpler. It’s okay to be yourself” (jibun rashiku de iindesu). He then added with an undertone of criticism, “although being normal is still valued in Japanese schools” (nihon no gakkō de ha mada futsū ga yoshi to sareteiru kedo). The instructor meant to say that it should be acceptable to make something else even when the rest of the class is making cranes. “Futsū,” in this context, denotes certain behaviors and abilities that are not necessary quantitatively derived from the average, but are based on more general and vaguely defined expectations for what constitutes normalcy.

The idea of “futsū” functions as a disciplinary device in the school setting, and in the larger society as well, to reference the unspoken expectation of the majority or the authority, and also to demarcate the boundary between acceptable and unacceptable diversion. At the same time, however, many parents and teachers seemed to have some reservations based on the fact that futsū rigorously enforces conformity to the collective, an aspect that some thought to be problematic and that, furthermore, represented a problem specific to Japanese culture. Thus there was considerable ambivalence associated with the use of the word “futsū,” particularly when the term was used in a way to mark the children with hattatsu shōgai as *not* futsū. For instance, the music teacher once said in the faculty room: “Before we had aides like you, we used to carry those kids under our arm while teaching class, so that they wouldn’t run out of the classroom. How I wished they’d behave like a normal kid

(futsū no ko)... I mean, like other kids (hoka no ko).” Beginning to refer to the problematic children as being not futsū, she quickly took back her words and rephrased. It was probably permissible to talk about these children as such, and they probably did so without giving it much thought, when those children were not associated with the hattatsu shōgai label. However, once it came to be understood that they are “disabled children”, the speech noting them as not normal suddenly began to bear a different undertone. The teachers’ ambivalence and discomfort, as expressed in casual conversations, seemed to speak for the ways in which they were beginning to learn the significance of the hattatsu shōgai label.

### **Management of difference**

It goes without saying that teachers play a significant role in mediating and shaping the experience of each student in class. In Japanese public elementary schools, a single teacher is assigned to each class to teach all subjects, usually with the exceptions of music, art, and English, which are taught by teachers with specialized training. Therefore, the homeroom teacher is primarily responsible for almost all aspects of classroom management. The size of a class could be anywhere within the range of 20 to 30 students, and most of the class activities involve the entire class, with very little time allotted for breakout sessions, learning centers, or individualized instruction. Given this system, I was particularly interested in how teachers managed the class as a group while also paying attention to individual children. Although hattatsu shōgai is attributed to a specific child, their disability usually becomes imminently visible when placed within a large class setting and expected to interact with others. It was not difficult to imagine how children with hattatsu shōgai would

have a hard time understanding and following rules and procedures. However, at an early stage in my fieldwork in the school, I realized that the teachers were focused more on orchestrating and mediating the group dynamics of the entire class in order to create a specific kind of a collective learning environment, rather than trying to spend extra time with children who need help. What I mean by “a collective learning environment” will, I believe, be made more salient with the description that follows, an account of the athletic meet (*undōkai*) held annually in every school.

The athletic meet is seen as an occasion to encourage the students’ engagement in sports and physical exercise. Just as importantly, though, it is also a crucial opportunity for students to learn about the importance of routine practice, the nature of competition (in a general sense), the necessity of mutual support and encouragement among peers, and the joy of sharing an experience with others. The athletic meet consists of dance performances, various track and field activities, collective gymnastics shows, and competitive physical games such as throwing as many balls as one can into a basket. Each student in every grade is assigned to either the red team or the white team, such that each team consists of the same number of students from each grade; upper-classmen are often imparted some responsibility for helping the younger students on the same team, thus fostering a sense of camaraderie across grade levels. Programs are organized so that that these two teams compete against one another, but participation in each activity is limited by grade level. The event is open to the public, and the parents almost always show up. The teachers therefore tell the students that the athletic meet is an opportunity to show the parents and the people from the

local area what the students have practiced and how much they have grown since the year before. The children begin practicing their dances and gymnastics weeks in advance.

As much as this is a big event for the students, it is also a very stressful and challenging undertaking for the teachers, as they carefully contemplate which student should take on the roles with heavy responsibilities, roles like leading the march in entering the track, or making the pledge on fair play in the opening ceremony. During the march, the students are usually lined up by height, the shortest student being at the front and the tallest being at the back. However, despite Ryo being the shortest in his class, the teacher decided that it would put too much burden on him to lead the class and he decided to switch his place with the second shortest student. Taking extra caution, the teacher placed tapes on the track to show the course of the march, and asked Ryo to stay after class for a week before the athletic meet so they could walk the track together and he could thereby help Ryo to memorize the course: “The fourth graders will come this way, but don’t get confused... Stop right here. Look, it’s right beneath the flag. Don’t forget this position,” he instructed, as he walked the tracks with Ryo. The teacher also decided the order in which students were to run, and he grouped them by ability so that fast runners would compete against one another and slow runners would not feel like they have no chance of winning. Since the start of the short track was marked with a fake gunshot, the teacher began using gunshots weeks ahead of the athletic meet to get students used to the noise. Daisuke seemed to be hypersensitive to auditory input, and he screamed and cried at the sound of the gun during the practices. The teacher told him to cover his ears with his hands and look for the referee waving the flag, which was another sign of the start. As for the dance performance, both Ryo and Daisuke

were very slow in learning the choreography. For this, the teacher decided to modify the order in which students lined up during dance performances so that those who were slow in learning the moves were in a position where they can see others and imitate their moves, rather than being at the front where they had no models to guide them. The teacher also consciously adjusted the order in which students sat during the opening and closing ceremonies, so that Ryo and Daisuke or any other known troublemakers would not sit side by side, and so that those who may have to be cautioned in the middle of the ceremony will not be at the front, where the teacher would inevitably catch the attention of every parent when walking up to him or her.

The teachers also choose the most capable sprinters to represent the entire grade in the mixed-grade relay race. Several students, including Ryo, who was one of the slowest runners in his class, were quick to point out that they too wanted to run the relay and that the selection was unfair. The teacher patiently took the time to speak to the entire class about what it means to have a representative:

This isn't about who got selected and who didn't. It's everyone's race. These students will be running for all of you. You should cheer them when they run, and give them the energy to run faster. You're doing your part by cheering and encouraging the runner. If the selected student wins, that's victory for all of you. If the student loses, don't blame him or her. Every single one of you is responsible for the defeat, so think about how you can do your part better the next time.

Ryo and the other students calmed down, convinced of the justice of the procedure.

The program was rehearsed numerous times during gym class. Observing this over and over, I began to realize that the athletic meet was not so much about the competition or

the actual physical exercise as it was about the presentation of the students as a collective group. The entire event was carefully designed not to let the athletes monopolize the scene; victory in ‘tug-of-war’ games depends on the power of the heavier children who hold the ends of the rope, and smaller, lighter kids are cheered at as they climb on the backs of their classmates in coordinated group gymnastic shows. In essence, the athletic meet was meticulously planned so that everyone gets a fair share of the glory of victory, the disappointment of defeat, a sense of accomplishment, and an opportunity to cooperate with and learn from others. Orchestrating the group dynamics within each class, grade, team, and school seemed to be of utmost importance for the teachers that I worked with, but in doing so, I realized that the teachers are in fact extremely sensitive to the different abilities and characters of each child, while seeking to “harmonize” them into the collective. The entire event was choreographed so that the less favorable individual traits are underplayed and the favorable ones are made visible to be cheered at. It could be said that the teachers were *managing differences* in striving to make the students successfully perform as a collective group.

In the course of preparing for the athletic meet, however, there were tense moments when students complained about their teammates’ inability to score points in games, or when they held a single student responsible for a defeat and threw harsh words at him or her. Ryo, being the smallest in class and having difficulties in coordination, was often the target of such criticism. In such circumstances, the teacher made an effort to show the class that it is okay to be different: “Ryo’s doing his best. What’s there to laugh at?” “How would you feel if you were him?” “Every one of you is good in some things and not so good in others, and that’s

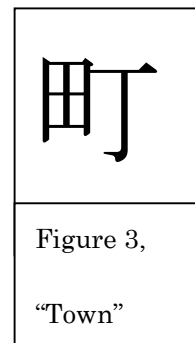
okay.” Such occasions were considered to be important educational opportunities to teach children about learning to accept others and collaborating in groups with peers who have different strengths and weaknesses. Sometimes, standing out from the crowd as being different led to the unfortunate consequence of “ijime,” or bullying among peers, which the teachers feared. Therefore, management of difference among students – how to highlight or downplay it, how to teach it, and how to orchestrate the collective dynamic and balance – was seen to be a critical skill for teachers.

### **Challenges of children with hattatsu shōgai**

One of the criticisms that has been brought up by the advocates of the hattatsu shōgai movement is that Japanese education rigidly enforces sequential learning and places unreasonably strong emphasis on the embodiment of knowledge through repetitive practice. For example, the Japanese writing system includes three distinctive forms of writing: hiragana, katakana, and kanji, taught in that order. Students enter elementary school with varying degrees of knowledge about the hiragana, and by the end of the first year, they learn to read and write all characters of hiragana and katakana as well as several elementary kanji characters. The lessons begin by teaching them how to sit, hold a pencil and copy the characters that the teacher writes on the board onto a notebook with boxed grids. Whenever a new character is taught, the students are instructed to write it down 10 to 20 times in order to memorize it. Many students with learning disabilities, particularly dyslexia, have trouble memorizing and reproducing the characters (Kosuga 2009; Tamanaga 2005). This was an issue for Ryo, and he often wrote a wrong character (with one too many lines, or with a stroke



extending too long) and had to rewrite the entire page. Being clumsy, he often ended up ripping the page while erasing what he had written, and would eventually get weary of the drill. I had him get permission from the teacher to redo the drill on a new page rather than erasing what he had already written, and I also tried to point out his mistakes early on without waiting to have him fill out the entire page. Despite such difficulties, Ryo showed a keen interest in learning kanji. During a quiz he was blankly looking out the window, and when I urged him to finish up, he pointed to the two high-rise buildings outside the window that stood side by side, and told me that he memorized the kanji character “machi” (meaning “town”; see Figure 3) as looking just like those buildings, and was trying to remember the image.



Another area in which Ryo was struggling was math. It took him more time than the average student to learn addition. The students all had “math kits” distributed by the school and the teacher used small plastic cubes included in the kit to teach addition, but counting them was a hassle for Ryo, who constantly swept these cubes off the desk or lost them in the middle of an exercise. However, as the exercises got more abstract and drill-oriented, he devised a unique way to count numbers; he tapped on his cheek with his fingers to keep track of the count. This method seemed to work well, and he was able to finish the quizzes with only a few mistakes.

Despite Ryo’s struggle, there were reasons to be optimistic about how he will do academically in the years to come. In 2006, MEXT began considering the distribution of textbooks with enlarged print and in digital format for children with weak eyesight or

learning disabilities (Tanaka and Oouchi 2008). The Digital Accessible Information System (DAISY), the standardized format used worldwide in transferring digital texts to auditory output, is also becoming increasingly common for use in helping the children learn from books without having to read them in a textual format. In addition, the National Center Test for University Admissions, a test administered across the nation for university applicants, began to include hattatsu shōgai in their list of qualifications for special considerations. Beginning in 2012, test takers with hattatsu shōgai have been given special options. They can choose to take the test in a separate room, use an enlarged copy of the test, have extra time, and/or have the instructions read to them – all this depending on the degree of their disability and on the considerations under which they have been working in high school. These are only a few of the changes that are being implemented to help the students with hattatsu shōgai attain their academic goals. Considering this context of reform, I felt hopeful that Ryo and Daisuke, along with other students with hattatsu shōgai that I had met, would be assured to have the educational opportunities that they need.

On the other hand, the social and behavioral aspects of school life – which were given equal weight to the academic expectations addressed in the early years of elementary school – seemed potentially more problematic and challenging for the two students in my charge. For example, taking care and responsibility for one's belongings and personal spaces was considered to be a critical aspect of school education. Students were instructed to write their names on every item of their belongings, including pencils, erasers, textbooks, rulers, and shoes. Although Ryo did this, he not only misplaced his things frequently, but he also held a very casual attitude about such issues, such that ownership did not occur to

him as a serious concern. One day, for example, he accidentally dropped a colored pencil on the floor and began looking for it during recess. His friend ran over and, with a worried look, joined Ryo in the search for the pencil. I went over and asked what was going on; they explained that Ryo had borrowed his friend's pencil (because he couldn't find his own) and now it had disappeared. I said to Ryo, "So you lost something again?" He smiled and replied jokingly, "yes, I can lose anything in three seconds!" I laughed at that and he looked pleased, explaining that his mother always tells him this. In the meantime, his friend, who was frantically searching for the pencil, interjected, with an upset look, "three seconds? Worse, you lost that pencil in a second!" Ryo seemed amused at this comment, but his friend was about to break into tears. To everyone's relief they found the pencil, but this incident stayed with me as exemplifying the contrast between Ryo and the other students with regard to their senses of ownership. Many things that the students owned were in fact identical. They were expected to buy the same gym clothes and indoor shoes; academic materials, such as musical instruments and the aforementioned math kits, were all provided by the school, so they all looked the same. Ownership was identifiable only by the names printed on the items. The practice of putting names on things, and the related value of owning and taking care of individual property, had an important educational function. It taught the students to demarcate personal boundaries and to take responsibility for one's belongings within those boundaries. Therefore, the teachers often assigned personal items even when it seemed to make more sense to share them as common property. For example, each class had six sets of numbered white gowns and hats to be worn when serving lunch. Students took turns being "lunch servers" for one week out of every two months or so. During their week as lunch servers, each student was assigned to a gown and a hat of a

specific number and they were instructed to wear the same gown throughout to week. At the end of the week, they would bring their gowns home for laundry and bring them back the following week to pass them along to the next servers. Students also brought in their own dust-cloth (with their names printed on them) to use when cleaning the classroom. Here again, Ryo often wore the wrong gown when serving lunch and the student who was assigned to that number complained to the teacher that his/her gown was lost. He also had trouble finding his dust-cloth and spent the entire cleaning time going through the pile of clothes with the names of his classmates to find his own. In the end, he would often give up mumbling that they all look the same anyway. If all of these items were shared, things would have been much easier for him. Ryo's classmate's frustration in being unable to find his colored pencil could be interpreted in many ways, but to me it seemed like it came not so much from his need to use that pencil or the inability to find a replacement, rather than from the fear instilled in him that losing his property would mark him as being irresponsible and sloppy. Ryo, on the other hand, was only concerned that his things to be there when he needed them.

The school's emphasis on the organization of things was not limited to personal property. To cite another exemplary situation, students in art class sat at large wooden tables in groups of four. On each corner of the table was a sticker with a different color. At the beginning of class, the teacher explained the project for the day. The teacher then asked the students sitting at the "yellow corner of each table" to come and get a pair of scissors for each member of the group, and those sitting at the "red corner of each table" to go to the back of the classroom and get a sheet of paper for each member of the group, and so on. The

students were to sit quietly and listen while the teacher explained the task assigned to each student sitting at each corner. Once the students started moving, Ryo almost always ran to get what he was assigned, and then walked over to the other students to see if they were getting what they were asked for and if they needed any help in bringing the things back to the table. He was very often taken to task for doing this. The teacher would spot him and call out, “Ryo, what are you doing over there? What’s the color of your sticker? You’re not supposed to be there, are you?” Once the materials had been collected, the teacher drew a picture on the board to show how everything should be laid out on the table. “The paper should be in front of you, and the watercolors should be on your right hand side. The bucket of water should be placed on the cloth on the left hand side. I will hand out a piece of paper to write your name on. Keep this on your right, far away from the bucket so that it doesn’t get wet. Raise your hand if you need to go and change the water...” Ryo had a lot of difficulty following these rules. He would start off as instructed, but as he became more involved in drawing, he would move the paper back and forth so that he could draw more easily, and he might occasionally shove the bucket over to his neighbor to secure more space. For doing so, Ryo would often receive a frowned look and perhaps a warning or two from the teacher.

On occasions where Ryo was deeply concentrating on his work, I was often hesitant to nag him or to otherwise distract his attention, so I silently moved his belongings so that they would not get in his neighbor’s way, or I would nudge back the bucket so that it would not get shoved over the edge of the table. More than once was I reprimanded by the teacher, who insisted that I was not supposed to be taking care of him, but should be teaching him

how to take care of himself or, in other words, that I should make him stop and organize his belongings before continuing with the work. I was fully aware of the expectation. But Ryo was already almost constantly being told how to behave properly and to take care of himself. It just did not seem right for me to intervene in the rare moments when he was involved in a challenging problem or a creative work, when he was experimenting and discovering things for himself. The kind of engagement he displayed on those occasions was assuring to me, because it showed his ability and willingness to be absorbed in the learning process without constantly comparing himself unfavorably to his peers (a habit that, unfortunately, teachers and aides were instrumental in perpetuating).

All in all, Ryo's problems rarely manifested within the actual process of learning and completing assignments. In fact, considered from where he started, Ryo was probably one of the students who made the most progress and learned the most over his first year in school. However, when it came to logistics, he was invariably sloppy, forgetful, and disorganized. He would forget to bring books to school, be the last one to get dressed for gym, and he lacked the patience to sit and listen to the 20-minute talks at assemblies.

After the children left school every day, I had brief conversations with the teachers and other aides about the day. Through these conversations, I eventually began to realize that I had a slightly different perspective about the students from other staff members. Ryo was indeed a troublemaker in class and he also seemed slightly less mature than others, both in character and academic/physical ability. However, at the same time, I saw in him a very optimistic attitude and a healthy self-esteem. He did not compare himself with others and was always proud of his accomplishments, and it seemed to matter little if his peers were

doing an even better job. It was not that he did not acknowledge others; he was always quick to show how much he was impressed by other students' work, and he also occasionally reprimanded his classmates for their mistakes. But he was comfortable with himself, even sure of himself. For example, at the end of the first semester, the teacher handed out the report card and asked the students to fill in the self-evaluation sections. One of the questions in the section was about organization of personal belongings. The teacher explained: "This is about how well you take care of your things. For example, look at your locker in the back of the classroom." All students turned around to look at the boxed shelves that were used as lockers. "Are your belongings stored neatly in your locker? What do you think? Mark your report cards." At that instant, Ryo quickly ran to his locker and pulled out his sweater that he had earlier shoved in, quickly folded it and placed it back to in the locker to make it look tidy, dashed back to his seat, proudly circled "very well organized" on his self-evaluation card, and smiled at me as if to underscore that he has earned this high evaluation. He was the only one in the class to do this, and it obviously was not the teacher's intention to have the students clean their lockers at that time. He could have been called out for this action, and he was well aware of that, but he often managed to fulfill the expectations in school in this creative way, risking certain things while trying to retain his personal sense of accomplishment and self-worth. I believed this to be his strength, and hoped that he would be able to hold onto it in the years to come. As long as he retained that affirmative attitude and positive self-image, he would survive his educational career. The teachers and the other aides, however, seemed more focused on the particular problems and issues that arose in everyday life. For instance, Ryo's habit of breaking his eraser into pieces, or his forgetfulness about using a piece of paper to cover the desk before applying glue on

something, were some of the issues that came up in group meetings. Some of them were important issues having to do with his inability to listen to and follow directions, which could result in serious accidents in certain circumstances. But most these issues seemed, to me, to be insignificant and harmless habits that he would eventually grow out of. I simply did not see how crucial it was to remember to cover the desk before using glue; I was more concerned with the potential problem of giving Ryo too much negative feedback and thereby undermining his innate enjoyment of learning from the process of discovery. The reports that we aides wrote at the end of the day were already filled with negative comments about his failures and inabilities, accounts of his violent outbursts of frustration.

My other student, Daisuke, presented quite a different set of concerns. Daisuke could not stay in the classroom for long and would frequently run out without apparent cause. In the beginning of the year, we would forcefully bring him back to class but he would scream and cry in resistance, at times punching and kicking the aides. The teacher eventually gave up and told us that, as long as one of us stayed with him to ensure his safety and as long as he doesn't leave the school ground, he can go wherever he wanted. So whenever he left, one of us followed him outside. Daisuke took long walks around the school building and took note of various kinds of plants and flowers, for which he displayed an encyclopedic knowledge, telling us their names, seasons, and characteristics. He also walked to different rooms inside the school building. He would playfully wander into the auditorium and enjoy the touch of the silk curtains, go to the library and talk to the librarian about his favorite book of plants, peek into science rooms that were used by older students, lie down on the gymnastics mat in the gym equipment room, and see what it feels like to sit in a basket full



of soccer balls. He was usually very calm when he was exploring the school like this. I was once sitting in the gym equipment room with him after following him around the school for a good half an hour. I asked him if he'd like to go back to class now, to which he replied, "I've decided I'm not going to leave this room. I'm going to live here." I said, "Really? Wouldn't you be scared when it becomes dark?" He replied, "No, I'll just sleep here on the mat." "What if you get hungry?" "I'll go to the lunch room. They have plenty of food there so I'll never starve." "What if you get lonely?" "There are lots of plants here. Even more plants than my home. I'll never get lonely!"

Daisuke was in fact more academically advanced than most of his classmates. Wondering if he was in fact bored by the class material, the teacher gave him the language and math drills that second-graders use, and kept a desk and a chair in the empty room adjacent to where his classmates studied so that he could sit there alone and concentrate on the work when he felt like it. He sometimes wandered into this room and worked on the drills, but he would quickly get bored. This empty room was also used as a cool-down room to bring him to when he panicked and cried. When and why he panicked was never predictable to us aides, and when we tried to calm him down by sitting him down in the empty room, he often got violent, hitting and kicking us. On one occasion he spat at one of the aides in the face, at which point I raised my voice. Incidentally, his mother was there (she visited the school at least once a week to see how Daisuke was doing) and she ran over to hug him, saying, to my astonishment, "I'm sorry, Daisuke, I should've never let these people take care of you. Don't worry. I'm here. We can go home if you want."

From what I had heard from the teacher, Daisuke's mother was very reluctant to put him in the SSE program, claiming that there was "nothing wrong" with Daisuke. Her suspicion towards us aides, and toward the school bureaucracy in general, seemed to be communicated to Daisuke, for he began to make denigrating comments to us as the semester progressed. His father, who held a very prestigious job, was not involved at all in the communication with the school or the board of education. The teacher suggested that Daisuke, being the only child and son, was probably under a lot of pressure to become successful. By the middle of the first semester, both the teacher and the aides were at a loss as to how to treat Daisuke. On the days that I was assigned to him, I was able to do nothing but follow him around the school campus listening to his lectures on plants. I wondered where all this is going to lead; how was he going to make his way through elementary school, then middle school and high school, eventually to become who he wants to become. SSE brought in us aides, as well as the school psychologist, who regularly came in once a week to observe Daisuke and provide some advice to the teacher. The school drafted an IEP on his behalf, and many professionals were involved in the process of formulating a treatment plan. However, SSE is simply a program; everything was left to the discretion of the individuals invested in Daisuke's day-to-day educational experience. Being one of those individuals, I was deeply disappointed and frustrated by my own sense of helplessness.

Although this was the only school where I had hands-on work experience, I had previously interviewed several aides, parents, and teachers who were working with students in junior high school. The problems that they were facing were quite different from what I had observed in elementary school; the students almost always had very low self-esteem and

were suffering from various secondary symptoms such as depression or suicidal thoughts. One student, who was in his second year of junior high school (equivalent to the eighth grade in the US), was having so many problems that the aide was on the verge of quitting. I was asked to observe the boy at his school and to speak with his teachers. This boy had to bestir himself to get to school every morning and was barely surviving each day. He was filled with feelings of misery, resignation and despair. He had no friends, and he barely spoke to anyone during the day except when absolutely necessary. (Earlier in the year he once made a sexually inappropriate comment to one of his female classmates and was thoroughly reprimanded for this.) He was frequently slumped over his desk during class, looking like he was half asleep. His aide had to prompt him to do everything, from retrieving his textbook to taking notes. And although he would grudgingly follow instructions, it was obvious that his deep-seated lack of confidence would not change with such ad hoc cues. When I once confided my impression of the boy, at the aides' training program, an administrative staff member responded: "by the time they reach adolescence, they've simply had enough; enough scolding and yelling from teachers and bullying from peers. Their sense of failure haunts them, and it's not easy to brush it away." The boy was not defiant or rebellious, he had simply and quietly withdrawn into his own shell. I could not even identify his hattatsu shōgai symptoms, for the only thing that was visibly identifiable was his hopelessness.

It was this boy's image that flickered in my mind when I was interacting with Ryo and Daisuke, chasing them in the hallway, interrogating them about uncompleted homework

and repeatedly telling them to be quiet and listen. I wondered what the future would hold for them.

### **Diligence and effort: the virtue of “ganbaru”**

Thirty years ago, Thomas Rohlen (1983) conducted fieldwork in Japanese high schools and argued that diligence is the most prized trait in Japanese secondary education. According to Rohlen, diligence comes hand-in-hand with conformity and with selfless dedication to and faith in the collective. By instilling these virtues in students, Rohlen wrote, the schools successfully produce industrial workers who shape the Japanese meritocratic system. Although these students are “highly socialized individuals capable of performing reliably in a rigorous, hierarchical, and finely tuned organizational environment,” Rohlen describes their training as far from the American democratic ideal, a training that leaves little space for the expression of individual uniqueness or inner self (Rohlen 1983:209). Goodman (1990) also points out that diligence and endurance are the cherished traits sought by Japanese society for their school-aged children. It is these traits that are believed to produce positive results, while natural talent and individual difference is undervalued. This emphasis on diligence comes up early in the anthropological literature. Singleton, in his 1967 study of a middle school, writes that “ganbari,” translatable as diligence or persistence, exemplifies the Japanese cultural theory of learning. He contrasts ganbari with the emphasis that American education places on natural ability in the form of intelligence and talent. In the school in which he conducted fieldwork, the teachers reportedly knew that the IQ test scores of students were on file but, according to Singleton, the scores seemed

irrelevant to the teachers' assessment of the students, for it student effort alone that counted in their estimation (Singleton 1967).

The notion of “ganbari,” as a trait that is, in itself, worthy of highest praise, still rings true in observing the Japanese educational system today. Diligence indeed remains to be a major element in academic evaluation and a highly prized trait, even for early elementary school students. I heard teachers encourage students with the phrase, “motto ganbare! (try harder!),” numerous times throughout my fieldwork. However, the emergence of students with hattatsu shōgai has raised questions around the notion of taking “ganbari” as the preeminent scale of evaluation, where the sole condition of success is predicated on the ultimate sign of conformism. In other words, it is increasingly understood that diligence does not necessarily yield the same result in every student, and that, furthermore, such a limited scale of evaluation may be particularly destructive to children with disabilities. Parents of children with hattatsu shōgai argue that their children are indeed working and trying as hard as anyone else, but are often weary and disillusioned by how their poor output is seen as a sign of nonconformity. If a dyslexic child practices writing a kanji character as many times as any other student and still fails to write it down correctly, is it right for that child's effort to be dismissed? Or if a student with ADHD puts in every possible effort to keep up the concentration and still has to leave the room half way through class, is it just for him/her to be labeled as a deviant? Diligence is indeed the most prioritized criteria of evaluation in the educational system and, precisely because of that, it has been suggested, there is a moral imperative for the educational system to seriously consider the differing levels of achievement that each student's effort yields. In essence, the perspective on the

“ganbari” of students with hattatsu shōgai destabilizes the simplistic link between diligence and success, thereby challenging the assumptions held by the aforementioned authors regarding its place in the Japanese educational system.

While interviewing mothers of children who were receiving SSE in different schools throughout Tokyo, I had often heard of their children’s academic performance being referred to through the rhetoric of “ganbari.” “It’s not that he/she’s not putting in enough effort” (gambari ga tarinai wake ja naindesu), mothers would say, insisting that their children’s inability to fulfill certain academic standards was not due to a lack of effort on the part of the child, but rather to the child’s disability. “The teacher would tell him to try harder, that he’s not pushing himself hard enough” (motto gambare, gambari ga tarinai, tte sensei ga iundesu). And, indeed, stories of how teachers push the children to “try harder” prevail. One parent recalled, citing experience with a teacher: “He said, if you can’t memorize the kanji character after writing it down ten times, then write it down 20 times, 30 times, 100 times! If it takes you that many times to memorize it, you do it! Don’t just sit there and do as everyone else does and complain that it doesn’t stick with you!” The ability to read and write kanji characters is considered to be the hallmark of Japanese literacy and intellect, and thus the inability to memorize them is considered to be a grave issue for both the teachers and the parents. However, memorization of kanji characters is, as mentioned previously, a stumbling block for many children with learning disabilities. The virtue of “ganbari” has such a strong foothold within the Japanese culture that the idea that one may not be putting in total effort to achieve an academic goal becomes a basis for social stigma. Shinagawa Yuka’s book on the experiences of those with learning disabilities is titled “I’m

not being lazy! (Namakete nanka nai!)” (Shinagawa 2003). This title directly addresses and speaks against the stigmatic label that the children with hattatsu shōgai often bear, being seen as guilty of “slacking off.”

While in our training to become aides, we were told to refrain from using the word “ganbare!” (work hard!) when interacting with SSE students. “Even when ‘ganbari’ does not yield results,” we were told, “children should receive positive feedback, rather than be questioned on the extent of their efforts. Give them credit for their work. Tell them that you know how hard they tried.” And it was, in fact, obvious to me that both Ryo and Daisuke were trying. In the beginning of the year Ryo was unable to sustain concentration for the entire day; in the afternoons he would wander around the classroom and it was a hassle trying to keep him in his chair. As the semester progressed, however, his attention span grew longer and he managed to keep his focus during the afternoon classes. When I wrote this on the daily report, the teacher returned it with a comment, “ganbattemasu!” (he’s trying!). I told him about this, saying that the teacher was very happy about his efforts. He returned a delighted look, and replied proudly: “of course!” Similar tips are shared among teachers and parents and approval and praise are increasingly considered as the primary driving force that helps children (and not only children with hattatsu shōgai) build a self-affirmative attitude. In other words, acknowledgement of “ganbari” was beginning to be considered an important part of classroom instruction. This was not the case a decade ago.

When I was participating in a self-help group for adults with hattatsu shōgai, I had met a woman in her 50s. Her name was Yoshida san, and she had come alone to discuss her 26-year-old son who was diagnosed with hattatsu shōgai. The first thing she wanted to

discuss was how her son decided to serve as a guarantor for some business. He apparently had signed the document without understanding what was written therein, and he was thanked by his friend for having done so. Yoshida san was worried that if the business failed he may be held responsible for a huge debt:

My son works relentlessly to be complimented by others. When he was younger, he'd steal expensive stuff from stores because his bad friends would praise him for the courage. At one point he became involved in a radical right-wing movement because of that. He has no political views, but he was happy that the members relied on the work he volunteered.

Yoshida san portrayed her son as a young man in desperate need of affirmation from others. He would even steal, or devote his time and energy to causes that he cared little about, because of his urgent need to fulfill others' expectations and thereby boost his sense of self-worth. To this, Nakazaki san, a young woman in her 20s responded, "some women with hattatsu shōgai find it so hard to make a living that they look for night jobs, you know, at sketchy night clubs and the sex industry and all that. People in night jobs are really nice to you, but in reality they're only taking advantage of you." Yoshida san quickly agreed: "Yes, I tell him that he's merely being taken advantage of." Yoshida san then went on to speak about how her son is now deeply involved in a small religious community. She seemed hesitant to show approval for his choice, knowing that it is an alternative religion, more like a cult. But she did comment: "He organizes events and leads the band in their church. He's putting in a lot of effort, and when he's frustrated, the people of his church are there to support him." Hearing her stories, I was imagining a young man who was constantly reminded of his limited capability and supposed worthlessness throughout his educational career, someone painfully in search of an advocate to assure him that he is needed



and that his dedication and commitment to an activity – any activity – is recognized and valued.

Kayama Rika, a prominent psychiatrist, once commented at a symposium on hattatsu shōgai where the audiences consisted of psychiatrists, psychologists and other professionals invested in the treatment of children with the disability: “Most of the people who come to psychiatrists after reaching adulthood are those who couldn't gain the affirmation during childhood that it is okay to be who you are. People who have had a great childhood and grew up to have problems only in adulthood are very, very few among my patients. I always wonder how great it would be if I could travel back in time and talk to my patients when they were children, and just tell them that it is okay (daijoubu dayo). Why couldn't anyone do that for them? Teachers who are working in schools are in the position to be able to say just that to today's youngsters. Such support would definitely shore up their self-esteem and become words to live by throughout their lives.”

As previous anthropological literature has pointed out, “ganbari” has indeed been the most valued behavioral characteristic expected of students in Japanese schools. However, the visibility of those with hattatsu shōgai has entailed the realization and the necessity to account for the diversity in the natural abilities and learning styles of students. It may be argued that acknowledgement of difference has begun to transform the ways in which Japanese schools view achievement and growth in their students.

## **Conclusion**

In Japan, where compulsory education (grades 1-9) is administered under a highly centralized system and a vast majority of students attend public (rather than private) elementary and junior high schools<sup>11</sup>, studying the educational system provides an important insight into the ways in which children are socialized to become productive members of the larger society. However, there has been surprisingly little ethnographic work conducted on the ways in which more traditional educational institutions are being contested by shifting social values; previously accepted value hierarchies are being challenged by the existence of nonconforming students. The significance of SSE is crucial to this process of reform. Descriptions of SSE on the MEXT website – even the latest accounts of the variety of new resources that SSE has made available – do not adequately represent the breadth of the program’s value or provide a true understanding of the scope by which the policy is transforming otherwise persistent ideas regarding ability, difference and diversity in Japanese schools. I hope to have shown how teachers, parents, aides, and others who are invested in the education of SSE students, have been instrumental in coming to terms with the challenge of needed reform – even as their efforts are confounded by all that the emergence of hattatsu shōgai and the implementation of the new policy has conducted – with an unmistakable sense of responsibility and conscience.

As a final note, I would like to provide a brief account following up on the cases of Ryo and Daisuke. Half way through first grade, Ryo’s parents were advised to enroll their

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<sup>11</sup> According to MEXT, roughly 98% of elementary school students and 91% of junior high school students attend public schools (MEXT 2011).

son in a special support class once a week so that he could get extra help. The school he went to did not have a special support class, so he was to miss a day of school every week to go to another school in a neighboring town. Since that school was rather far to walk, both he and his parents became weary of the routine. At the end of the year, when I told his mother that I was going to quit my job as the aide, she said that she was considering transferring him to an American school in Tokyo. “The transition might be difficult since he doesn’t speak a word of English, but I think he’ll get used to it.” It was then that I learned that Ryo’s mother had gone to college in the US. Enrolling Ryo in an American school would be an expensive choice, and it would limit his opportunities of receiving higher education in Japan (only a few universities in Japan accept an American school diploma as the equivalent of a Japanese high school diploma), but Ryo’s mother was undaunted by these factors; she had other reasons for the choice: “He can study abroad if he wants. After all, having ADHD or hattatsu shōgai means nothing in the US, right?” Having ADHD in the US is obvious is not as insignificant as Ryo’s mother assumes it to be, but her optimism left a lasting impression on me, for it was in stark contrast to all the difficulties (both emotionally and administratively) that Ryo and his family had gone through during this year.

Daisuke, on the other hand, gradually began to miss school for many days, and by the end of the year he was almost entirely absent. The teacher was very concerned about this. He visited Daisuke’s house every week, hoping for the opportunity to check on Daisuke’s well being and personally provide him with assignments and materials for the week. Apparently, however, Daisuke’s mother did not open the door for the teacher so he would leave the materials in the mailbox and go. The teacher summarized the situation to

me in a worried tone: “It’s okay if Daisuke doesn’t want to come. But if he wants to, and if his mom is keeping him from coming, that’s a problem.” Eventually, Daisuke’s mother contacted the school to say that she wanted to transfer Daisuke to another school in the vicinity. The teacher prepared the documents for the transfer but she never came to pick them up, which likely indicates that Daisuke had not transferred and had been staying at home. Nevertheless, we aides went to school every day, only to learn that Daisuke was again absent. We wandered around the room helping other students in their classwork, hoping that he would eventually return. After some time, the teacher told us that he finally did see Daisuke while visiting his house:

We got on the same elevator, Daisuke, his mom, and I. His mom was really awkward, but I asked Daisuke how he was doing and he answered cheerfully. He had grown! He is taller now. It was kind of sad to see him like that, I was thinking about the time I missed spending with him.

Home-schooling is not an option in Japan, and there is little that the school can do for Daisuke to help him in his education. Students who refuse to come to school for various reasons will still graduate from elementary and middle schools for there is no system of repeating the grade level in compulsory education. However, for such students, the opportunities beyond compulsory education are severely limited. Some adults with hattatsu shōgai that I spoke with had a history of truancy caused by academic pressure, bullying and a general sense of failure and inadequacy. But to witness a case first-hand, particularly among the students that I was partially responsible for, was a painful and frustrating experience that made me reflect on the possibilities and limitations of SSE as a program.

## CHAPTER III: INTERVENTION

In recent years, educational and welfare policies for children with hattatsu shōgai in Japan have been emphasizing the importance of early diagnosis and intervention. The mandatory physical checkup for three-year-olds has been instrumental as one of the primary opportunities for screening, as has the pre-enrollment checkup for elementary school enrollment. Many children who receive diagnoses early on through these processes are referred to *ryōiku* programs or remedial education programs for the purpose of scaffolding their development and learning, and for helping them better adapt to preschool or elementary schools regimens. Ryōiku programs vary greatly. Since there is no institutionalized system to accredit license to these programs, it is solely up to the parent to choose among a vast range of programs administered by different organizations and based on diverse methods of instruction. Some intervention programs are run by children's hospitals or clinics, while others are run by non-profit organizations, private corporations or parents' organizations. Some meet weekly, while others enforce a more intensive commitment or involve overnight stays; still others are based on distance learning. Their approaches are similarly diverse, but the most common type of program consists of social activities and individualized learning exercises, implemented in ways that are informed by practices in Applied Behavior Analysis (ABA), social skill training, TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children),

and play therapy, among other clinical methods of intervention. Some parents elect to try other, less conventional methods such as art therapy or animal therapy, and some program administrators are venturing to collaborate with emerging approaches such as the applied use of robots to assist in social interaction.

The term *ryōiku* is short for *chiryō-kyōiku* (treatment education) and was originally introduced as the Japanese translation of the German term “Heilpädagogik.” For more than four decades, the term has been used to refer to remedial education programs for children with various disabilities, including physical as well as cognitive disabilities. Early scholars have defined *ryōiku* as “a special educational scheme that incorporates findings in medicine, psychology, education, sociology and engineering, among others, to help with the self-fulfillment of children who will not fully benefit from regular education and instruction” (Ito 1970), and as “education with the purpose of medical treatment, education that includes treatment, or a method of treatment utilizing educational means” (Kan 1969). As implied by these early definitions, the relationship between *chiryō* (medical treatment) and *kyōiku* (education), in the context of *ryōiku* practice, has been, and continues to be, interpreted in multiple and divergent ways. Today, *ryōiku* programs for children with *hattatsu shōgai* are rarely conducted by psychiatrists and, in that sense, the “medical treatment” aspect of *ryōiku* is somewhat unstable. There exists, instead, a progressively ambivalent sentiment towards the notion of corrective intervention. The “education” aspect, on the other hand, is incorporated in *ryōiku* practices in a very generalized sense, in that most *ryōiku* programs include very little academic curricula and focus more on the training and growth of behavioral and social dimensions.

In examining the diverse modes of intervention, it is useful to frame ryōiku practices in terms of the intertwined notions of “care” and “cure,” as various ryōiku practices can be positioned vis-à-vis these two axes, which sometimes manifest together and at other times stand in mutual contestation. This chapter is primarily based on the ethnographic details from my fieldwork at several ryōiku programs. The common purpose of all ryōiku programs, despite their diverse methods, is to help children “fit in” in school and in the larger society. The question of what it means to “fit in” entails larger questions regarding individuality and membership in Japanese society. In other words, the designs and practices of intervention programs are informed by external factors that define the type and degree of individual “difference” that can be subsumed into the mainstream population. Children with hattatsu shōgai are considered to be inadaptable to the regular classroom without the extra support provided by these programs. By looking closely at how these programs function and how they engage with the ideas of *caring* for children with hattatsu shōgai and *curing* the disability, I aim to shed light on the meanings of difference and adaptation, as practically expressed in the ryōiku setting.

To be sure, the prescription of drugs also constitutes an integral part of intervention, particularly for children with ADHD. Many children receive prescription to control and manage their symptoms, and compliance to the prescription is in itself an important dimension of intervention (Singh 2002), particularly with regard to its intersection with ideas regarding mothering, bodily control, discipline and surveillance in the school setting. However, for the purpose of this chapter, which focuses on the interactive exchange within

the spatially bounded realm of ryōiku programs, I will not go into the details of how drug prescription and intake are managed as part of the intervention regimen.

My fieldwork involved spending time at three ryōiku programs in Tokyo and Kanagawa prefectures during the period of 2008 to 2010; one was a weekly day care program run by a public hospital, another was a summer camp run by a private clinic, and the third was a weekly afterschool program run by a non-profit organization. The three programs varied in many ways and attracted children from distinctly different backgrounds. They also had a number of characteristics in common: the programs were all tailored for children between the ages of 4 and 12, they all maintained a student-staff ratio of roughly 3:1 or lower, they shared a strong emphasis on social skill training, and they were organized by clinical psychologists and child therapists. In what follows, I will examine the day-to-day practices of these ryōiku programs, paying particular attention to how the two key concepts of “care” and “cure” were both variously embraced and adopted while also being productively interrogated and contested.

### **Spacial disposition and structure**

On the first day of my visit to one of the programs, I was welcomed and told by a staff to wait in the playroom until the day’s program started. Several staff members were standing in the room, chatting about the activities that were to take place that day. I sat by myself at the corner of the room, by a wall filled with boxes that contained toys. The room was about 700 square feet, the size of an elementary school classroom, and was divided into distinct



sections by the placement of low cabinets. The section that I was in was carpeted so that children could play on the floor. Another section was organized as a workshop with large tables and arts and crafts equipment. The largest section looked like a classroom, with wooden floors and several small chairs and a blackboard mounted on the wall. About fifteen minutes before the program, parents began dropping off their preschool-aged children. The children were allowed to play freely with the toys

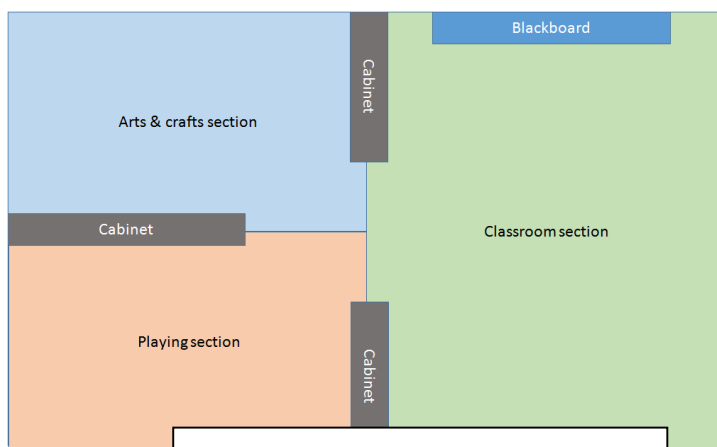


Fig. 4 Ryōiku room layout

until the beginning of the program. Knowing that, they walked right into my section and started opening the boxes to look for their favorite toys. One boy among them took out a train and started dragging it across the floor. When the train bumped into my foot, the boy looked up and glanced at me uninterestedly. A staff member who was standing nearby spoke out in a cheerful tone: “Wow, you’re the first one to notice her! She’s Junko-sensei.” The boy didn’t respond, and he continued to drag the train on floor, avoiding me.

Seeing that everyone has arrived, the staff members brought the children to the main section and sat the children in small chairs organized in a circle. There were six children, all of them in preschool, and only one of them was a girl. One of the staff members took attendance. When their names were called, children responded by saying “hai (here).” Some yelled and excitedly jumped up from their chairs. The girl had turned her chair sideways and sat as if turning her back to the center of the circle. When it was her turn, a

staff member walked up to her and held out her hand while calling the girl's name, and the girl temporarily turned around and slapped that hand in response. Another staff member standing nearby whispered to me: "That girl has *bamen kanmoku* (selective mutism). She doesn't speak here. Her mother says she talks just fine at home, though."

After attendance was completed, a staff member placed colored magnetic stickers with illustrations of activities on the board, explaining what activities would take place that day and the order in which they were to be done, thus giving the children a general overview of the day's schedule. Visualization of the day's agenda at the beginning of the day was a crucial part of all the ryōiku programs that I observed. It was explained to me that children needed to have a grasp of the larger picture of how the day was going to be organized. Throughout the day, the staff members would continue to remind children of where they were in the schedule, when the current activity was going to finish ("Look at the clock. When the long arm hits eight, you have to come back here"), and what would be coming up next. Such instructions were often paired with the disposition of space; certain activities were associated with particular spaces, so that children would move to different sections of the room to read, eat, play or study. Often times, children had difficulty letting go of one activity to move onto the next, even when the time was up. They would linger in the reading section, unable to give up the book that they couldn't finish, or would be caught in the ordeal of arranging their crayons in a particular order of color long after the drawing time was over. In such cases, a staff member would stay with the child and remind him or her that the rest of the group had moved on to a different activity in a different part of the room. This seemed effective, as the child often glanced across the room where everybody else was, and

recognized that he or she was behind by that spatial distance from where he or she was left alone. In some cases, the staff members pointed at the agenda on the board or to the clock, helping them recognize that the time was over. When even that failed, they would tell the child that they will count to 30, and encourage him or her to finish up with the activity within that time frame so as to join everyone else. Activities were compartmentalized in this way through spatial and temporal allocation, and a great amount of emphasis was placed on the child's ability to perceive the rule of this structure and to regulate their behavior according to the collective schedule.

As an additional measure to enforce this rule, the staff members gave out stickers at the end of each activity; one sticker after the reading period, another after snack time, and another after the art activity. The children were told that they had to "be good" during the activities to earn these stickers, and the staff members often explained a rationale by which they had earned the stickers: "Thank you, Sakura, for being so quiet while I was giving out instructions. This is for you." "Yuuichi, you did a great job in helping your friends. Here's your sticker." The distribution of stickers was part of the routine and seldom did any child fail to earn one. Even when a child threw a tantrum in the middle of an activity and had to be taken out to a different room to "cool down," he or she would be given the sticker upon returning: "Do you feel alright now? Can you promise that next time you'll talk to sensei (teacher) rather than screaming like that? Okay, here's yours then." It seemed that the distribution of stickers was more about demarcating the end of a certain activity, helping the children move on to the next event in the day, rather than about rewarding praiseworthy behavior. The practice is comparable to the school setting, where children with hattatsu

shōgai often encounter similar kinds of trouble moving from one activity to another, where the bell is the primary cue defining the boundary between class, recess, and lunch. On the other hand, however, the time/space organization within the ryōiku setting clearly enforced a certain mode of governmentality that seemed to me somewhat militaristic. It undoubtedly disciplined the children to follow the regimen of the existing school system, but it seemed to leave little room for the children to explore their interests, creatively engage with the activities, or to freely interact with others without the constraints of time and space.

The use of picture cards represented another salient feature of the kind of communication that took place between the staff members and the children. Not only were the day's activities depicted with large cards with colored pictures of toys (indicating play time), snacks, and books (for study time), but smaller picture cards were also used in various circumstances during the session. On one occasion, when one of the children displayed unwillingness to participate in an activity, a staff member walked up to him and showed him several cards, asking what he would like to do. He glanced through the cards and, without a word, slapped on one displaying a picture of a toy car. Seeing his response, the staff member said, "Okay, you want to play with cars. Good. The cars are in that basket. Let's go and fetch them." Holding his hand, the staff member led the boy to where the toy cars were stored. Unlike the aforementioned girl with selective speech mutism, this boy was capable of expressing his opinion through words, but it was explained to me that an open-ended question like "what do you want to do?" is often more difficult to answer for children with hattatsu shōgai; communication is made easier by offering them clear choices. This method seemed to work particularly well with children who are stronger in visual input than auditory

input, for they often seem to have difficulty taking in a full set of options when choices are spoken or read to them.

The physical layout of the room, visualized schedules, and clear task organization are all adopted from Division TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children). TEACCH was originally developed in 1966 by Eric Schopler, scholar and psychologist from the Department of Psychiatry at the University of North Carolina (UNC), as a statewide program for the treatment of autistic children in North Carolina. Sasaki Masami, a Japanese child psychiatrist and a close friend of Schopler's, made numerous visits to UNC and, from the early 1980s, was instrumental in bringing the ideas and practices of TEACCH to Japan. Today, components of TEACCH's treatment style are invariably incorporated into almost all ryōiku programs, although very few programs make the claim that their practices are strictly and exclusively aligned with TEACCH. In some ways, the essence of TEACCH, called "structured teaching," has become common knowledge among the professionals in the ryōiku industry, wherein the "best practices" of ryōiku often refer directly to Schopler's innovations: effective room layouts, schedule visualization and successful use of picture cards.

Despite the fact that "structured teaching" is widely adopted in ryōiku programs as an effective method, the reality of the social adjustment that the children face when they take a step out of the enclosed space of ryōiku is not as clear-cut and predictable as the model might imply. I found there to be something rather unsettling about its laboratory-like disposition of time and space, which I recalled during a conversation with a university colleague, a music therapist working with children with autism. The therapist's sessions

are improvisational; the children she works with are free to choose from a variety of instruments and to play them any way they please. On the day that I observed a lesson, a child chose to play the guitar. The strums and sounds the child produced with the instrument were at first disjointed, but they slowly intertwined to engage one another, making music. The music therapist confided to me that she was rather suspicious of the kind of “structured teaching” taking place in ryōiku, for it enforces a narrow framework for learning, implying that there are always a limited number of clearly defined options to choose from. In the words of this therapist, the implication “doesn’t sit well with the creativity and open-endedness of improvisational music.” Indeed, real-world interactions are more often filled with the uncertainties that come with affecting or being affected by others, operating in the very way that these music sessions may enable. The benefits of flexibility or experiential spontaneity may be something that ryōiku programs do not very well address.

### **Social skills training and strategies of self-care**

One day, the staff members of the ryōiku program that I was observing decided to have the children interview one another. While the children got into pairs and started talking about their favorite TV programs and sports, a boy wandered off to a different section of the room and began playing with toys. A staff member walked up to him and spoke to him in a soft tone. “This isn’t the time to be playing. What’s wrong?” The boy glanced back at the staff member but didn’t answer. “If you don’t want to do the interview, you need to talk to Yamada-sensei” (Yamada was in charge of the interviewing activity). With this, the staff member held out his arm, encouraging the boy to stand up and go to Yamada-

sensei. The boy hesitantly stood up and went to Yamada-sensei who was watching this interaction. He spoke slowly: “I don’t want to do the interview.” “Why not?” “It’s not fun.” After a moment of silence, Yamada-sensei said, “Alright then. Thank you for telling me. You have permission to sit at the back of the room and watch, but don’t play with the toys because everyone else would want to do the same, and it won’t be fair if only you are allowed to play.” The boy nodded with a relieved look and walked to the back of the room, where the staff member who first approached him had pulled out a chair for him to sit in. He spent the next five minutes watching the rest of the class, but became increasingly restless. He finally decided to return to the group and was warmly welcomed by Yamada-sensei. At the meeting held later in the day, I asked what the staff members thought about this incident; Yamada-sensei replied:

Of course there are times when kids don’t feel like participating. We make it a point that that’s alright, as long as they can speak to one of the staff members about it. We’re not forcing them to do anything. But it’s problematic when they just wander off like he did; it’s not an acceptable behavior in school or at work. You need to be able to talk about it. I’m glad you brought this up, because it took us so much time and effort to make the kids understand that rule.

Another staff member added:

He said the interviewing wasn’t fun, and that’s okay for preschool kids, but if he were a bit older we wouldn’t have tolerated that. Things you do in school aren’t always fun, and that’s not reason enough to leave the group. Kids in our older-aged group can be exempt from an activity only if they’re not feeling well, or something.

Hearing this explanation, I realized that this was a form of social skills training. Social skills training (hereafter referred to as SST) constituted a major part of intervention practices in the ryōiku setting. In fact, SST has come to be a prevalent part of various

programs for individuals with hattatsu shōgai; it is practiced in self-help groups for adults with hattatsu shōgai, and there are various training courses held for schoolteachers and parents to learn the basics of SST. The SST training concept was originally developed by Dr. Robert Paul Liberman, a psychiatry professor at UCLA, in the 1970s and 1980s as a rehabilitation program for persons with schizophrenia. His original work, however, is seldom referenced in the Japanese context. Instead, the term is used in a more generic sense to refer to a diverse range of activities and exercises aimed at enhancing children's capability to relate to others in socially appropriate ways. In this instance, the emphasis was not so much on making the children follow the strictly defined routine of the program as it was on helping them understand what constituted acceptable and unacceptable behavior within the context of a given circumstance.

I was remembering my fieldwork in the elementary school (Chapter 2), where Ryo, one of the students I worked with, could not resist his impulse to stand up and wander off during class. Towards the end of the first semester, he began to understand that if he asked to go to the bathroom he could legitimately take some time off from being in the classroom, and so he started asking to go to the bathroom now and then. Upon getting permission from the teacher, he would wander around in the corridor for a time, but, within a reasonable period, he would return to class. The teachers praised him for having learned to cope with his short attention span without disrupting the classroom rules. This was precisely the kind of social skill that the staff members were trying to teach the children here.

Social skills training was taken up in more explicit ways in most ryōiku programs through activities such as role-playing. The roles were typically set up to simulate a



situation where there was a clash of interests among different actors; the session led to discussions about what was the appropriate course of action to resolve the given conflict. For younger children, the general purpose was to instruct when to thank or apologize to others, and how to ask for favors. For older children, the scenario was often more realistic and thus complex, involving issues such as bullying, taking sides, reciprocating friendly approaches, and being sensitive to the age or social rank of others. Apart from this structured training, the staff members also gave frequent feedback on the way children spoke to one another and to the *sensei*. During a drawing activity, one boy asked for an extra piece of paper. Turning to a nearby staff member, he murmured, “kami (paper)” to which she handed him the paper replying, “it would’ve been better if you said, ‘kami kudasai’ (please give me a piece of paper).” In another instance, one child tripped over some lego blocks with which another child was playing. The boy immediately apologized “funde gomennne (sorry for stepping on it)!” Seeing this, a staff member instantly gave him a positive feedback: “That was a good way of apologizing. Well done!” It was through the accumulation of these consistent micro-level interventions that the children slowly learned the “correct” way of interacting with others.

Acquisition of such social skills was considered to be an important component of ryōiku programs, for it helped the children better get along with their peers in school and other social occasions. Instructions such as “try to think in other people’s shoes” and “you should reciprocate kindness” often didn’t register with them, especially with those with autistic tendencies. Expressions of appreciation and apology do not come naturally for many children enrolled in ryōiku programs. It was, therefore, integrally important for children to

have these typically unspoken rules of social interaction be overtly stated through specialized instruction. The staff members often joked about how children first participating in the program would, without intending to hurt anyone, make mildly offensive comments about staff or the other children. One staff member reported, with a laugh: “When we first met, the first thing he said was ‘you’re too fat.’ He was just being honest, you know. These kids are really honest (*sunao*) and have beautiful hearts.” Not only the staff members of ryōiku programs, but also many professionals and parents seem to think highly of the children’s honesty (*sunao*). The distinction between “*honne*” (private self) and “*tatemae*” (the persona/mask) is learned early on in preschools and elementary schools; these principles constitute a critical aspect of Japanese socialization. The difficulty that the children with *hattatsu shōgai* experience in understanding and making use of this distinction in conversation is precisely what necessitates intervention in this field, but many adults, at the same time, seem to think of such honesty as an expression of “beautiful hearts,” untainted by social imperatives. As one staff member confided, such honesty is representative of a candidness that fully socialized members of the society are deprived of: “We all think like that, you know, when you try to remember someone, you think, ‘oh that bald man’ or ‘that short woman’ but you can’t say that out loud, right?”

SST, therefore, is a form of intervention in the broad sense of the term. But, more precisely, it is a means of having the children acquire the skills to cope in a society filled with people who interact and socialize in ways that may seem unintelligible to them. Without entailing a fundamental transition in their worldview or personhood, SST helps them effectively “translate” between cultures, so to speak, through the acquisition of a particular

mode of language. In this sense, SST is a technique of self-care; it is a skill of survival that helps the children to avoid unnecessary conflicts or tensions with others.

### **Caring for the caretakers: mothers as recipients of support**

While ryōiku programs are principally designed according to the needs of the children with hattatsu shōgai, they also serve an important function for the children's mothers. The brief visits – when mothers come to drop off and pick up their children – often entail chats with staff members, when casual reporting takes place regarding how their children had been doing over the past week. The conversation naturally flows to complaints about the mothers' interaction with other family members or with the child's primary school administrators. More than once I had seen mothers shedding tears while confiding their emotional burden and the sense of helplessness and solitude they sometimes felt in raising their children. Such conversations were semi-private. With voices kept low; the content of the discussions rarely entered the weekly staff meeting. I often eavesdropped on such conversations while helping the children get ready to go home. “My mother-in-law disapproves of his disability and says he's just being lazy and keeps asking herself how he ended up this way. She's talking to herself but she knows I'm listening, so it's sort of directed at me, you know...” “Yes, it's hard for people of that generation to understand.” “Yeah I know, but...” “*Okāsan* (mother), you're his only mother. I know it's hard, but you've got to hang in there (*shikkari shinakya*).”

The staff members listened, encouraged, supported, and sympathized with the mothers. It was clear that many of these mothers had very few other places to share their feelings. Other than *ryōiku*, there is in fact a dearth of communities and resources directed specifically toward parents who need emotional help in raising children with disabilities. Although the parents' organizations (*oya no kai*) fulfill this function in some ways, these are usually run by parents of relatively older children, given the amount of time and commitment that they require. Parents' organizations are also more inclined towards political advocacy and public awareness campaigns, rather than toward peer support around issues of day-to-day care. Mothers with younger children, therefore, have limited opportunities to interact with understanding professionals and sympathetic peers.

Raising a child with *hattatsu shōgai* is different from raising a child with congenital physical or intellectual disabilities. Because *hattatsu shōgai* is usually not visibly identifiable, the child's behavior and inability to comply to certain rules or directions tends to be mistaken for a sign of irresponsible child-rearing practice and lack of discipline by the parents. Mothers involved in the parents' organizations often share bitter episodes of being wrongfully accused of some kind of complicity in their child's (mis)behavior. This social stigma is historically deep-seated, for there is a long genealogy of scholarship, as well as popular representation, that has been instrumental in producing and perpetuating the parent-blaming (and especially *mother-blaming*) discourse. The “refrigerator mother theory” (Bettelheim 1967) blamed mothers as the primary cause of their children's autism. and the book's Japanese counterpart, the notion of *bogenbyō* (illnesses caused by the mother; Kyutoku 1979), has critiqued industrialization as having “negatively” shifted the lifestyle of

Japanese women, the argument being that modern women have become “narcissistic” and thus lacking in “child-rearing instinct” (Lock 1987).

Although these ideas are rarely voiced in such explicit ways today, mothers raising children with hattatsu shōgai continue to be the target of suspicion and criticism. As exemplified in the conversation cited above, mothers also find themselves in difficult positions within the extended family. The responses of the parents-in-law (the husband’s parents) usually manifest as either mother-blaming or plain indifference. First, family members all too often blame the mother for the child’s condition, directly or indirectly, hinting at her inadequacy as the primary caretaker. Mothers tend to internalize this accusation to varying degrees, which consequently shakes their confidence in child-rearing. In the second pattern of response, that of extended family indifference, family members might mention that their children (the husband and/or his siblings) had tendencies similar to hattatsu shōgai when growing up, suggesting that the mother is being too sensitive, over-reacting to behavior that is “normal.” In such cases, mothers often have to fight against the family’s passive resistance in order to enroll their children in ryōiku programs and to get other professional help<sup>12</sup>. In either case, what further complicates family relationships is the idea of blood and heritability.

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<sup>12</sup> In either case, the presence of the father of the child is minimal. In some of the interviews with mothers, I had explicitly asked what their husbands were doing about the situation, but was unable to elicit much information. A typical response was that he is busy with work, had agreed to send the child to ryōiku when his wife brought it up, but there hasn’t been any further discussions on the topic. Only once did I see a father pick up his child from ryōiku, but he left quickly without talking to the staff members.

Research shows that hattatsu shōgai is to some degree genetically inherited, although it cannot be traced to a single gene and its mechanism of inheritance is as yet unclear. Most mothers are aware of this, having gained the information through self-help books or other media. Members of the extended family, on the other hand, seem to be mostly unaware of up-to-date information, and thus their responses rely on popular beliefs and uninformed assumptions. In spite of, or precisely owing to this knowledge gap, mothers tend to take in their in-laws' comments at heart, interpreting them in light of ubiquitous misinformation and conferring their legitimacy. In the typical parent-blaming scenario, the mother is blamed for introducing a problem that had not existed in the husband's family lineage. One mother I interviewed said that her mother-in-law explicitly stated, "it's not on our side, so it must be in yours. You know someone in your family like this, don't you?" Sometimes the mother herself identifies with the child, recalling that she had similar experiences during childhood, which often deepens and exacerbates her sense of inadequacy. In the typical scenario of extended family indifference, it is very often the case that the father of the child, and/or his siblings, has had similar issues, triggering the suspicion of the in-laws that the mother is making a "big deal" out of the child's uniqueness. In this case, the mothers believe that there is indeed a genetic component to the child's condition and that it just went unnoticed for the earlier generations, which only reinforces the mother's urge to seek support and intervention for the child despite the lack of cooperation from her extended family members.

It is under such circumstances that the mothers come to rely on ryōiku staff members as supportive mentors. Ryōiku staff members are not psychiatrists (if they were, they might,

in fact, appear too professional – too distant – to the mothers), nor are they schoolteachers or officers of the public welfare administration (who might be threatening in another sense, as stakeholders with authority to provide or with-hold resources for their children). Instead, ryōiku staff members are both accessible individuals with specialized knowledge, and providers of the service that the parents have purchased. The relationship they provide, as such, aims to strike a balance between the personal and the professional. There is also a gender component to this relationship: a majority of the ryōiku staff members are women between late-20s and 40s, meaning that they are usually around the same age group or slightly older than the mothers, making them reassuringly approachable.

Staff members know that the mothers' understanding of, and commitment to, ryōiku practice – including its application at home – counts a lot towards a fruitful intervention. Given the limited time that the children spend in ryōiku programs (typically around 2-3 hours a week), the staff members try to engage the mothers as much as possible. Such engagement also entails that the staff members be the mothers' best listeners, at times providing a shoulder to cry on. Thus ryōiku programs become a place where mothers can confide their stories and release their stress and pressure, providing a short respite from their daily lives. The staff members then encourage them and help them to move forward.

### **Ambivalence towards the notion of “curing”: ryōiku as a liminal space**

As I have discussed, ryōiku involves the practice of *caring* in multiple dimensions. The other key component of ryōiku this chapter seeks to engage, the idea of *curing* hattatsu

shōgai, is similarly complex. When defined as the complete elimination of its symptoms, the concept of “cure” becomes a controversial issue among professionals in this field. Throughout my fieldwork, I was taught by the staff members – both explicitly and implicitly – that cure (or *chiryō*) is not the goal of their program, and that it is quite inappropriate to question ryōiku’s efficacy in those terms. Indeed, there is a consensus within the medical community that hattatsu shōgai cannot be cured completely through intervention. Still, the sensitivity displayed by ryōiku administrators towards the idea of curing went beyond a simple embracing of this notion, which triggered my interest in exploring this issue further. While distancing themselves from the idea of cure, the administrators usually designed their programs to help children expand the realm of their achievement in order to facilitate a positive change in their developmental trajectory. In that sense, it can be said that ryōiku staff were negotiating a blurred line between *care* and *cure*.

Part of this negotiation has to do with ryōiku’s close relationship with mothers. As I have pointed out, there is an existing genealogy of literature on mother-blaming and, not surprisingly, similar discourses persist. *Sankei News*, a newspaper with nationwide circulation, did a series in 2010 on “*oyagaku*,” or parental education (Sankei 2010). The series emphasized the importance of the parents’ roles in supporting the healthy development of children, stating that hattatsu shōgai can be prevented if the parents would reclaim the “traditional” Japanese childrearing ways. This article stirred a great deal of controversy within the online community of parents, not only because the claim was unsubstantiated, but also because it reads as a shameless revisitation of the *bogenbyō* idea. In this discursive context, the notion of curing hattatsu shōgai becomes a highly sensitive issue, for it evokes



the supposition that it is somehow possible to undo the disability through appropriate training and discipline. This idea, then, alludes to the problematic and stigmatizing conclusion that the disability in fact results from certain parenting dynamics.

This is obviously not the only story. The informed ambivalence the ryōiku staff holds towards the notion of cure has much to do with the idea of liminality associated with the space of the program. In a way, the ryōiku program is considered, by both staff members and mothers, as an experimental space where children are trained to acquire basic social skills through trial and error. Failing to comply with social norms and expectations is not seen as a problem, as long as non-conforming behaviors are contained within the space of the program, because, in that context, they do not result in significant practical consequences such as having strained relationships with friends or being reprimanded by schoolteachers. So a staff member will gently tell the child what is wrong and lead him or her to make corrections, so that new behaviors could be practiced in real-life settings. In this sense, ryōiku constitutes a liminal space, one free from the social imperatives of the actual society. It is a field of rehearsal – a “mock” society that simulates real-world events. At the same time, though, I found that many staff members shared a romanticized idea of ryōiku space being the space of metamorphosis, where children come to self-awareness and reach significant developmental milestones through support. Staff members took meticulous notes of children’s behaviors and reactions, awaiting those transformative moments with hope. Accounts of best practices, as reported in publications and conferences, are filled with glorious stories of children going through visibly identifiable changes and positive transformations in social engagement. In this sense, the space of ryōiku functions

as a buffer zone; the programs help bridge the gap between the personal and the social realm, home and school, and relative immaturity and age-appropriate development.

This unique characteristic is the heart of many ryōiku practices. As I have discussed, the process of trial and error is considered to be an integral part of the learning experience. The staff members would quietly observe as the child made mistakes, postponing intervention as the child found his way on his own, praising his accomplishments when he did so. This kind of practice, the staff explained, provides an education that cannot take place in schools with large class sizes and standardized, impersonal curricula. The rules are generally looser than those in the public schools. Staff members have room to provide and engage in alternative modes of communication, such as in the case of hand-slapping of the girl with selective mutism that I discussed earlier.

Rather than focusing solely on the children's adaptability to the existing educational system, ryōiku programs place particular importance on fostering a space where children can experiment and learn in a less structured way, expressing themselves uniquely and interacting with others more freely. In this sense, although they prepare children for school, ryōiku programs do not see themselves as an extension of the public school system, nor do they emphasize the need to mold the children's behavior to adapt to the regular classrooms. In fact, many staff and administrators that I met during the course of my fieldwork seemed to believe that adaptation to school is merely one of the short-term goals, and that ryōiku should be conducted with a vision of the life beyond, so as to help the children grow up to be independent members of the society, with fulfilling jobs and rich social lives. This promise was reflected in conversations during staff meetings; the staff members very rarely, if ever,

spoke from a paternalistic position. They did not see themselves as representative of an institution to which a child should adapt. Rather, they tried their best to put themselves in the children's shoes and to understand how they see and experience the world.

The way in which ryōiku grapples with hattatsu shōgai as a category of disability can be understood as a force of resistance to ableist ideology. Ableism views disability as a deviance from normalcy and thus establishes an imperative to train children to “overcome” their difference and behave as “normal” as possible (Linton 1998). In other words, although ryōiku aims to scaffold the children's development, it does not embrace the corrective undertone of authoritatively disciplining the children to forcefully fit them into the mainstream society. Being a “buffer zone” or a space of in-betweenness, it is one of the few places for the children to engage in learning experiences at their own pace, to comfortably be who they are without having to worry about their deviation from the idealized norm. Ryōiku staff members are well aware that the ideology of “curing” hattatsu shōgai would entail a more paternalistic, top-down approach that identifies pathology in the children's behavior and frames difference as a problem to be resolved. In that sense, they reject the premise that children are “afflicted” with a disability that necessarily bars them from mainstream society until they are appropriately treated and trained to conform to the norm. To be sure, the general public's understanding of ryōiku is often not too far from the pathologizing model that ryōiku staff seek to avoid, but those who work in the industry would see such an agenda as denying the heart of their practice. As much as it is an institutionalized program which tailors to and maintain links to external resources such as clinics, hospitals, schools and welfare offices, it is also one of the very few places where

children and their mothers can feel safe and accepted without being pushed and shoved to “fit in.”

### **Cultural notions of embodying illness/disability**

At the end of each day’s program, there was a staff meeting to go over the day’s activities. On one particular day, the seven staff members who were present sat around a small table in the meeting room and opened their notebooks to take notes. One of the senior members took the initiative and began by going over the operation of the activities: “Some of the children didn’t understand the instructions in the role playing activity and were confused during the first round. Next time we should have a visual board to explain the roles.” Others added comments: “Perhaps it would be a good idea to have several staff members come up to the front and play it out, wearing paper masks of the characters.” “I think the confusion was caused by giving actual names to the characters. We should’ve just named them ‘student A’ ‘student B’ ‘teacher’ and so on.” All members actively participated in the discussion, nodding to one another’s suggestions and taking notes. The members often referred to ideas and practices they had heard from colleagues in other ryōiku institutions that had demonstrated positive outcomes, or cited from journal articles and conference presentations that they recently read or attended. In fact, ryōiku for children with hattatsu shōgai has grown into a large industry; major bookstores invariably have sections devoted to ryōiku practices, and there are conferences, journals and funding sources available for professionals. This has entailed the professionalization of ryōiku workers and

enabled the creation of a forum where knowledge gained from practice is accumulated, evaluated, and disseminated as standardized practice to other ryōiku settings across the nation.

The meeting continued, and the discussion began to turn attention to individual children. Each staff member reported on the child in her charge. Many of the comments made in this part of the meeting anticipated how each child is experiencing the environment around him or her: “I think the noise coming from the air conditioner was so overwhelming that he couldn't make out my voice” “He was having a hard time folding the origami, and he finally panicked because he couldn't tolerate his own clumsiness” “I didn't look closely enough, but perhaps she was doing it according to a pattern...” are some of the few comments that I heard being made at these meetings, each alluding to how a particular child is experiencing the day's activities in ways that may be different from others, and thus not immediately apparent to the observer. Their narratives were based on the shared understanding that children with *hattatsu shōgai* experience the environment in a different way, and that the disability is manifested precisely in their unique cognition.<sup>13</sup> In essence, *hattatsu shōgai* is seen as deeply embedded in and inseparable from the individual's embodied experience, in a way that is perhaps close to “*jibyō*” (chronic/constantly present illness) and “*taishitsu*” (inborn weaknesses of constitution) as described by Ohnuki-Tierney (1984). The author writes: “Written in two characters, the first one meaning ‘carrying’ and the second one ‘illness,’ *jibyō* means an illness that a person carries throughout life, and

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<sup>13</sup> Adults with *hattatsu shōgai* have written about their unique bodily experiences. For example, see (Ayaya and Kumagaya 2008).

suffers at some times more acutely than at others. People very often attribute their ‘down’ condition to an attack by *jibyō*” (Ohnuki-Tierney 1984:53).

Ohnuki-Tierney cites rheumatism, weak stomach, and high blood pressure among her examples of *jibyō*. *Taishitsu*, on the other hand, is defined as the nature of the constitution with which one is born, which might be healthy, weak, or susceptible to certain illnesses, and as Ohnuki-Tierney points out, *jibyō* and *taishitsu* are at times interchangeable. Although hattatsu shōgai is not listed in the repertoire of *jibyō* or *taishitsu*, it could just as well be considered as either or both, in the sense that it is something that one is born with, and that one has to deal with throughout life; it is inseparable from the character of the person and is also an embodied trait, which manifests itself strongly in some instances while at other times remains latent. The staff meeting can be understood as an exchange of information and ideas regarding the management of *jibyō*, over which the child, him/herself, still has little control.

Ohnuki-Tierney goes on to argue that, although Japanese culture provides various means to deal with *jibyō* illnesses, they are “aimed not at the elimination of pathogens, as in biomedicine, but at the restoration of the balance between opposing forces in the body” (Ohnuki-Tierney 1984:73). In other words, it is essential to learn to live with *jibyō*, effectively managing it to circumvent difficult situations. The idea of “curing” hattatsu shōgai, on the other hand, evokes the outdated premise of eliminating a foreign pathogen that is inhibiting the child's true individuality. The ryōiku programs, in seeking to help children to embody their disability, can be seen as a practice guided by insights echoing those informing Ohnuki-Tierney’s work. Ryōiku staff guide children with hattatsu shōgai toward

coping with disability in a way that they fulfill their academic and social responsibilities while feeling comfortable in the expression of their own uniqueness.

### **Beyond care/cure**

What I have attempted thus far is to organize my ethnographic data and lay out my thoughts in that context, in light of the key concepts of *care* and *cure*. Certainly the actual activities, interactions, and exchanges that take place in the programs are more complex than I have described here. The care/cure axes are experimental theoretical devices that I utilize to distill and reframe the essence of ryōiku practice. My informants never explicitly referred to the dichotomy of care and cure, nor did they categorize or identify their jobs in these terms. They did, however, have a very specific understanding of what intervention should and should not entail, which seemed to be founded upon a particular understanding of hattatsu shōgai and the children who struggle with it. By theorizing this interpretive framework, I am attempting to capture and illuminate some dimensions of the “culture of ryōiku,” which are not always apparent, even to those in closely related fields such as education and child psychiatry.

It deserves to be noted that there were moments when I felt a rupture in the system of ryōiku. I have described how SST trains children for real-life social interaction. But the kind of social interaction that is simulated in the ryōiku setting is distilled of various “noises,” subtle events or nuances that inevitably impact real practical experience. In real-life, knowing when to thank and to apologize is most often not enough in handling stickier

situations. I would like to describe one episode from my fieldwork, one that made a lasting impression on me as a story of an unfinished intervention. One mother was speaking to a staff member while I was present, and she voiced concern about her son's relationship with his peers in preschool:

The other day, I thought they were playing together in the sandbox, but when I went a little closer, I realized that his playmates were stuffing sand in his shoes. And there's this big kid – you know, my son's a bit small for his age – well, he would hold up my son and then drop him in the sand. I felt that the atmosphere wasn't entirely friendly. It was a bit like teasing, or bullying. It was all of them, against my son. I didn't know how to intervene, but I later asked my son how he felt, and he seemed content that everyone was engaging him. But it wasn't just engaging. He doesn't realize, and he won't say no to them.

This mother was hesitant to speak to the preschool teacher about this incident, because he was enrolled in a rather prestigious private preschool that had affiliated schools up to high school, and she feared her son could be forced to leave the school. Her son was doing relatively well in the ryōiku program. I had seen him participate in social skills training, where he took the initiative and always came up with the “correct” answers. His interaction with his peers in preschool, however, was much more complex than what was being simulated in the experimental space of ryōiku, and he was obviously unable to identify the presence of the slightest malicious intent in what seemed to be playful engagement. This story that the mother recounted was actually a realization of a concern that I had held throughout my fieldwork in ryōiku programs. I had never asked to interview or observe the children outside the program, but had wondered how they are, in fact, applying what they have learned in real life, and whether and how it is actually helping them get by. Ryōiku is, for better or for worse, a safe laboratory, one that does not replicate the world outside. As



a means to move beyond this limitation and to envision a kind of intervention that unfailingly prepares children for the world outside, perhaps there needs to be a stronger focus on peer interaction and on “self-learning” as a practice apart from the adult-initiated learning model that ryōiku may still tend to privilege.

### **Application of robotics: an experimental approach**

As one of the experimental and emerging fields of research on ryōiku with the potential to shift the mode of intervention in this direction, I would now like to turn to the application of robotics to the treatment of children with hattatsu shōgai. The link between hattatsu shōgai and robots was first pointed out by Shinichi Watabe, a cognitive scientist and professor of education at Tohoku University. In his book, *Roboticizing Children: Cognitive Science of ‘Learning’* (Robotto-ka suru kodomo tachi: ‘manabi’ no ninchi kagaku; Watabe 2005), Watabe refers to the “frame problem” that epitomizes the structural stalemate experienced by robotics scholars. Watabe writes:

Prior to 1980, or prior to the “frame problem,” researchers of robotics had a single basic principle. That principle was to “schematically program the robot one action after another to make it close to human beings.” Thanks to the significant improvement of robots and the efforts of the researchers, by 1980 we were able to produce robots of substantial quality. [Watabe 2005:17]

However, when the researchers attempted to bring the robot outside the laboratory, they were faced with the “frame problem” where the robots were unable to deal with the complexity and unpredictability of the real world. While humans are capable of selectively taking in the necessary information to perform a task, robots, being developed within the stable and

calculated setting of the laboratory, predictably fell short in adapting to the “ambiguity and complexity of daily life” (Watabe 2005:18). Faced with this issue, roboticists came to the realization that the existing scheme of development was not going to produce a truly human-like robot; it was decided that they would need to make a fundamental alteration in the design. The solution was to install a self-initiating learning function that lets the robots perceive and adapt to the existing environment through trial and error. It was in the context of this research that Watabe first came to the realization that education of children, both in school and at home, may be making the same mistake. Watabe’s work questions the validity of “teaching correct knowledge, from simple things to more complex things and accumulating them one by one” (Watabe 2005:19) and goes on to discuss the question of intervention in the education of children with autism in light of his research and development in robotics.

This may be precisely the kind of issue that the aforementioned mother’s story seems to underscore. In other words, research in robotics may provide an invaluable clue to the process of liberating intervention from the present laboratory-like setting of *ryōiku* and opening it up to different styles of learning and interaction.

There are several roboticists in Japan who currently work on the development of robots for use in *ryōiku* settings. Michio Okada, who began his career in NTT, Japan’s largest telecommunications corporation, is one of them. His initial specialization was in auditory science and he eventually shifted to the application of communication studies within the field of robot engineering.

Okada's creation, Muu, has a very simple interface. It is round, with a smooth horn-like tip at the top of its head, and has one eye where a camera is hidden. It is an amiable character-like robot equipped only with the function to tilt and turn its body. It has



Fig. 5. Okada's robot: Muu

no hands or legs and thus cannot grab things or walk. Okada: "When I bring this robot to engineering conferences and symposiums, people ask me what it can do. But it's not about what it can do; it's rather about what it can't do. It needs help in doing anything." Okada brings Muu to a ryōiku program in Kyoto, and with the cooperation of the staffs, he uses it to interact with children. Surprisingly, the children engage with Muu as if it is their younger brother or sister, trying to teach colors and numbers to it and asking what it would like to do next. This kind of interaction brings out a sense of responsibility and leadership in some of the children; qualities that they did not display in the existing ryōiku activities. In the context of their daily lives, the relationship between the staff members and the children is as fixed as that of the conventional teacher-to-student relationship. Although children interact with one another, they are mostly in the same age group and there is limited opportunity to offer guidance to younger, less capable children. Muu, however, seems more vulnerable and less knowledgeable than most children, tilting its head confusedly and often giving erroneous answers. Children sometimes scold it ("I told you not to do that!"), teach it new things ("This is green. Greeeen. Can you say green?"), and take care of it ("What do you want to do now, Muu-chan?"). Okada writes:

A robot that ‘cannot do anything on its own’ is in fact ‘assisting the children’. This is not an active type of assistance that takes the hand of the child and leads him/her somewhere. It’s more like the ground that responds to and safely supports the first step that the child takes with uncertainty. Its role is passive, yet productive. [Okada 2012:151-152]

Okada also describes Muu’s function as that of a “social mediator.” He doesn’t see robots as engaging in social interaction with humans as an interlocutor, but experiments with the ways in which the existence of robots can shift the power relationships within the given space, triggering a different type of communication among the individuals present. In my interview with Okada, I asked him about the distinction he draws between robots as social mediators versus robots as interlocutors. Okada recounted a compelling episode. “Several years ago, I was taking a walk in the park. It was a cloudy day, and in the light drizzle, I saw an old woman standing under a cherry blossom tree. In her hands she was holding Paro.” Paro is an interactive robot that looks like a stuffed baby seal. It was developed by Takanori Shibata of the National Institute of Advanced Industrial Science and Technology (AIST) for therapeutic use for patients with dementia, and it is carefully designed to perceive the environment and patterns of interaction through multisensory functions, so as to provide a user experience similar to that of animal therapy<sup>14</sup>. Okada continued: “This woman was talking to Paro. She was looking up at the cherry blossom tree, cradling the robot and whispering ‘look how beautiful the cherry blossom is.’ She was holding Paro as if it were really something precious, as if it were her newborn grandchild or someone, you know. But

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<sup>14</sup> For details on the design and function of Paro and research results on its effectivity for dementia treatment, see AIST’s website (AIST 2004).

of course it's only a robot, designed and engineered by people like us. And the light drizzle... There was nobody around. It was just she and her Paro in the spring rain. At that moment, I realized that there was something unsettling about that scene. I thought to myself that that's not the kind of work I want to do. It's just ethically questionable, you know. I don't envision the robots that I create to take on a role like that."

Okada seemed to be overwhelmed with his emotions as he recounted this vivid image of the old woman with dementia gently cradling her Paro. Cherry blossom, the national flower of Japan, has a cultural significance that symbolizes the season of transition, for the Japanese school year and fiscal year ends in March and starts in April, when the cherry blossom is in full bloom. They are also associated with ephemerality and transience, for the flowers are fragile and can fall with gentle rain. Was the old woman remembering something of her past as she looked up to the tree? Was she associating her failing memory with the fragility of the cherry blossom? She was obviously sharing that precious moment with her companion, Paro. Okada's discomfort with this scene was probably coming from a sense of something insincere about having robots, or programmed machines, fulfill this role of heartfelt companionship. Robots can simulate empathy and emotional ties, but they are obviously not genuine, humane relationships. To render the responsibility of care, and particularly emotional care, to these robots poses an important ethical question, as Okada makes eloquently clear. This is a particularly significant aspect of Okada's philosophy behind the use of Muu for ryōiku practices, as it defines the nature of the kind of intervention that robotics makes possible.

Hideki Kozima, a professor of design informatics at Miyagi University, is another roboticist working on the application of robots to ryōiku. Kozima works with a program in Shiga prefecture, where he has introduced his chick-like creation, Keepon. Keepon has two eyes, which function as a camera, and a mouth that is actually an embedded microphone. Hideki sets up the space so that there is an observation room next to the playroom. From there he can monitor the interaction through Keepon's camera and microphone and also talk with the children through a speaker he has installed under the robot.

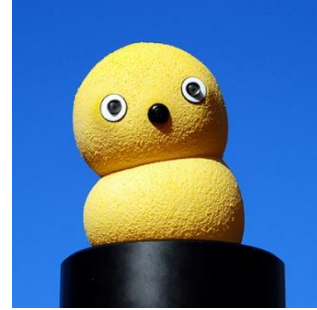


Fig. 6. Kozima's robot: Keepon

Keepon is designed to automatically detect the eye movement of the interlocutor. The robot can respond to the information it monitors, moving its body in reaction to certain cues, but Kozima emphasizes the importance of the remote operations performed through the human operator. “Socially meaningful interaction is only possible when actual people are making it move. The idea of a standalone, automated robot is a fantasy.” He has worked with very young children, of about three years of age, who have very limited or delayed speech. The longitudinal data from his research, taken over the course of three years, reveals how children who were at first approaching Keepon with suspicion and fear eventually began to interact with the robot – placing a hat on it, mumbling words to it and kissing it. In his conversation with me, Kozima recalled a moment when one girl who, after her fifteenth session with Keepon, finally reached out her hand, touched the robot's nose, and laughed, glancing back at her mother as if to share that moment. “The mother looked like she was going to cry. The girl had autism, and had never glanced at her mother like that, to share an emotion through eye contact. It came as a realization of and an attestation to the fact that she has the

desire to exchange and share her psychological state with others.” This episode reveals how Keepon is being used to bring out the children’s ability to engage with other people in ways that they previously could not; in other words, the robot can act as an agent to shift the mode of interaction among humans, even humans who have known one another for years.

As Kozima points out, Keepon’s appearance is critical in bringing out the social life-world of the child. Children with hattatsu shōgai, and particularly autism, are known to have difficulty “reading” the facial expressions, gestures, and other cues that suggest the emotional state of others. Keepon’s simple interface lacks threateningly complex cues, making it easier and more comforting for the children’s engagement. Comparing Keepon to other socially assistive robots developed in other countries (such as Kasper from the UK and Movellan, Mataric and Scasellatti from the US), Kozima argues that there is something specific about Japanese robot design:

We’re inspired by the tradition of anime (cartoon films) in Japan. We have this urge to create a character and bring it to life. I guess it also has to do with the ‘kawaii<sup>15</sup>’ culture of Japan. I feel that there’s something distasteful about robots that look too much like machines, and something uncanny about humanoid robots that don’t look like humans at all. Life-likeness is what it is, I think. It’s what brings out the social aspect of autistic children.

Indeed, both Keepon and Muu seem very much like characters that may appear in cartoon films. Their appearances are not realistically human-like, nor are they modeled after specific animals. However, they are equipped with minimal cues to suggest that they are

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<sup>15</sup> For more information on ‘Kawaii’ culture, see Allison (2003, 2006).

living beings with emotions similar to that of humans. Because of the very ambiguity of their representation, children sometimes show astonishment at their unexpected reactions. And yet they come to feel comfortable enough to treat Muu or Keepon as a toy and, at times, even as a younger sibling or a friend.<sup>16</sup>

The initiatives of Okada and Kozima are few of the emerging practices in the nascent field of applied robotics to approach hattatsu shōgai intervention from a perspective that significantly differs from the existing ryōiku practices. On the one hand, robots rely heavily on the children's initiative, providing an opportunity for a manner of playful engagement and learning that has been relatively underplayed in the existing ryōiku programs. On the other hand, while use of robotics has been successful in drawing spontaneous interactive exchanges, it remains a highly experimental method of engagement. At present, vision is still lacking regarding how robotic practice will scaffold the children's development in the long run; it is yet to be seen how Muu or Keepon, for example, will adapt to a child's shifting needs.

### **Reconsidering intervention**

Throughout my fieldwork, I had heard the word *kakawari* used numerous times by those in the ryōiku industry. Literally meaning *involvement* or commitment in a relationship, staff members of programs used the term to refer to the ways in which they engage with the children; thus, in that context, the term is defined and shaped through their

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<sup>16</sup> See Robertson 2007 for more on Japanese perception of robots and representation of personhood.



understanding of the ideal style of intervention. “We need to change the way of *kakawari* with him, because he’s not responding well,” was a comment that I heard often in meetings. *Kakawari* is a particular mode of interacting with the child; a way of talking to them and responding to their behavior according to a pattern that has been agreed upon. Their *kakawari* could be friendly or authoritative, directive or open-ended, and focusing more on verbal or bodily communication. In essence, the chosen mode of *kakawari* is at the very core of intervention, defining the relationship between staff members and each child. However, at the same time, *kakawari* is a word that refers to interpersonal relationships in a very general sense. To ask about one’s *kakawari* with another person is to inquire into how one met that person, what the two have in common and what ties them together. The image behind this lay usage of the term is that of two equal individuals involved in a mutual relationship. The conflated interpretation of *kakawari* therefore brings intervention and relationship together, indicating that the practice of *ryōiku*, when stripped of its techniques and methods, can be distilled to personal relationships among the individuals present, be they staff members or children. It is a practice of engaging with the children while enhancing their ability to engage with others. In this sense, *ryōiku* should be open to multitudinous and diverse forms of interaction, not limited to the one-directional endowment of knowledge and care from the giver to the receiver. The application of robots is one of the innovative and experimental modes of interaction implemented in these programs. The increasing awareness towards *hattatsu shōgai* among the general public may entail the involvement of other experts from unexpected fields and industries in the near future, opening up new and different possibilities of intervention.

## CHAPTER IV: NARRATIVES OF ADULTS WITH HATTATSU

### SHŌGAI

When hattatsu shōgai initially emerged into the public discourse, it was primarily understood in the context of childhood development. Discussions regarding diagnosis and intervention were focused heavily on children, and the first advocacy organizations were formed by concerned parents. However, with the growth of public awareness towards hattatsu shōgai, an increasing number of adults with the disability – most being in their 20s and 30s – began to “come out” in order to seek medical treatment, welfare assistance and, ultimately, peer support. A loosely knit network of adults diagnosed with hattatsu shōgai began to form. These individuals are collectively referred to as “chūto shindansha” (those who received diagnoses after reaching adulthood) or “*seijin tōjisha*” (literally translated as “adults who are concerned” but, in practice, used to refer to “adults with hattatsu shōgai”). As their visibility increased, they came to be seen as an important part of the hattatsu shōgai community, providing testimony of the disability experience in the era prior to the implementation of the Special Support Education.

Typically “*seijin tōjisha*” individuals are portrayed as having struggled in school, had strained relationship with family and friends, experienced difficulty in keeping jobs, and

suffered low self-esteem and a high incidence of depression and other psychological problems. This is certainly true for many, as depicted in their personal narratives and life stories. It should be understood, however, these stories have been strategically cited by stakeholders arguing for early diagnosis and early intervention of hattatsu shōgai among children. Thus, unfortunately, the narratives of adults with hattatsu shōgai have been utilized as negative, cautionary examples showcasing the pain and suffering endured by individuals being left without adequate support, thereby serving as testimonials shoring up the case for early intervention. Adults with hattatsu shōgai are often invited to seminars and symposiums to share their experiences, but their stories are too often reduced to serve a political end. Being deployed to instill fear in parents with young children, chūto shindansha stories are used to motivate parents to take advantage of intervention programs and special education resources. A few adults with hattatsu shōgai have explicitly criticized this. For example, Koumori (2008) writes:

Even when we are asked to comment on special support, there is a stark distinction between those who have received early intervention and those who received diagnosis at an older age. Those who received early intervention are asked to give a success story about “what kinds of intervention you benefited from” while the latter are asked to give a regretful account about “what kinds of intervention you were in need of”. There is a premise that “those who received early intervention are blessed, and those who didn’t are doomed”, and we’re solicited to answer accordingly. And what’s lost along the way is the perspective of how individuals who reached adulthood without diagnosis or treatment can lead fulfilling lives, for now or in the future. [Koumori 2008:58]

It is against this backdrop that I write this chapter, which is based on the collection of interviews with three adults with hattatsu shōgai whom I met during my fieldwork. All

of these individuals grew up when hattatsu shōgai was virtually unknown outside of a small circle of medical experts. Thus they have all “realized” their disability years after having experienced troubled childhoods and adolescence. Many of them voluntarily went to psychiatrists to get their diagnoses after learning about hattatsu shōgai through various sources, gradually coming to the self-realization that they seem to fit the hattatsu shōgai criteria. The opportunities that are made available to the young children today, as well as the heightened level of awareness towards hattatsu shōgai among school teachers and the degree of involvement of parents, differ greatly from the experiences of my interviewees, who were generally left to manage their personal difficulties and navigate the academic system on their own.

Here I have attempted to stay true to my interviewees’ personal accounts and to refrain from linking their stories to any particular agenda or political end. The stories that I introduce collectively provide an alternative voice representing the hattatsu shōgai community, a first-person voice that engages with the critical question of what it means to be living in Japanese society feeling different and inadequate, lacking the language to describe that sense of discomfort and displacement. These are the people who have had to cope with their disability throughout their educational careers without a biomedical label to resort to or identify with; they have experienced tremendous trouble finding and keeping jobs, particularly as they began their career during the Japanese economic downturn. Their narratives illustrate how emotionally taxing it has been to carve out a place for themselves in society. In other words, their stories of receiving the diagnosis, coming to terms with the disability, and redefining their identity through (but not necessarily buying into) the hattatsu

shōgai label, serve to shed light on the understanding of what it means to be a “hattatsu shōgaisha” in a way that is crucially different from the stories of children who are being diagnosed early and receive the benefits of intervention programs at a young age.

In less than a decade, the generation of children who are currently being educated under the Special Support Education system will reach adulthood, and the narratives of “hattatsu shōgaisha” adults will most likely make a qualitative shift, rendering the experiences of chūto shindansha rare and outdated. It is precisely because they live in this transitory moment that they are able to share these rich narratives of the processes by which they became a hattatsu shōgaisha. These are telling stories of discovery, assurance, negotiation and identification by those who survived the “dark ages” prior to the current context of intervention.

## **Kaori**

When adult hattatsu shōgaisha speak of their childhood, many bring up episodes of falling behind in academic work in school, being unable to build personal relationships with others, and having difficulty doing things that seemed to come naturally to others. Memories of their inability to fulfill various expectations and goals since childhood permeate their narratives.

Kaori, the interviewee of this case, is a woman in her 30s. Kaori had dreamt, ever since high school, of becoming a hair dresser, but she could not pass the national qualification exam. She left Japan for England to study art at a university and, when she came back, she

continued her attempts to pass the exam to become a hair dresser. Finally giving up after more than five tries, she began working as an administrative assistant for several foreign companies.

I just couldn't pass the exam. You need a license to become a hair dresser. I began a distance learning program to become a hair dresser when I was in 11<sup>th</sup> grade, and took two years to finish the program. During the first year I was also working at a hair salon. After the program, you still need to take the exam to get the license, but I didn't pass. The exam involves a paper-based test and an actual performance test, but I just couldn't pass. Sometimes people fail, but they say if can't fail the second time. But I failed five times, and I got tired of myself. The exam is held twice every year. I went to England to study, and came back and tried again. Five tries would be equivalent to two and half years, but I kept on thinking about passing the exam for about six years. Even after I came back from England, having the license means having a secure income, and hair salons these days won't employ if you don't have a license. So I tried and tried, but kept on failing... It was unbearable, but I decided to shift my career to a different direction.

While she was in England, Kaori spent much time at the study support center at her university to get help in her academic assignments. The staff at the center told her that she may be dyslexic and suggested that she take a screening test. She did so, and the results showed that she was indeed dyslexic. After receiving the diagnosis, she began to interpret her past failures to acquire the hair dressing license as an inevitable result of her dyslexia. However, her experience of repeated failure and her sense of disqualification persistently haunted her in her career that followed, even after she came back from England and took on a corporate job.

I had to make use of my English skills to make money, so I decided to take an administrative job at a foreign firm. But I was fired for making mistakes. My job was to punch in product codes, you know, numbers that are given to their products. As an

assistant, I had to type up 500 or so product codes, but I made mistakes, turning up the wrong products. My boss scolded me because I couldn't complete such a simple task. I didn't tell them that I have hattatsu shōgai when I was interviewed for the job. I actually said that I'm good at tasks like that. Nobody would hire me if I told them that I make mistakes, right? The boss would scold me. At that time, I'd get hired, then fired, and then get hired at another firm again, but then get fired again... It was a difficult time. They said, 'How can you make mistakes at such a simple task!' I didn't tell them. I thought I had to suffer all this by myself, and I myself was disappointed and sad about making so many mistakes. There were times like that. My boss said it's because I don't go back and make sure, and I thought he had a point, but I can't identify my mistakes even when I go over them. I was sure about the figures when I wrote them, so it's hard for me to identify the mistakes (laugh). I don't think I'm good at checking papers for mistakes anyway, but it was a difficult time... some people said that I shouldn't go home until I finish. I'd say yes, I'll work hard ("ganbarimasu") and try to think positively that I'd get paid for the overtime work, but I can't make out where I got the numbers wrong. I'm bad at reading two or more alphabets or numbers at once, or documents with little spacing between rows.

Kaori almost never reads for enjoyment. What she reads in her private time is limited to things that are absolutely necessary, such as labels on drugs. She says she cannot imagine why people would leave books at their bedsides to read before going to sleep. One might imagine how hard it was for Kaori to accurately punch in meaningless numbers and letters, given that even reading the captions on her favorite hair artists' photographs is a painstaking task. Kaori had changed her job several times, and although punching in product codes probably wasn't the only thing that she did in every position she held, she didn't offer any other description of her jobs, nor any other explanation about why and how she was fired. In other words, in her narrative, her failure to comply to the expectations of her corporate jobs is essentially attributed to her inability to read and type in product codes, a task that most saliently highlights her dyslexic traits. In reality, the difficulty that she

experienced in her workplace was probably much more complex, entangled in multiple layers of unfortunate circumstances such as miscommunication with her boss, competition among workers, lack of reliable mentors, unfavorable working conditions, and poor effort on the part of the employer to identify and address conflicts. However, by the way Kaori attributed the problem to her inability to type in product codes, we realize how her newly acquired understanding of dyslexia is shaping the way she sees and interprets her experiences and, in particular, her failures.

Kaori also mentions several times that her boss described her task as “simple.” The fact that the task was considered uncomplicated and straightforward for anyone to handle was a burden for Kaori, leaving her in disappointment at her own lack of skills and inadequacy. Kaori is not alone in uncritically internalizing others’ negative evaluations and forming a self-image that is burdened with a sense of failure and disqualification. Very few people with hattatsu shōgai speak of feeling anger or resistance regarding what might seem like an absurdly overwhelming demand or assignment from their teachers or bosses. As exemplified by Kaori’s narrative, their sense of inadequateness comes first and foremost through other people’s evaluative comments; after internalizing a catalogue of critical remarks, they eventually form a negative self-image.

In the years after receiving her diagnosis in England, Kaori began to reframe her sense of “failure” as “having certain shortcomings.” While recognizing her difficulty in reading and writing, she began to focus more on her artistic talent and good social skills. In the attempt to make the most of what she excels at, she began to work as a salesperson at an insurance company. During the weekends, she works as a freelance makeup artist and hair



stylist (although her work is limited to hair arrangement, which doesn't require a license) and at times holding cooking lessons at her home. Kaori:

I'm really lucky for realizing what I'm good at, and what I'm not good at. Since, maybe last year, I really began to enjoy life. I don't feel as disappointed when I fail. I've always been optimistic, but I feel much stronger now. If I hadn't gone to England, I probably would have lived my life feeling that I'm a failure. I'm glad that I went to England and received the diagnosis at my university. In Japan, there still are people thinking that they must be dumb (*chie-okure*), so we need to help them.

In the last sentence quoted above, Kaori has alluded to the fact that, in Japan, in contrast to England, there are many people with *hattatsu shōgai* who have not received diagnosis and so typically remain unsure of why they feel different. In referring to their self-image, she chose to use the word *chie-okure*, which is a lay term that literally means, “intellectually delayed,” and is often used as a derogatory label for people with intellectual disabilities. Her choice of the word illuminates Kaori's understanding of where *hattatsu shōgai* stands within the landscape of disability politics in Japan, as well as her effort to draw a distinction between *hattatsu shōgai* and other disabilities. The concept of an “intellectual disability,” in Japan, is typically understood as representing an overall delay of intellectual abilities, the manifestation of which can be quantitatively identifiable through various tests, the most common of which is the IQ test. On the other hand, it is generally understood that people with *hattatsu shōgai* are different in that they have difficulties in limited, specific areas such as reading and writing or social skills. In fact, the discrepancy in performance over various sections of standardized tests is often described as “*dekoboko*,” or “*zig-zag*,” alluding to how their achievements vary greatly by the skill that is being measured (Sugiyama 2009). Kaori's strategy to cope with her sense of failure is to focus on her talent in art rather than on

reading and writing where her disability is most clearly manifested, and to build a career based on what she does best. By referring to people who “think they are chie-okure,” Kaori is alluding to people with hattatsu shōgai who feel so devastated by their underachievement, which seems to permeate all areas and subject matters, that the disability renders them incapable of realizing their talents or abilities in other things.

Inability to read and write, in a highly literate society like that of Japan, does often crush the hope and self-esteem of young students. Particularly because the public educational system places a strong emphasis on reading, writing and social skills, children with hattatsu shōgai are often so overwhelmed with their difficulties – which seem to influence their achievement in every area of academic training – that they become blinded to what they actually enjoy or are good at. Placed in this context, Kaori’s reference to intellectual disability can be read as an empowering statement that liberates people with hattatsu shōgai from their strong sense of failure. At the same time, however, her ambivalence raises a problematic question regarding the positionality of people with intellectual disabilities. Kaori continues:

The image (of hattatsu shōgai in Japan) is dark and heavy. It’s not like how it is in the US or Europe, where they say, ‘Right, you’re dyslexic. Big deal.’ It’s not like we can’t live a normal life because we have hattatsu shōgai. Over there (in England), it’s just a heads up, like you can’t eat spicy food. They actually asked me why I was so obsessed about it. We round it all up with the word ‘disability’ but intellectual disability and hattatsu shōgai is totally different, and it’s a pity that we treat them as if they’re the same.

In this passage, Kaori problematizes how intellectual disability and hattatsu shōgai are treated “as if they’re the same,” and she questions Japanese society for the conflation of

what she sees as two fundamentally different conditions, a conflation that does not take place, Kaori maintains, in the British social context. In British society, as Kaori depicts it, dyslexia doesn't carry the burden of being a "disability"; rather, it represents a purely physical trait that is no more significant as one's inability to eat spicy food. Whether dyslexia is truly as insignificant and trivial in England as Kaori depicts it to be is questionable<sup>17</sup>, but Kaori's perception led her to embrace a new understanding of her condition. Through the reference to British society, Kaori's narrative points to alternative ways in which people with hattatsu shōgai are perceived, and in which the society accounts for the diverse "inabilities" of different people. The episodes that Kaori offers from her experience of living in England draw our attention not so much to specifics of British society but to a potential criticism of Japanese society that the national comparison elucidates. Although Kaori's interview focused very much on her personal struggles to cope with her perceived failures, her stories also inform the ways in which her experiences are structurally shaped and defined. Her suffering is not an immediate result of her technical difficulty in reading and writing, but is mediated by the social necessity to read and write in order to prove one's competence in other areas, as well as by the ways in which "disability" is perceived in Japanese society.

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<sup>17</sup> For example, there has been reported cases of bullying of students with the disability in England (*Daily Mail* 2011).

## Shōta

I've been aware of it since childhood. Since first grade, I wasn't interested in reading and I couldn't memorize the multiplication table. I moved to New York in second grade because of my father's job and lived there for two years, and I also lived in Texas for a year when I was in eighth grade. I always thought that I couldn't read because I was living abroad at the age when children learn to read, but once I met someone who had lived abroad longer than I did, and this person had no problem reading and writing. That was when I thought something was wrong.

Shōta is a Japanese man in his 30s who lived in the US for a significant portion of his youth, owing to his father's job reassignment. Shōta had always been aware that he was not reading or writing as well as his peers, but he had interpreted the difficulty as a result of living abroad in a bilingual environment. When he returned to Japan in fourth grade after spending two years in New York, he enrolled in a third-grade class for a short period to catch up on what he has missed. He also received individualized instruction in the principal's office. By the time he went on to middle school, Shōta was falling behind in class and was often in trouble with his classmates. "I did go to school, but I was withdrawn and my classmates bullied me. I was almost like what they call hikikomori<sup>18</sup> today." However, when he again left the school in Japan, in a move to Texas, the situation changed. Although he was still without diagnosis, his school counselor recognized a problem and helped him. A classmate was asked to take notes on carbon paper and share copies with Shōta so that he

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<sup>18</sup> "Hikikomori" refers to individuals who withdraw from society and confine themselves in their rooms, minimizing contact with others. In this context, however, he seems to be using the term to indicate that he wasn't very social, although he continued to attend school. For a more detailed discussion on Hikikomori, see Horiguchi (2006).

could file them. Allowances were then made so that Shōta could take his exams in a resource room where a teacher read him the test. The counselor also suggested that he take a typing course so he could work around his difficulty with handwriting. Shōta:

I didn't want to come back to Japan. I used to think that I was behind in Japanese school because I spent several years in the US while I was in elementary school, so I was reluctant to move to the US again in middle school. I thought I'd fall behind again. But when I went, I didn't want to come back to Japan. I got good grades in America, while I was failing in Japan.

Shōta initially attributed his academic failure to the fact that he had lived in the US, but after receiving assistance in his school in Texas, he was able to regain his confidence. The fact that his grades in Japanese and American schools were so different greatly influenced his understanding of the diagnosis he received later in life.

Shōta finally received diagnosis in his 30s. By then, he had graduated from an agricultural high school, worked for several years in related businesses, and had returned to school to earn a college degree in agriculture. He was suffering from a sleeping disorder and from depression, while also having trouble building social relationships. He wondered if he had “some sort of a personality disorder” and saw a psychiatrist. Although he hadn't heard of *hattatsu shōgai*, he knew about ADHD after reading the book *Madogiwa no Tottochan* (1981), a biographical account by a prominent television show host Tetsuko Kuroyanagi (1933-), on her troubled childhood<sup>19</sup>. When Shōta told the psychiatrist that he

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<sup>19</sup> The book sold over 7 million copies, making it one of the most popular best-sellers in Japan. Although Kuroyanagi does not mention anything about having a disability in the book, her account of being labeled as a nonconforming trouble-maker in school before transferring to a private school with a unique

had had tendencies as a child that were similar to the author's, he was screened for hattatsu shōgai and received a diagnosis of PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified). In the years following, as he continued to see the psychiatrist, his diagnosis was changed to learning disability.

Since receiving the diagnosis, he began to realize that his school counselor in Texas had offered him “special accommodations” that minimized the effect of his disability on his overall academic performance. Such accommodations were difficult to obtain in Japanese schools; documenting one's qualifications with the local board of education entailed a tedious bureaucratic procedure that, furthermore, cast a burden on the school and the teachers responsible for the arrangements and paperwork. As Shōta's problems had gone unnoticed in the Japanese educational system, it is hard to imagine that the process would have proved fruitful. Recalling his school life in Texas, Shōta seemed genuinely impressed by the flexibility of a system whereby one counselor was able to adjust the logistics of his coursework, thereby enabling the success of his education. He spoke of the discrepancy between his performance in the school in Texas and back home in Japan as not only a difference made by “special accommodations,” but also as the difference between the two cultures of Japan and the US.

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educational philosophy is a story that many individuals with hattatsu shōgai have come to identify with. Kuroyanagi is considered to be one of the iconic celebrities with hattatsu shōgai, but I have not been able to find any reliable sources on her disclosure of disability status.

These days in Japan, they use words like KY,<sup>20</sup> and call people Aspergers' for showing the slightest tendencies. They say people with ADHD can't 'read air' either. But I think that there's also a cultural aspect. In Japan, I feel that I behave more in an Aspie-ish ("asupe-ppoi") way than I did when I was in the US. There are cultural and national differences, like some cultures being more strict about time. In Japan, they say resumes have to be handwritten, but it takes me more than three days and five miswritten drafts to write a single proper resume. But you know, in Japan they ask for handwritten ones to see if your writing is good or not. Also, in the US, people say things more clearly than in Japan, and they try to explain things particularly clearly to me because I'm a foreigner, so I didn't have as much trouble communicating.

It takes time for Shōta to prepare a handwritten resume because of his learning disability. Reading and writing is even more time-consuming for Shōta in English than in Japanese, because the phonetic nature of English makes it more difficult for him to make the connection between the written text and its oral sound. However, he believes that his true difficulties lay not so much in the technicality of reading or writing, but in the social context that necessitates the enforcement of those skills, including the social value and meaning attributed to those abilities. If companies would accept printed copies of Shōta's resume, he can apply to multiple companies only with the effort of typing up a single resume, but since the companies ask for hand-written copies, he spends a tremendous amount of time in the preparation of his resume. However, as long as it is the prevalent custom to privilege hand-written documents, and as long as handwriting is considered such an important element

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<sup>20</sup> "KY" (kay-wye) was a popular slang in Japan when the interview was conducted. It is short for "*kūki ga yomenai*" ("cannot read air"), referring to how some people behave regardless of the unspoken expectations in social situations. The word has a critical connotation condoning their behavior.

of self-presentation in the job application process, Shōta has no choice but to write them out, one by one.

Shōta makes a relatedly important point regarding the difference in communication practices between Americans and Japanese. Autistic people, including those with Asperger's syndrome, tend to experience difficulty in “reading between the lines” to understand the subtleties of unspoken or indirect intentions. From Shōta's perspective, Americans tend to “say things more clearly,” in comparison to the Japanese, thereby minimizing the amount of information to be inferred contextually.

As previously discussed, Shōta's initial diagnosis was PDD-NOS before it was modified to learning disability. He then notified his university of the diagnosis and asked for extended time when taking exams. He has also considered applying for disability certification, which is issued by the government, and could help him secure a job under the disability quota.<sup>21</sup> So Shōta has been keen on taking advantage of available resources, including the social and political opportunities afforded by the diagnosis. In this sense, he is embracing the legitimacy of his medical diagnosis. On the other hand, however, he is quick to recognize the ways in which disability is manifest according to “cultural differences” as described above. Shōta's reflection on his own experience points to the possibility of interpreting hattatsu shōgai from a perspective entirely separate from that of the clinical. For example, he speaks of “asupe-pposa (Asperger's-ishness)” in a way that suggests the

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<sup>21</sup> Disability certification is not granted for hattatsu shōgai alone, but Shōta had consulted his doctor and found a way to receive certification through some of his secondary symptoms.



assuming of an identity that is as likely to be self-ascribed as it is to be assigned by lay individuals, that is, family, friends, colleagues or peers. Doing so, he illuminates the presence of a discourse that produces, describes and attributes this “ishness” at a level that circulates entirely independent of the clinical standards of diagnosis that are shared and adopted by psychiatrists across national and cultural boundaries. The fact of having received the diagnosis, on the one hand, and being perceived as someone with that diagnosis, on the other, become two different realities which then produce two quite different sets of circumstances; the true difficulty lies in having to live under a certain kind of environment which necessitates a stronger manifestation of “ishness.” Shōta:

I’m also a bit Aspie-ish (asupe-ppoi). When I was a kid, friends used to tease me a lot because I was easily deceived. There were things I had to have by my side when going to sleep. And even now, I can’t wear clothes that are itchy on my skin, like turtleneck sweaters. I tend to become friends with a very specific type of people. Once during class, I wondered what would happen if I sharpened my pencil until the very end, and I tried to do it. I even made it a rule not to let the shaved skin break in the middle (laugh). I was concentrating so much in this, when the teacher lightly knocked me from behind (laugh). I also used to stare out the window a lot. I forgot to bring a lot of things to school. I kept an encyclopedia in my book bag. I guess I took it out and read it whenever I had time.

Shōta maintains that he not only has a learning disability (for which he has received diagnosis) but that he has Asperger’s as well. And he points to several reasons to shore up his position. Being easily deceived has to do with his tendency to take people’s words at face value without being able to identify a joke from its context. His dislike for itchy clothes is likely a symptom of the kind of sensory overload suffered by many people with Asperger’s

(which explains for the strong preferences many people with Asperger's will register regarding the textures of their clothing). Shōta's attachment to his encyclopedia, along with his playful game of pencil sharpening, represent examples of a preoccupation with collection, organization and maintenance of order around certain items or categories of items. All of these behaviors are consistent with clinical traits known to be expressed by individuals with Asperger's, what Shōta describes as his "Aspie-ishness." Without a medical diagnosis, he does not claim to have Asperger's. However, at a level that is entirely different from medical diagnosis, Shōta proclaims his "Aspie-ishness" as a tangible, "legitimate" way to articulate his "ikizurasa," or "difficulty of living."

### **Yoshiko**

When I was working as a salesperson of cosmetics, my boss was very strict. I had trouble doing my job. For example, when I had to clean the shelf I would take all the products off the shelf, and then forget the order in which they were lined up when putting them back. Also, when a customer wanted change and asked for so-and-so number of 1000 yen bills or so-and-so number of 500 yen coins I couldn't just memorize it so I had to write it all down. The store manager saw me and said, 'can't you memorize that?' so I said 'I'm not good (*nigate*) at memorizing.' Then she said, 'well if you're not good at it, you just try harder and you'll be able to do it.' Whenever I say I'm not good at something, that's how people respond. It's hard to draw the line between not being good at something and having a disability. They fired me from that workplace, and when they did so, they said something like I wasn't doing my job, so I came out to them that I actually have this disability. Hearing that, she asked me why I didn't tell her that from the beginning. But I work for the same wage as people without disabilities, so there's really no use coming out about things like that, is there?

This is an excerpt from an interview with a woman named Yoshiko. Yoshiko had particular difficulty in retaining short-term memory; she diagnosed in her 30s as having

hattatsu shōgai. She had frequently changed jobs throughout her adult life, and after receiving the diagnosis she held various positions as a part-time worker and a contract worker. Yoshiko had experienced a pattern of being fired for her inability to do what she was told.

A diagnosis of hattatsu shōgai, in itself, does not qualify a person for disability certification under the Japanese welfare system. However, if the individual is suffering from depression or other secondary symptoms, it is possible to acquire the certificate for those mental illnesses. Some, in fact, see this provision as a loophole of the system, and feel that, as such, it is being exploited for advantage. Yoshiko had been advised by her psychiatrist to acquire the certificate, as it would provide her an opportunity to work with certain accommodations while also giving the employer the advantage of qualifying for tax waiver. However, since Yoshiko chose not to apply for this certification, she figured that it would make no difference whether she “came out” to her employer or not.

If I have a certificate, I can work under the quota, but it means a lot to me that I'm working just like any normal person is. I feel uncomfortable about getting a certificate and asking to let me work as a disabled person; I guess that's the last resort. If can't find any other way, I might do it. But until then, I'm going to hang in there and face it by myself. I know this might sound discriminatory.

Throughout all the stories that Yoshiko shared with me, there developed an underlying theme around her conflicted relationship to the label of “shōgaisha” or “the disabled.” Yoshiko spoke about the conflicting emotions regarding the disclosure of her disability to family and colleagues and how she fluctuated between wanting to be understood and feeling uncomfortable about taking on the label of “shōgaisha.” She made a clear distinction between “working just like any normal person” and “asking to let me work as a

disabled person.” I wondered what kind of emotional tension would account for the discrepancy between these two expressions. Yoshiko had an answer:

Five years ago, I read the book, *Women with Attention Deficit Disorder*<sup>22</sup> and thought that I was precisely the kind of person described in the book, so I went online to look for a clinic where I could get diagnosed. At that time, the doctor first said, ‘I don’t think you have it (hattatsu shōgai). You can talk normally, like we’re doing right now.’ But they did the examination just in case, and then they were like, ‘Oh so you do have it.’ My IQ was really low too. When I got the diagnosis, I got a name for it, and I felt like forgiving myself for not being able to work properly and changing jobs so often. These days, I talk to the doctor, and it’s not like he would give me much advice, but I feel better after having someone listen to me talk. At the clinic that I go to, there’s day care and night care, and people with hattatsu shōgai get together to chat and do things, but most of them have Asperger’s and are doing stuff like SST (social skills training). I’m just watching them, thinking it really isn’t for me. I’ve never met anyone like myself, with just short-term memory disorder. When I talk with people with Asperger’s, I know that it’s because of their disability, but I get offended by the things they say. I know that they can’t help it, but still. It’s difficult to become good friends with them.

Yoshiko's narrative is filled with ambivalence about her diagnosis. She had taken many jobs in the past and had blamed herself for not being able to hold on to any of them. After receiving the diagnosis, she felt, for the first time, that her inability to keep a job was

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<sup>22</sup> The original book was written by Sari Solden (1995) and it was translated to Japanese by Rinko Niki who is an interpreter with autism. The Japanese title of the book is “Katazukerarenai onnatachi (Women who cannot clean up)” and was published in 2000, as one of the first books introducing the notion of ADHD to the Japanese audience. Consequently, more than a few adults with hattatsu shōgai (particularly women, because the title is of interest to female readers) that I interviewed referenced this book as their first encounter with the idea of hattatsu shōgai.

not entirely due to her lack of effort; and she “felt like forgiving myself for not being able to work properly.” Clearly the biomedical label of hattatsu shōgai had helped to ease the burden that had accumulated with her experiences of failure. And yet, on the other hand, the diagnosis has not been instrumental toward acquiring resources, other than her taking the opportunity to talk with her doctor once in a while. As will be discussed in more detail below, Yoshiko has not disclosed her disability status to others, with the exception of her family members and very few friends. Her narrative about her relationship to others at the clinic suggests that she finds it difficult to relate to others with hattatsu shōgai, because their experiences do not mirror hers. Yoshiko said she “gets offended” by the things they say, referring to the fact that people with Asperger’s or high-functioning autism disorder tend to be less sensitive to social appropriateness in interpersonal interactions and thus they would often do or say things that would inadvertently offend others. Her comment, “I know that they can’t help it, but still,” implies that traits or conditions categorized under the single rubric of hattatsu shōgai are in fact different disabilities entailing varying experiences. It might be as difficult for people with varying manifestations of hattatsu shōgai to understand one another – despite their shared difference from normative society – as it is difficult as someone without hattatsu shōgai to understand those with the disability. Yoshiko also mentioned that she had never met anyone with “just short term memory disorder,” referring to the fact that she has never been able to meet another hattatsu shōgaisha who shares her experience and fully understands the specific difficulties she encounters in everyday life. Yoshiko’s concerns underscore the fact that hattatsu shōgai is merely a generic term for multiple – and often very different – kinds of disabilities and combination of symptoms. The ways in which people experience difficulties in their everyday lives, including their

unique ways of coping, vary greatly by individual, making it nearly impossible to identify with others based on the diagnosis alone, let alone to make friends based only on that identity.

Yoshiko related a story about coming out to her friend:

When I was in college, my friends used to say I was a bit scatterbrained but I accepted that as my character and felt good about it. When you're in school that's just your character, but it's different when you enter the job market. I couldn't keep a job and I've tried many part-time and contract jobs but I've been hired numerous times and have changed my job so many times that I can't even list them all in my CV anymore. Some friends worry about me, and I've come out (that I have hattatsu shōgai) to some of my closest friends. One friend from college has a job in welfare; she's a counselor at a child counseling center. She asked me a lot of questions like 'Are you bringing in money to your parents?'<sup>23</sup> and 'Do you have a vision for the future?' so I came out to her. She thought I did so because I trust her, and said 'Thanks for telling me.' She knew about hattatsu shōgai because of her job. But then I said, 'it's not that I trust you; I had to tell you because you're being nosy. Shouldn't you be more aware of how depressed I am about my inability to hold down jobs? Isn't that part of your profession?' and our relationship got a little awkward. We're okay now, at least at the surface level. I'm actually very careful when it comes to communicating with others. Even when I think I know that person, in reality I might be totally off the point, and might be misunderstanding that person. I think about these things a lot.

Yoshiko explains that when she told her friend about her diagnosis, it was not from the urge to be understood but from the weariness of being pushed. There is a stark contrast between Yoshiko's motivations and those of her friend; Yoshiko thought that she could do away with the constant questioning by coming out to her friend, but the friend who took her confession as a sign of friendship and trust. Yoshiko's final comment alludes to her hope

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<sup>23</sup> This question is referring to the cultural expectation for children who finish education and begin working while living with their parents to contribute a part of their income to the household.

that others would reciprocate her concerns about (mis)understanding one another. She says, “even when I think I know that person, in reality I might be totally off the point,” indicating her awareness toward how her job-hopping may be seen as lacking endurance when, in reality, she has been constantly faced with challenging tasks at work and was forced to negotiate her identity as a disabled person along with her will to keep a job without disclosing the truth. To accept a realization that your close friend might not be the kind of person you think she is, and yet to be there when she needs you and to support that person, this is precisely the kind of attitude that Yoshiko seeks in her friends. Indeed, such a relationship may provide the most supportive context in which to negotiate the either/or choice of “coming out,” and to comfortably live with the consequences either choice.

I took Yoshiko’s word to be an implicit caution to myself as the ethnographer. Writing about other people’s stories requires constant self-reflexivity on the part of the ethnographer as the one who interviews, interprets, crafts, and narrates individual stories to the reader. Yoshiko was one of the few informants who had deliberately engaged me on this issue, asking at the end of the interview why I had chosen to study hattatsu shōgai and how I see myself to be related to this subject in writing about individuals with the disability. I told her that I had spent a significant part of my childhood in the US and Europe and returned home as a “*kikokushijo*,” a returnee student who had been raised abroad because of family obligations. During the 1980s and 1990s, when Japanese corporations were sending a great number of employees on foreign assignments, the readaptation and resocialization of the children of those employees became a significant issue in Japanese schools. “Kikokushijo” was one of the most visible and significant (and one of the most studied)

minority population in the Japanese school setting back then; having gone through the educational system as a “kikokushijo,” I had held a particular interest in children with hattatsu shōgai as an emerging group of marginalized students with the potential to challenge and alter the status quo in the current educational system, in ways that may be similar in some aspects to the impact that “kikokushijo” had. Yoshiko listened intently. Although she didn’t say much, she gave me an affirming nod, for which I felt respected for my own (although different) minority status<sup>24</sup>.

Yoshiko went on to talk about her experience of “coming out” to her family:

I told my brother [that I was diagnosed with hattatsu shōgai]. My brother is very smart, and he's a science/engineering type of person. He said, ‘doctors like to categorize and label things. Why couldn't you just think of those things as “nigate”?’ [silently weeps for a while...] I always thought I couldn't tell my mother, but when we got into a fight this year, I spontaneously told her. I had kept it to myself for four years. My mother was shocked. At least for three months. When I was young, there was a child with intellectual disability living in the neighborhood, and we used to play together. Once, this kid threw a clock at me and it almost hit my head. My mother used to talk about this incident with a discriminatory tone, like ‘I’m glad you were born without any disabilities unlike that child.’ So I think it must have been very shocking to her. When I went to see the psychiatrist, I needed my maternity health record book (boshitechō)<sup>25</sup> and had my mother look for it, so she said she “thought there must be something going on.” My parents spent a lot of money sending me to a private high school, and let me do all the things I wanted, so I'm really sorry for them... [cries].

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<sup>24</sup> I will return to this point about my positionality to the field in the Epilogue.

<sup>25</sup> A notebook distributed by local governments for new and soon-to-be mothers to keep record of the milestones of their children’s growth, vaccination dates and results of physical checkups.



Yoshiko broke down to tears twice in the above dialogue. One of these moments was when she recounted how her brother dismissed the doctor's diagnosis, trying to convince her that she is simply not good at certain things (nigate). The second time was when she recounted how she came out to her mother, and by imagining how her mother is feeling about her daughter's disability (given her previous discriminatory remarks in reference to a child in the neighborhood), Yoshiko cried because she "felt sorry" for her mother. In the first case, Yoshiko's brother blatantly denied her disability, and in the second episode, her mother hesitantly tries to accept her disability. But in either case, Yoshiko felt uncomfortable. With regard to her brother's remarks, Yoshiko herself is very well aware of the critical implications of identifying her difficulty as caused by a "disability," as opposed to framing it as something that she is "nigate," and has struggled with these very labels while working at the cosmetics store. It is not difficult to imagine how it must have hurt to have that pointed out by her brother. For Yoshiko, the challenge was not in framing her short-term memory disorder as a "nigate," but in knowing that the problem could not be overcome by effort alone and yet, at the same time, continuing to maintain the impression that she was putting in her best effort.

Turning to her confession to her mother, what lies behind her mother's "shock," and also behind Yoshiko's sentiment in response to that shock, is the social imperative regarding disability. The child who lived in the neighborhood becomes representative of "the disabled." And while expressing reservation that her mother's attitude towards that child may be discriminatory, Yoshiko shows empathy to her mother's feelings. "Discrimination" is not only a function of her mother's values, it is connected, as well, to larger societal values,

ideas and prejudices that potentially implicate her mother along with herself, which is precisely where Yoshiko's lingering sense of guilt is coming from. Yoshiko's feelings towards her brother and her mother seem, on the surface, to be contradictory, but they speak eloquently of her ambivalence in dealing with the stigma associated with being disabled. The politics of "coming out" is intricately related to the social stigma evoked in the process of communication, and the ways in which personal relationships are reconstituted through that act.

Yoshiko eventually signed up with an agent for contract work and told them that she "is not good (nigate) in responding to phone calls and also has difficulty multi-tasking." Consequently she was assigned to a job that requires neither. She continues to speak of her short-term memory disorder as a matter of "nigate." When her boss criticizes her for her lack of effort, at times she takes it to heart and at other times she fends it off. On the other hand, she also reveals the stress of keeping her diagnosis a secret: "I'm always afraid when they might find out. When would they start saying, 'you're not just being careless, are you?'..."

The problem of "coming out," as seen in Yoshiko's narrative, represents the negotiation of the prevailing image of disability in Japanese society more than it does her personal struggle to come to terms with her diagnosis. Although hattatsu shōgai is being increasingly acknowledged in recent years, there is a general lack of awareness regarding the fact that, for example, one's neighbor or colleague may have the disability. In other words, the presence of hattatsu shōgaisha is noted, but they are perceived as a community of anonymous individuals, living "out there somewhere" but not next door. The choice

available to those like Yoshiko is between not coming out – insisting on the language of “nigate” and resigning to the criticism for the lack of effort – or disclosing the disability and attempting to reconcile oneself to an existing (negative) image, an image with which one would rather not identify.

### **Politics of personal narratives**

The narratives that I have presented collectively shed light on some of the critical issues concerning membership within a minority population. What immediately stands out is that the narratives of adults with hattatsu shōgai seem to be very private: personal rather than political. Their narratives are subjective and introspective, lacking the inclination to stand up against society to fight for independence and empowerment. In this sense, they share little with the existing disability rights movement that works overtly and to raise consciousness regarding minority populations and that has formed a collective activist project to make material changes in the socioeconomic status of disabled people. However, when we take a closer look at the stories of the three individuals that I have quoted, it is obvious that the various ways in which those with hattatsu shōgai are trying to cope with their everyday lives – their struggles, efforts, and strategies – are relevant to the values held by the larger society that demands them. Although their stories are not about engagement in explicitly political projects, they may be read as stories of enacting agency and resistance against the dominant culture and the status quo of the Japanese society.

Kaori, the first interviewee, was frustrated and devastated by the sense of failure that she had developed through her education and career, but tried to overcome it by marking a clear boundary between the technical inability to perform certain tasks and the social implication of that inability. The fact that one's inability to eat spicy food is considered to be a trivial matter while the inability to input product codes is considered to be highly significant is, in Kaori's view, simply contingent upon culturally imposed values. Based on her experience of living in the UK, Kaori devised and deployed this strategy of thinking to maintain her self-esteem, at the same time shedding light on the arbitrariness by which societies place particular importance on certain abilities over others.

Shōta, the second interviewee, discussed his experience of having enrolled in elementary and middle schools in Japan and the US, pointing out how the experience of living with a disability could vary greatly by cultural and institutional differences. He uses the word “(Aspie)-ishness” to indicate the range of experiences that cannot be adequately illustrated by the medical diagnosis alone. Shōta feels himself to be “more like a person with hattatsu shōgai” in Japan than in the US, alluding to – and implicitly criticizing – the fact that the Japanese educational system is instrumental in framing the characteristic traits of children with hattatsu shōgai in a negative way.

Yoshiko, the third and final interviewee, speaks mostly about her inner feelings and struggles, especially with regard to the issue of “coming out” and disclosing her disability status to family, friends, and colleagues. Although her story focuses on each particular case and recounts several personal conversations, it is also closely related to social values and the stigma imposed by the acceptance of “disability” status. In that sense, her narrative signals

critical questions regarding the image and representation of disabled people in the larger society, specifically in relation to how the disability label affects intimate relationships in the personal sphere.

When looking at the stories of the three interviewees from this perspective, we realize that while the narratives of hattatsu shōgaisha seem to be personal and introspective at the surface, they are actually reflexive accounts of individuals striving to carve out a position for themselves in the society of which the values and demands restrain their decisions and actions. The activists of the existing disability rights movement have fought against social structures; for hattatsu shōgai, however, the tension seems to have shifted to the personal sphere<sup>26</sup>. Their struggles are no longer contextualized in terms of the collective activist project of engaging the public, but represent the personal endeavor to relate comfortably within the larger society and to find fulfillment as a part of a diverse whole.

As I stated in the beginning of this chapter, the voices of adults with hattatsu shōgai are easily subsumed into the larger discourse that advocates for early diagnosis and early intervention. I hope I have shown that their stories can be read and heard in a different way, a way that reveals the intricate means by which my informants negotiate and identify with

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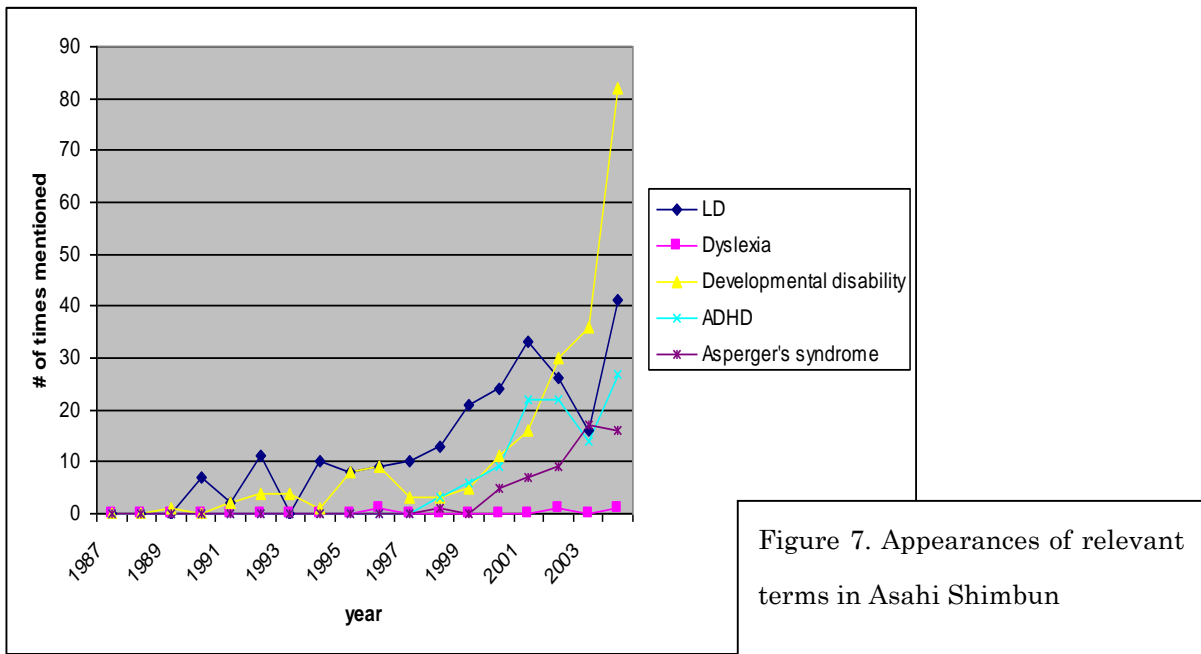
<sup>26</sup> The existing disability rights movement (concerning physical and intellectual disabilities and mental illnesses) have engaged in anti-discrimination campaigns, independent living movements, and political advocacy campaigns. For historical/comparative accounts of these movements, see Sugimoto (2008) and Tanaka (2005).

the hattatsu shōgai label as but one aspect of each of their individual pursuits of hopes, dreams and well-being.

## CHAPTER V: ON THE QUESTION OF NUMBERS

### The increase of hattatsu shōgai

As discussed in the introduction to this dissertation, it was only during the late 1990s and early 2000s that hattatsu shōgai as a category of disability began to gain popular recognition and awareness. The figure below is based on a brief search that I conducted on the archive of Asahi Shimbun, one of the largest newspapers in circulation in Japan, on the number of times that the terms “LD,” “disurekushia (dyslexia),” “hattatsu shōgai,” “ADHD” and “asuperuga shokogun (Asperger’s syndrome)” appeared in the newspaper.



As the graph shows, the number has steadily increased, and the trend is particularly salient for the term “hattatsu shōgai,” the umbrella term used to encompass all of the other designations. In the earlier years these terms were more often used in the context of reports on findings within the medical community, including announcements of conferences and symposiums for a professional audience. By the later years, however, after around 2000, the terms begin to address a wider, more general reader readership, describing the school lives of children with hattatsu shōgai and providing an explanation of the symptoms. The increased attention to hattatsu shōgai in the popular media reflects the rising number of reported cases of children with the disability; child psychiatry clinics began to fill with appointments for months ahead, and public counseling centers were receiving incessant inquiries regarding where to get help. An increasing number of self-help books and autobiographical books were also published. In the education section of any of the larger bookstores in Tokyo today, one can find several hundred books on hattatsu shōgai, which attests to the growing public interest on the topic.

The impression that the need for diagnosis, treatment and support for children with hattatsu shōgai is increasing has been reinforced by many working in the community, and has also been substantiated with small-scale data provided by local governments, clinics and other institutions. For example, Kobe city reports that, between 2001 and 2012, the number of inquiries regarding hattatsu shōgai received by their public Child Household Center increased from 445 to 2344 (Kobe City Child Household Center 2005, 2012). In Sendai, the number of cases that the city’s developmental counseling center handled has doubled over the ten-year span between 2002 and 2012 (Sendaishi Hokubu Hattatsu Sōdan Shien



Sentā et al. 2013). The situation in other municipalities is similar, and the need for a greater number of counseling centers and human resources is recognized as a pressing issue in many regions throughout the nation.

### **Debates on the causality**

The 2010 edition of the annual white paper on hattatsu shōgai published by Japan League on Developmental Disabilities (Nihon Hattatsu shōgaisha Fukushi Renmei) featured the question, “Is hattatsu shōgai increasing today?” as their cover story<sup>27</sup>. The article is based on a survey with 5000 responses and over 40 interviews with children, parents, and teachers who are enrolled in or working with special support schools. Respondents also included a small number of non-teaching professionals, such as doctors and staff members at preschools. While the article points out that there is a general impression within the school setting that the number of children with characteristics of LD, ADHD and autism are increasing, it makes a distinction between a “true” increase, where hattatsu shōgai is in fact becoming more prevalent, and a “false” increase, which is understood as a function of

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<sup>27</sup> The survey and interviews that this group conducted for this cover story includes intellectual disability, and I have purposefully omitted this part of the article. As mentioned elsewhere, the lay usage of the term “hattatsu shōgai” generally excludes intellectual disability, but the Japan League on Developmental Disabilities, the publisher of this white paper, was initially founded in 1974 as a nationwide umbrella organization for various parents, teachers’ and welfare workers’ organizations focusing on intellectual disability and its activities remains focused on intellectual disability while gradually expanding its scope to encompass non-intellectual developmental disabilities. It is because of this background of the organization that the scope of the article includes intellectual disabilities.

diagnoses accompanying the shift in the concept of hattatsu shōgai and its diagnostic standards. The authors are clearly approaching this question of increase with skepticism, but the distinction between “true” and “false” increase is indeed slippery. The “true” increase, in the authors’ sense, seems to refer to a situation where more and more children are showing symptoms that were not present (or not as prevalent) among the cohort of children a few years ago. The “false” increase, on the other hand, is a matter of representation; it speaks for a situation where methods and modes of categorization have shifted to represent children in a different way, although the children themselves have, from the authors’ perspective, not changed. However, the distinction between reality and representation is often not as clear-cut as the authors assume; they are more like the two sides of the same coin. There is no way of recognizing the “true” increase without resorting to the representation through numbers, but the process of counting, which mediates the representation, imposes classificatory labels on a population that reduces them to abstracted and dehumanized numbers, which can hardly be seen as a neutral reflection of reality. In any case, the need to make this distinction between “true” and “false” increases seems to be stemming from a concern that if it were “true” (ie, if it were not just a matter of tinkering of numbers, but was representative of a real shift in the nature of our children), then there must be actual measures taken to accommodate for these children, as well as to consider the possible causes. In other words, the significance of social numbers is implicated by political, financial and administrative concerns. This is an issue of population management, that is to say, of the acknowledgement and governance of a minority population. The researchers who conducted the surveys and interviews for this article were unable to give a substantial answer to their question, leaving the conclusion open to the interpretation of the reader.

When these authors held a conference to report on the findings of the research, they asked the 250 conference participants to provide feedback on what they believed to be the causal factors behind the increase (they didn't distinguish "true" and "false" increases in this question, so the assumption behind the answers vary). Among the top five factors raised by the participants, the first was: "A shift in diagnostic standards (expansion of the concept of hattatsu shōgai)." The researchers who wrote the article had conducted research on domestic and foreign academic publications on the epidemiology of autism and concluded that while all the articles that they had reviewed concluded that the frequency of autism has increased, the articles also mentioned that this may be because of (1) the shift in diagnostic standards, (2) the circumstances making it easier to diagnose, and/or (3) the increased awareness for autism. The responses from the conference participants may be reflecting this finding, but the diagnosis of hattatsu shōgai has indeed become more prevalent, at least in Japan, and this phenomenon in itself is confounded by various factors within the field of child psychiatry, as I will discuss later in this chapter.

The second factor that the participants raised referred to a "shift in ideas regarding disability (parents are less uncomfortable about hattatsu shōgai)." There may be a discernible difference in the attitude of parents, as the social atmosphere towards individuals with disability is indeed becoming gradually tolerant. It may also be worth noting that the younger generation of parents were schooled after the 1979 amendment of the school law mandating compulsory education to children with disability, thereby having first-hand experience interacting with peers with disability through occasions such as koryu kyoiku (an educational activity where students in special schools and regular schools meet and play or

work together on projects) or the experience of having gone to school with a special class designated for students with disability. The shifting attitude of parents – toward a more “liberal,” or less “difference-averse” perspective – may well make them less hesitant to send their children to receive diagnosis and to openly ask for support and resources in schools.

The third point raised by the participants was a “shift in educational system (improved special support education and heightening expectation for education).” As I have documented in the chapter on education, MEXT, in 2007, introduced a new special education system that has – through the placement of aides and the drafting of individual education plans, among other measures – integrated children with *hattatsu shōgai* into regular classrooms. This white paper was published in September of 2009, two and a half years after the new system came into effect. Due to discrepancies in the availability of budgets and other resources by region, the effects of the new system were beginning to be seen, gradually but steadily, in many areas throughout the nation. Thus there was introduced a “heightened expectation” for swifter, more widespread change, which may have prompted parents and teachers to identify students in need of help and to reach out to them through the allocation of newly available resources.

The fourth factor considered was, “anxiety and reduced capability for raising children.” Discourses suggesting that parents, – and, in particular, mothers – are becoming less capable and confident in raising children, when compared to the past generations, have long been present. However, this is also a politicized discourse, in the sense that the argument has been used by conservatives to criticize the shifting role of women in society, providing an oversimplified explanation for social problems such as child abuse and neglect.

In this context, the relationship between child-rearing practices and hattatsu shōgai is a particularly sensitive issue. I will discuss the significance of this factor in more detail below in this chapter.

The last factor under consideration in the paper was: “improved medical care for prematurely born children and increasing low-weight birth.” In 2009, I had interviewed a child psychiatrist, Dr. Junichi Furusho, at his office in Aoyama Gakuin University. He had also cited the improvement in perinatal care as one of the primary causes of the increase in diagnoses of hattatsu shōgai. Dr. Furusho explains: “Prematurely born babies who could have died if it were a decade ago are surviving. But they survive with various medical complications, and hattatsu shōgai is one of the things you see more often in these babies when they grow older.” Studies have shown that prematurely born babies do in fact have a higher risk of having ADHD, autism spectrum disorder, and motor coordination disorder, among other disorders (Doyle 2004; Nagai et al. 2006; Cornelieke 2009).

These five factors cited in the white paper reflect the thoughts and sentiments of a broad range of individuals invested in the field of hattatsu shōgai. Time and time again during my fieldwork, I asked my informants the same questions: “Do you think hattatsu shōgai is increasing? And if so, why?” The answers that I received were generally, “yes,” and the reasons given were in line with one or the other of these five factors. However, when discussing their answers in depth, I came to realize the different ways in which they were interpreting the word “increasing”. Their reasons were also more nuanced than what the survey reveals, shedding light on the different interests, beliefs, and positionalities of the respondent. In what follows, I will look more closely at how this question is being

approached by different groups and individuals, and at how the issue of increased numbers ties into larger questions regarding the significance of data, labels and visibility.

### **Advocacy groups: the “dark ages” discourse**

In EDGE (a non-profit advocacy group concerning LD) and JDD-Net (a national umbrella organization of various parents’ groups and professional associations concerning hattatsu shōgai), where I spent a large portion of my fieldwork time, I was told that hattatsu shōgai has become “visible” over the past decade. One leader of an organization that I had worked closely with said, in referring to children with hattatsu shōgai: “They’ve always been there. They were hiding in the darkness, but now you see them.” By “darkness,” my informant is referring to the times when hattatsu shōgai was unknown to the general public. She explained that students who would now qualify for special support education were always present in the schools, labelled “strange” and “unique (in a negative sense).” They struggled on their own to get along with others and to not fall back in academics, while vaguely realizing that they were somehow different. Indeed, this is the most typical kind of narrative seen in adults who have received diagnosis beyond school age. For example, Takahashi Kyoko, in the book that she coauthored with several other individuals with hattatsu shōgai, writes: “I have been aware of my difference since preschool, because for as long as I can remember, I was told that I was ‘strange.’ I didn’t notice it myself when I was young, but as I grew older I realized that I was different from the others. I felt like I was some other animal wearing the skin of a human being” (Takahashi 2008:12). Kyoko’s metaphor of an animal wearing the skin of a human not only speaks for the way she understood herself, but

also for how parents, teachers and other adults saw these “undercover” hattatsu shōgaisha. They looked just like any other child, and so had gone unnoticed and unidentified until later in life when they sought diagnosis on their own.

Therefore, with regard to the question of whether hattatsu shōgai is increasing, all of my informants affiliated with parents-led advocacy organizations stated that it is increasing only in the sense that those with hattatsu shōgai are now receiving diagnosis and coming out with the disability, making them visible and quantifiable, as opposed to the “dark ages.” One member, an interviewee from an organization focusing on autistic children, was particularly clear on this point: “You know how MEXT reported that 6.3% of students in regular classrooms have it? Well, if we could do the survey for the cohort of students 10 or 20 years ago, although it’s not realistically possible, I’m sure we’d get the same results. It’d be silly if we didn’t. You know, it’s proven, epidemiologically and all that.” What brought hattatsu shōgai to light over the past decade is largely considered to be the effort and commitment of the parents and their organizations in awareness-raising campaigns and public lobbying activities. Increased public awareness and political engagement by the government in this issue promoted the establishment of multiple screening processes and has helped parents as well as preschool and schoolteachers to better identify children who can then be referred to professional help. The idea, therefore, is that there has always been a constant rate of children with the same symptoms, with or without diagnosis. What seems like an “increase” in the number is only a result of those with hattatsu shōgai becoming more visible as a group with a name.

It is also important to note that leaders of these parents' organizations stay well read on the topic, attending international conferences and seeking information from foreign publications and studies referenced or reported on such occasions, particularly those of US and Europe. Frequency rates and epidemiological data from other countries are often cited to substantiate the fact that Japan should have a comparable rate, and that it is "silly," or just not feasible, that Japan be an exemption where hattatsu shōgai is emerging and increasing out of nowhere. As one of my informants stated, "I hear that over 10% of the children over there (in the US) have ADHD.<sup>28</sup> The rate here in Japan is much lower,<sup>29</sup> so perhaps there are many kids who are falling out of the screening process. There may be many more who are just considered to be troubled, at-risk kids, but in fact have ADHD." The increasing rate of ADHD in the US is in itself disputable (Diller 1998), but such issues are rarely addressed. These advocacy organizations strategically make use of data from other countries to legitimize the existence of children with hattatsu shōgai at a constant rate over time.

In around 2009, there was much talk in the American media regarding a possible link between vaccines and autism. The source of the controversy was an article published in 1998 in the *Lancet*, a science journal, written by Dr. Andrew Wakefield and his colleagues

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<sup>28</sup> This information was probably based on the CDC (Centers for Disease Control and Prevention) report, which states that approximately 11% of children 4-17 years of age (6.4 million) have been diagnosed with ADHD as of 2011 (CDC 2013).

<sup>29</sup> There is limited reliable epidemiological data on the frequency rate of ADHD in Japan. The speaker was alluding to the figure of 6.3%, reported by MEXT as the rate of children with hattatsu shōgai (including ADHD as well as LD and ASD).



suggesting that the MMR vaccine (a combined vaccine of measles, mumps and rubella) may be related to symptoms of autism (Rope 2010). Although this hypothesis was proven false by multiple epidemiological studies since then – and, in fact, Dr. Wakefield’s medical license was revoked over the matter – parent’s resultant terror and skepticism over the MMR vaccine was long-lasting, especially as it was fueled by sensational stories in the popular media (stories on, for example, “normal” children who had stopped talking and had completely changed after getting vaccinated). As a direct result of this, the coverage rate of MMR vaccination in Britain fell from 92% to 73%, and similar (although smaller) impacts were seen in the rates in US as well (Smith et al. 2008).

In the meantime, there were very few publications in Japan during this time on the relationship between vaccines and autism. Knowing that my informants were trying to keep up with the English-language news and publications, I had asked them what they thought about the controversy. Surprisingly, many of them were not even aware of the controversy, and those who were brushed it off as nonsense. Even when I explained what the story was about to those who had not heard of it, many returned a quizzical look, asking why American parents would take such bizarre theories to heart. As if to reflect this reaction, the Japanese press remained strangely silent about the issue; major hattatsu shōgai advocacy groups did not even issue official statements regarding this controversy.

The reasons why the vaccine/autism story never got a foothold in Japan are multifaceted; a thorough analysis of this question would require historical and ethnographic research on vaccine administration and disease control in Japan. One reason may be that MMR as a combined vaccine is no longer administered in Japan. In Japan, the MMR

vaccine was first introduced in 1989, but there was a high frequency of reports of aseptic meningitis, which was suspected to be a side effect of the mumps vaccine included in MMR. As a result, the program was terminated in 1993 and from thereafter, the three vaccines were administered separately with an interval of at least four weeks in between. Beginning in 2006, the MR vaccine, which combines measles and rubella but excludes the mumps vaccine, was launched and is widely administered today<sup>30</sup>. Therefore, the controversy over MMR vaccine in the US and Europe may seem to lack direct relevance to the Japanese context<sup>31</sup>. On the other hand, however, when viewing this controversy from the perspective of the advocacy organizations of hattatsu shōgai, another reason emerges as to why the matter received so little publicity: The vaccination hypothesis provides an alternative story behind the perceived “increase” of hattatsu shōgai cases. In other words, to suggest that external factors such as vaccine could contribute to the rate of the disability would undermine, if not contradict, the story that the advocacy organizations had been telling, namely, that the disability is congenital and the rate is fixed, a position which is substantiated by legitimate American sources. Introducing the debate over vaccination would only confound the

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<sup>30</sup> For coverage rates in Japan, see NIH (2013).

<sup>31</sup> A group of doctors from the Yokohama City Rehabilitation Center have published an interesting article in the *Journal of Child Psychology and Psychiatry* regarding the autism controversy, arguing that the rate of ASD has increased in Yokohama City regardless of the termination of the MMR vaccination, casting question on the causal relationship between the MMR vaccine and the increasing rate of ASD (Honda et al. 2005).

situation, potentially eliciting doubts and suspicions over what accounts for the increase of hattatsu shōgai in Japan.

As I have shown, the advocacy organizations' positionality in this issue is politicized in its own way. However, for the most part, their view has been widely adopted by the popular media as well as by many professionals working with children with hattatsu shōgai in the fields of education and welfare. There was only one instance when I heard a leader of a parents' advocacy organization voice doubt about this view. It was in 2011; a time when the new special support education had been fully implemented and awareness towards hattatsu shōgai seemed to be reaching its peak. This individual had been instrumental in the organization of various political campaigns and was one of the well-known speakers on hattatsu shōgai. During the Q&A session held after a symposium in which she was one of the speakers, a man from the audience raised the question of whether hattatsu shōgai is increasing. She answered that the "increase" is simply a matter of impression and that the numbers have not actually changed, except for the fact that advocacy by organizations such as hers has made the disability more visible and identifiable. The man nodded and sat down, and after a few more questions from the audience, the symposium came to a close. Since I was there as a staff member of her organization, I approached her and waited while she packed to leave. It was then that she confided in a very private tone: "...but these days, I sometimes feel like maybe it's not just advocacy. When I look at how prevalent hattatsu shōgai has become, I wonder whether this is really all due to our efforts in advocacy." She continued:

Perhaps there's something else – food, health, environmental hormones...something different about the ways in which children are being raised these days. I don't know.

But when we were growing up (this woman was in her 50s), we didn't eat packaged food from convenience stores and we didn't do our homework at midnight under the bright light of florescent lamps. I sometimes feel like perhaps hattatsu shōgai is indeed increasing in ways that we hadn't expected.

Knowing her all along as one of the strongest proponents of the “dark ages” discourse, I was struck by her personal confession. It was not the first time that I had heard of people attributing the increase of hattatsu shōgai to transitions in diet, sleeping cycles, and the lifestyle of children. In fact, I had attended a symposium where the speaker spoke at length about how the city of Tokyo has transformed over the past generation, leaving little space for children to run around in nature, roll around in dirt and play hide and seek among the trees in forest. According to the speaker, the lack of opportunities for children to play in nature was precisely what was to be held accountable for the increase of hattatsu shōgai. The final section of the symposium was devoted to the advertisement of an organization that ran play/study tours to the remote islands of the country. The highlight of the tour was animal therapy; the children would swim in a pool with dolphins and “interact” with them. The speaker enthusiastically articulated how putting children in an environment abundant with nature and wildlife would revitalize their instinctive senses, curing them of hattatsu shōgai. The parents present at the symposium seemed convinced, and many remained afterwards to sign up for the upcoming tour, which seemed outrageously expensive. I had left the venue intrigued by how the expansion of the industry around hattatsu shōgai was triggering the emergence of such sketchy businesses offering alternative remedies for desperate parents. Being fully immersed in the discourse of the parents' organizations, I was able to come up with more than a handful of “facts” to refute the ideas presented at the symposium, including that the rate of hattatsu shōgai should not differ by region, be it Tokyo

or some less populous island. The presentation simply seemed like an unsophisticated reminiscence of the “good old times”, framing hattatsu shōgai as a pathology of modernity. Therefore, I was taken aback when a similar sentiment was voiced by the leader of one of the most prominent organizations in Japan, which had led the political changes to enforce special support education and the Act on the Support for People with Developmental Disabilities (Hattatsu shōgaisha shienho). I realized then that the competing discourses regarding the increase of hattatsu shōgai were not as distinctive as I had assumed, but that they in fact coexist, in individuals and in communities.

### **Backlash: criticism on the increase**

The “dark ages” theory has its own opponents. In May 2012, a sensationalized news story circulated on the Internet. The municipal council of Osaka city, the industrial center of western Japan with the second largest population in the nation, submitted a draft of an ordinance on home education support (katei kyōiku shien jōrei). In the draft was a section titled “prevention of hattatsu shōgai, child abuse, etc.,” which stated the following:

#### Article 15

It has been pointed out that the insufficient formation of emotional attachment during infancy is a major cause of mild developmental disability (keido hattatsu shōgai) or similar symptoms, which is deeply related to abuse, delinquency, school-refusal and hikikomori (social withdrawal). Considering this, we will implement measures to prevent it.

#### Article 18

Developmental disability (hattatsu shōgai) may be prevented through our country's traditional ways of child rearing, and we will provide opportunities for parents and those who will become parents in the future to learn from such wisdom of child rearing [Osaka City 2012].

In reaction to this, 14 local advocacy groups got together to organize a protest campaign, stating that hattatsu shōgai is a congenital disorder of brain function; neither is it caused by lack of parental love nor can it be prevented through specific ways of child rearing. Autism Society Japan and Japan Developmental Disabilities Network also issued similar statements. The issue caught fire, and enraged voices were raised throughout the nation. Critics charged the draft as not only incorrect and unsubstantiated but also harmful, for it casts a false stigma on parents. The story was featured in newspapers with nationwide circulation such, as *Asahi* and *Yomiuri*, and came under scrutiny, not only by parents and activists, but by the general public. Hashimoto Tōru, the then mayor of Osaka city and the president of Osaka Restoration Association, himself posted a criticism of the draft on twitter using rough language: “If I were on the side of citizens, I’d say (of the draft) ‘shut up you bastard, that’s none of your business.’” The city council responded swiftly. Within a week, they made a public apology and withdrew the draft for further consideration, stating that the content was taken from an ordinance draft used in another (unspecified) prefectural government and was provided to council members as a reference for discussion.

One name came up as central to the controversy. Takahashi Shirō, professor of education at Meisei University, was until then known only within a small circle of parents and activists. He is the head of The Association for Promoting Parental Education (Oyagaku Suishin Renmei), an organization devoted to the promotion of a conservative view

on parenthood, family and discipline towards children. The organization, known as Oyagaku, periodically holds training courses for parents and parents-to-be in locations across the nation and has established a certificate program for Parental Education Advisors. While the organization is committed to a wide range of issues, the recent increase of hattatsu shōgai has become one of its primary concerns. Takahashi has authored books such as, *Japanese Traditional Child-Rearing from the Perspective of Brain Science: Hattatsu shōgai can be Prevented and Improved* (Takahashi 2011), where he theorizes that the problems increasingly seen in children these days are representative of a foundational lack of empathy and self-control. Arguing that empathy and the understanding of others' pain are learned through motherly love, and that self-control and the understanding of rules, manners and order are learned through fatherly love, he posits that methods of discipline and education within the household is becoming corrupt. By referring to children lacking in empathy and self-control, he is obviously alluding to children with hattatsu shōgai, or more precisely, children with autism and ADHD, respectively. His analysis is highly gendered and enforces a strikingly normative portrait of the family and its function. What he refers to as “traditional child-rearing” includes intensive engagement with the child during his/her first few years, such as exchanging glances, smiling at and talking to the baby, and playing simple games using body parts. He also recommends that autistic children should engage in “traditional” child play, such as marble play, origami, beanbag juggling and tag, rather than spending time watching TV or surfing the internet. In many respects, the style of child rearing that he proposes requires the presence and commitment of both the mother and the father. Takahashi is harshly critical of the fact that the Japanese government is working to extend childcare to all families in need so that the mothers can keep their careers while raising their

children.<sup>32</sup> Without identifying the source, he cites what he claims to be the testimonies of people who are critical of the government's policy:

The mothers bring their child to childcare early in the morning so as to relieve her own burden, as if childcare is a temporary hatchback for baggage. She picks them up at late hours. The child is asleep at both times, and they go home just to sleep, just like salary-men do. There is no communication between the parents and the child [...]. Aren't extended childcare hours and childcare for newborn babies depriving the opportunities for parents to learn things from raising their children? Aren't they also exacerbating the long working hours of the parents?

Takahashi goes on to argue that the "modern childcare system" prioritizes convenience and efficiency over the emotional connection of the family, creating mothers who are incapable of loving their own children. In essence, Takahashi's point seems to be that *hattatsu shōgai* is a negative and inevitable consequence of mothers working outside the household for long hours and not being able to spend the time and energy to engage with their children in "traditional" ways. What he calls "traditional" child rearing, however, was probably practiced only by a particular generation of mothers belonging to a specific social class (after all, there have always been working mothers and single-parent homes, as well as

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<sup>32</sup> This is based on the Basic Outline of the Promotion of Countermeasures to the Falling Birth Rate (*Shōshika taisaku suishin kihon hōshin*) drafted by the government in 1998 with the purpose of preventing the rapid decline of birth rate in Japan. Childcare for working mothers was limited and highly competitive, leading to a situation where many women had to choose between leaving the job to become stay-at-home moms or opting to not have children. Considering this to be one of the prime issues behind the declining birth rate, the Japanese government pushed forth to make childcare available for all who need it. The most recent policy by MHLW aims to enroll 38% of children under three in day care programs (from the 20% as of 2008) and 60% of students in grades 1-3 in after-school programs (from the 19% as of 2008) by 2017 (MHLW 2008).



“traditional” families in rural areas sustaining themselves through agriculture where mothers are kept busy with fieldwork and housework). Such is the ideology behind Oyagaku. The hattatsu shōgai community was quick to point out that it was Takahashi, along with his associates at Oyagaku, who were behind the controversial bill in Osaka regarding the prevention of hattatsu shōgai. Oyagaku confirmed this by issuing a statement to respond to the controversy.

Oyagaku is not a one-off attempt by a radical individual to start his own social movement. In fact, in April 2012, a non-partisan caucus of Oyagaku was formed and over 80 Diet members or their agents attended the first meeting, attesting to the program’s popularity among politicians. It particularly enjoys support from the conservative right, and from *Sankei*, a right-wing newspaper with nationwide circulation. *Sankei* has been Oyagaku’s strongest proponent and advertiser in the media industry, publishing a series called “kaitō ranma (series name refers to an idiom that depicts a brilliant way to disentangle a difficult problem)” promoting the program’s ideology.

For Takahashi and the supporters of Oyagaku, the increase in cases of hattatsu shōgai represents more than an epidemiological question of a particular category of disability; it is proof that younger mothers are incapable of raising their children “properly.” For example, in their book titled, *Ways to Raise Children to Prevent Hattatsu shōgai: Japanese Traditional Child-Rearing Prevents Hattatsu shōgai*, authors Sawaguchi, Kataoka, and Kaneko write: “Although hattatsu shōgai is considered to be a genetic thing, if the environment during early childhood is good – meaning, if it is EEE or close to it – it doesn’t appear as a disability, and even if it does it will be in the range of normalcy. On the other

hand, if the environment is bad, it will worsen” (Sawaguchi, et al. 2010:62). Referencing EEE, the authors are endorsing the principles of “Evolutionary Expected Environments” (sic), which they summarize as “the normal, old-school environment.” They argue that, even if a child is diagnosed with hattatsu shōgai, early intervention (up until two years of age) can significantly mitigate symptoms, even to the extent that the child would “develop mostly normally” (3). The authors write: “The child rearing technique that we are suggesting is nothing difficult. It was implemented in every household in the past. It’s not new, and it doesn’t use drugs. It doesn’t cost money, either” (3). As for the specific measures, they argue that children should be kept away from TV and radio until two years of age, and parents should look at and talk to them more often, sleep with them and sing to them. They also point out that when carrying the baby on the mother’s back, she should avoid using a baby carry but should use the “Japanese-style onbu-himo,” an old-style sling that is rarely used today, so as to carry the baby closer to the mother’s body. They also argue for the importance of having fathers and other adults interact with the child more often. They cite the fact that up until around the 1950s, extended families lived under one roof and the responsibility of child rearing was imparted to grandmothers and siblings: “[Mothers] were able to learn about child-rearing from the grandmother, and the grandmothers used to cradle the baby a lot. And since children had experience taking care of their siblings, they were good at taking care of their own child when they grew up” (Sawaguchi et al. 2010:99). As is evident from these quotes, nostalgia for decades-old style of child-rearing unmistakably underlies their theory. The kind of parenting that they promote is unrealistic for many families today, particularly if both parents have full-time jobs and the grandparents do not live close by. Indeed, it is this, Japan’s normative contemporary lifestyle that these authors

(as well as Takahashi and other conservatives) seem to be implicitly criticizing. For these polemicists, the increase of hattatsu shōgai is a problem of modern parenting and family structure.

There are others, too, who direct criticism toward Japan's relatively recent educational policies. Miyazaki Ryutaro, a specialist in education for children with disabilities, who has 37 years of experience teaching in special classrooms, has authored a book titled, *Disabled children who are made to increase: the truth about LD/ADHD and special support education*. Miyazaki's argument is grounded in his teaching experience and his commitment to the deinstitutionalization movement. He argues that the new special support education – as well as the various treatment programs and the new group of professionals that it has created – slots children into the category of disability in a matter-of-fact fashion, thereby deflecting attention away from individual children, their day-to-day experiences, lifestyles, thoughts and aspirations. He lists a series of questions directed to psychiatrists, clinical psychologists, researchers, counselors and other experts:

1. After you 'diagnose' [children with hattatsu shōgai], can you provide actual suggestions about what they should do next? 2. Are those suggestions based on 'so-and-so therapy' or 'so-and-so program'? Or are they created by yourself, looking at the child in front of you? 3. Can you establish relationships with children based on the understanding that they have individual names and personalities, regardless of what kind of 'disability' the child may have? (Miyazaki 2006:62-63)

These are only a few of the questions he raises, but Miyazaki's argument concludes with the contention that SSE and the new hattatsu shōgai professionals will be unable to do much more than to ascribe a name to a disability "based on some standard of diagnosis." The author shows little faith in the value of "someone's treatment program," and characterizes the

psychiatric community's contribution as merely a function of "prescribing drugs." In a rather emotional tone, Miyazaki argues that identifying a child as having hattatsu shōgai, and thereby slotting them into the established special support system – which to him represents a highly professionalized and bureaucratic system that mechanically allocates ready-made resources based on the diagnostic label – is a way of trapping the child in that label and the course of life that has been prepared for him/her. As a long-time practitioner and activist in the field of special education, he strongly advocates the idea of individuals with disability living in the mainstream community (*chiiki no naka de*), alleging that the current ryoiku programs – with their heavy reliance on TEACCH – foster the impression that individuals must be trained to assimilate if they are to join the broader society (an approach that runs counter to his belief of a truly inclusive society), and that, within the constraints of a packaged treatment program, communication and interaction with children with hattatsu shōgai are too predefined. According to Miyazaki, the present situation is fostering the wrong attitude; by relying on treatment guidelines rather than on the cultivation of an individual interpersonal relationship, the professional apparatus is framing children with disability through their symptoms rather than through their humanity. In describing his own practice, he underscores that he rejects the use of picture cards or photos to explain things to autistic children. Rather, he talks to children, over and over if necessary, with the hope that they come to understand his *words*. Although he is aware that picture cards and photos work better in preventing panics on an ad hoc basis, he feels that it is important to help cultivate a relationship where the child's parent can communicate with the child through words. "There needs to be integrity. But when you think about it, this is important for any relationship between two individuals" (Miyazaki 2006:204).

Miyazaki's concern stems from his own experience and commitment in the disability rights movement, and others with similar backgrounds share his apprehension regarding the enforcement of special support education (Tokuda 2007). Long-time activists on inclusive education have been engaged in grass-roots movements to enroll disabled children in local schools, rather than in special education, expressing strong beliefs that individuals with disability can and should belong to the local community. The fact that bureaucratic measures were taken to account for the large number of children with hattatsu shōgai – who seemed to appear suddenly out of the blue – while little was changing in terms of the treatment of children with other disabilities, seems incongruent with the ideology of inclusive education that the advocates were ostensibly promoting. While the increasing visibility and publicity of hattatsu shōgai offers an opportunity to raise popular awareness towards the situation in which children with disabilities in general are rendered, there is strong resistance towards the top-down fashion in which children with disabilities are being “managed” and educated.

### **Doctors' debates: on “over-diagnosing”**

In the field of child psychiatry, the question of whether cases of hattatsu shōgai are increasing entails a complex debate over the standards and processes of diagnosis. The specialists in this field are far from reaching a consensus over the effects and ramifications of the increasing demand for the hattatsu shōgai diagnosis.

Here, I would like to briefly review the history of hattatsu shōgai as a diagnostic category. As previously discussed, hattatsu shōgai consists of three disabilities: LD, ADHD, and autism spectrum disorder. Autism was first “discovered” by Leo Kanner, an American psychiatrist, whose foundational case was reported in a 1943 paper, “Autistic Disturbances of Affective Contact” (Kanner 1943). This paper, along with Hans Asperger’s work on “autistic psychopathy” (Asperger 1944), became the monumental works in autism. In 1950, Sumi Taeko, a psychiatrist at Nagoya University, reported the first case of autism in Japan. The case was presented at a conference in 1952, and the debates at that time focused on its distinction from childhood schizophrenia,<sup>33</sup> partly due to the fact that linguistic and cognitive disorders of autistic children were seen as a consequence of some other underlying functional process. Over the three decades that followed, Japanese psychiatrists gradually adopted the linguistic-cognitive approach to autism, which posits that a dysfunction in the brain causes the linguistic and cognitive disorders that represent the primary symptoms of autism. However, most of the reported clinical cases and research conducted until the late 1990s focused on autism with intellectual disability. Takaoka writes that, among the 18 papers on autism presented at the 1988 conference of The Japanese Society for Child and Adolescent Psychiatry, not one focused on high-functioning autism or Asperger’s Syndrome. The same was true for the 1994 conference. However, in 1995, there were four papers on high-functioning autism and, in the following year, five. The numbers then took a steep

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<sup>33</sup> This debate is often referred to as “Makita-Hirai dispute” for it was between Makita Kiyoshi, who closely followed Kanner’s definition and argued that autism is a form of schizophrenia, and Hirai Nobuyoshi, who followed Asperger in arguing that autism is a form of psychopathy.

increase towards the end of the 1990s, with the heightened level of interest owing to, unfortunately, juvenile crimes committed by those diagnosed with Asperger's or high-functioning autism (Takaoka 2007:93-94).

As for LD, on the other hand, Samuel Kirk, an American scholar of special education, first coined the term in 1963. It was only five years later that Makita Kiyoshi published an article claiming that the incidence rate of dyslexia in Japan was a mere 0.98%, with the low numbers theorized as owing to the structural idiosyncrasy of the Japanese written language (Makita 1968). This theory got a strong foothold in Japan and, as a result, research on learning disability and dyslexia remained slow. ADHD, on the other hand, was first reported in Still's 1902 article, published in the *Lancet* (Still 1902), and was initially believed to be caused by a slight, undetectable damage incurred to the brain. During the 1960s, the concept of Minimal Brain Damage/Dysfunction (MBD) was used widely to account for children with symptoms of LD and ADHD. However, for the lack of detectability or quantification, and for the fact that the concept had come to be extrapolated to encompass a vast range of symptoms, psychiatrists were advised to refrain from overusing the term, and it quickly became obsolete in the 1970s.<sup>34</sup> Consequently, diagnosis for ADHD and LD came to be focused more on the observable symptoms rather than on the etiology, as evidenced in the early definitions of the terms as listed in the earlier version of Diagnostic and Statistical Manual of Mental Disorders (DSM-II), a standard of diagnosis published by

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<sup>34</sup> Suzuki Masaki was instrumental in introducing MBD to Japan in around 1968, and in the case of Japan, it remained a valid diagnostic label well into the 1970s.

the American Psychiatric Association. However, diagnosis of LD and ADHD in Japan were very limited during the 1970s and 1980s, and many psychiatrists were rather skeptical of these labels. In the late 1990s, when parents began to read about ADHD in the popular media, and subsequently started turning up in clinics in great numbers, child psychiatrists were not yet ready to offer the diagnosis; many children were turned away, receiving only insistence on the part of professionals that there is no such disability (Sasaki 2011).

The general understanding among child psychiatrists is that the precursors to hattatsu shōgai are child schizophrenia and MBD<sup>35</sup>. However, the media frenzy that covered hattatsu shōgai starting in the late 1990s (as well as the series of juvenile crime cases that fueled the coverage) led to increased numbers of patients seeking diagnosis, such that the scale that was not comparable to the previous rate of cases of child schizophrenia or MBD. “Hattatsu shōgai is taking child psychiatry by storm,” is a comment made by a psychiatrist that I had spoken to. “Interestingly, it also made child psychiatry a popular field in medicine; it used to be a rather obscure field.” He laughed.

The increasing diagnosis of hattatsu shōgai has indeed become an issue of controversy within the psychiatric community. Takigawa Kazuhiro writes: “For example, when a case where maladjustment and deviance seems salient is presented at a case conference, someone will most likely raise the question ‘could it be hattatsu shōgai?’ This

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<sup>35</sup> In the field of education, on the other hand, the precursor for hattatsu shōgai is *jōcho shōgai* (emotional disability), a non-biomedical label for special classes designated for students with autism, selective mutism and other disabilities that were considered to be of psychosomatic origin.



is a phenomenon that we didn't see before (at one point it was 'could it be personality disorder?'), and the clinical stance of questioning hattatsu shōgai whenever there is a mental problem is clearly becoming prevalent" (Takigawa 2007:9). Similar concerns – specifically the supposition that hattatsu shōgai has become too readily available as a diagnostic category – are increasingly echoed by other practitioners.

There seems to be multiple factors behind this situation; I would like to elucidate three that I see as particularly salient. First, standards of diagnosis tend to be somewhat arbitrary, leaving much to the discretion of each practitioner. To begin with, psychiatric medicine categorizes disorders through the outwardly manifesting behavior of the patient. Unlike other branches of biomedicine, where illness is categorized through site, etiology and pathology, diagnosis in the field of psychiatry tends to rely heavily on the observation of each practitioner rather than on biological markers, leaving relatively more room for subjective decision-making. While most practitioners administer the Wechsler Intelligence Scale for Children (WISC), together with various other domestic and international battery tests, and refer to the International Classification of Diseases (ICD, published by the World Health Organization) and the DSM, there still remains a considerable discretion on the part of individual psychiatrists. In fact, particularly during the early years of my fieldwork (2005-2008), I heard of cases where a child was taken to several different psychiatrists, only to receive a different diagnosis from each one. Perhaps these represented particularly complicated cases, but there seems to be a lot of room for the doctor's background, training, and personal beliefs and preconceptions to be reflected in the diagnosis of hattatsu shōgai.

The second factor worth underscoring is the innate complexity that the concept of hattatsu shōgai embodies. In addition to the symptoms of the condition being mostly behavioral, individuals with hattatsu shōgai mostly do not convey a remarkably “different” impression in the way that do, for example, patients with schizophrenia.<sup>36</sup> Their difference, rather, is mostly a matter of degree (being too active for one’s age, etc.) and thus relies on socially and culturally defined values determining where the lines are drawn between the “normal” and the “deviant.” To add to this, young children are in the process of development and their developmental trajectories are often unpredictable, even to psychiatrists. Therefore, diagnosis during early childhood tends to be tentative and prone to adjustment as the child grows older. Since hattatsu shōgai refers to a relative delay in development, it encompasses a broad spectrum of conditions. Instead of identifying irreversible impairments, such as is the case with Down syndrome, a diagnosis of hattatsu shōgai always leaves the possibility of change depending on the environment and treatments available. As “early discovery, early intervention” is a slogan for hattatsu shōgai, children are often screened for detailed examination at an age of as young as 18 months to three years. To give a fixed name to the expression of developmental delays seen at this age is obviously difficult. On the other hand, when the child’s first visit to a clinic is at a much older age, he/she tends to come with various complications, including a high possibility of having developed secondary symptoms. This is particularly true for those in adolescence, for

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<sup>36</sup> Japanese psychiatrists often use the word “*praecox feeling*” (originally coined by a Dutch psychiatrist, Rümke ) in referring to the characteristic feeling that an encounter with a schizophrenic patient evokes in the doctor. It is an intuitive sense of dissociation and strangeness, identifiable only by those with long experiences in interacting with schizophrenic patients. For a detailed discussion, see Parnas (2011).

lowered self-esteem and a sense of failure could result in depressive thoughts, suicidal tendencies, and other symptoms that can be mistaken for a result of other mental disorders. Due to these issues, hattatsu shōgai tends to be a relatively accessible yet rarely definitive diagnostic label that is open to the applicability of a whole range of cases, sometimes identified in service to a tentative purpose.

The third factor I will point to has to do with the consequences and implications of the diagnosis. There is an increasing number of treatment programs available for those with a hattatsu shōgai diagnosis, and the Act on the Support for People with Developmental Disabilities (Hattatsu shōgaisha shienho), along with other related legislative measures, has been effective in institutionalizing various services; these include, as we have seen, special support in schools, special treatment when taking the centralized college entrance exam, and job coaching for those in search of jobs through the public placement program. Because a diagnosis opens up various possibilities and opportunities for the patient, envisioning and planning a life course with the disability becomes relatively feasible, in comparison to the apparently limited choices often faced by those with other psychiatric disorders. In fact, many parents bring their children to psychiatrists with the hope of getting a diagnosis of hattatsu shōgai so as to qualify for special support education (although one can usually receive special support education without a doctor's note, particularly if the student is in the lower grades of elementary school). Thus, diagnosis and the proscribed treatment/services to follow are closely linked with one another; psychiatrists, being aware of this, often give the diagnosis based on the patients' and their parents' strong will and need for intervention.

It is due to these issues that the diagnosis of hattatsu shōgai has become popular and useful to practitioners, while also becoming a conflated category to which a broad range of conditions could possibly correspond. In fact, many psychiatrists have attempted to identify an “underlying” hattatsu shōgai in cases where the individual has received other diagnoses and treatments. For example, Kinugasa Takayuki and his research group have identified an overlap in personality disorder and hattatsu shōgai and have named this combination of cases “layered-clothes syndrome.” This syndrome refers to patients who fulfill the following criteria: (1) is over the age of 18 at the time of first clinic visit; (2) has no intellectual disability (IQ 85 or over); (3) visits the clinic with the major complaint being various mental conditions and behavioral disorders (the clinical diagnoses based on the immediately apparent conditions are diverse, including schizophrenia, bipolar disorder, eating disorder, neurosis, personality disorder, etc.); (4) can identify high-functioning pervasive developmental disability as the underlying pathology, as a result of in-depth examination; (5) has been an achiever in school due to high IQ and has not been questioned of hattatsu shōgai during school-age; and (6) may have a history of school refusal and neurosis in some cases, but has not been questioned of hattatsu shōgai (Kinugasa 2008:58). Kinugasa’s theory of the layered-clothes syndrome stems from his experience as a psychotherapist. In conducting psychotherapies with patients with personality disorder, he has recognized a group of patients who do not have the “psychological mind” necessary for the deep self-reflection that the therapy requires, thus he has suspected that these patients have hattatsu shōgai as an

underlying pathology.<sup>37</sup> Kinugasa understands these patients as having a particularly mild case of hattatsu shōgai, one that would not be easily identified without an in-depth examination and so would likely have gone without proper diagnosis had they not developed the concomitant mental illness.

The research of Kinugasa and his colleagues has been cited by various sources, and the term “layered-clothes syndrome” is used widely, not only among psychiatrists but also among social workers and remedial education experts at symposiums and conferences. In a way, the concept of layered-clothes syndrome speaks for the uncovering of yet another group of individuals with hattatsu shōgai who have gone unnoticed, similar to the “dark ages” discourse that I have discussed earlier. In fact, identification of an “underlying” hattatsu shōgai in individuals with various other minority statuses has become popularized to the extent that, towards the end of my fieldwork, I was beginning to hear similar suppositions from anthropologists and social scientists working in other fields. For example, while participating in a research group with scholars in education, it was pointed out to me that many newcomer children<sup>38</sup> having problems adapting to Japanese schools are receiving special support education based on the teachers’ suggestion that he/she may have hattatsu shōgai. On a similar note, in the self-help groups for hikikomori (people who have shut

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<sup>37</sup> It has been pointed out that psychotherapy is not effective for patients with autistic tendencies (Rhode and Klauber 2004)

<sup>38</sup> “Newcomer children” refers to children with roots in foreign countries. Their parents have settled in Japan relatively recently compared to the “oldcomers” who are Zainichi Koreans and Chinese that have lived in Japan for generations.

themselves in their rooms and have withdrawn from social contact over long periods of time), both ex-hikikomori individuals and their supporters commonly distinguish those having hattatsu shōgai as the underlying trigger of withdrawal and those who do not (Teruyama and Horiguchi 2012). Relatedly, as I have recently heard from Ushiyama Miho, an anthropologist working on atopic dermatitis (*atopi*) in Japan, a similar discourse is present within the self-help group with which she has been involved. The list goes on. It has been suggested by psychiatrists, for example, that some patients with eating disorders have hattatsu shōgai (Wada 2010). The identification of hattatsu shōgai as an underlying factor of causality among these minority groups is usually considered to be a positive discovery, for it puts the individuals on the right track in getting appropriate help toward accessing resources that may otherwise have been unavailable to them. However, after hearing such numerous references to hattatsu shōgai coming out of a surprisingly diverse array of communities, one begins to wonder whether hattatsu shōgai is providing some kind of an easy answer, an avenue to “explain away” individuals who cannot be neatly categorized and adapted to particular groups and communities.

The psychiatrist Sugiyama Toshiro argues that there has been a “paradigm shift” in hattatsu shōgai, that is, a shift from diagnosis of disability to the judgment of needs. For Toshiro, to confirm the diagnosis of hattatsu shōgai is to articulate a position stating that the developmental trajectory of that person would improve with individualized support. In other words, the resources and support systems that would be made available to the patient identified as hattatsu shōgai become precisely the factors driving the diagnosis. Consequently, Sugiyama’s own definition of hattatsu shōgai is rather broad: “hattatsu shōgai

is a condition where, during the developmental stages of childhood, due to one reason or another, there is a disorder in a certain area of development that has the possibility of entailing a problem in social adaptability” (Sugiyama 2007:5). The reason why he writes “one reason or another” is because Sugiyama considers the relationship among biological impairment, emotional disorders and secondary symptoms (lack of self-esteem, victim mentality in interpersonal relationships, inappropriate behavioral patterns, etc.) to be so intricately intertwined that they become inseparable. He also argues that children who have been victims of child abuse and neglect are prone to show symptoms similar to congenital hattatsu shōgai (Sugiyama 2012). Therefore, rather than focusing on etiology, he shifts his focus to the consequences of the disability, that is, to the “problem in social adaptability” that the disability could possibly entail, and to the social benefits that a diagnosis would make available. In this way, Sugiyama’s definition eloquently describes how the diagnosis of hattatsu shōgai is contextualized as part of a larger process where sociocultural values and imperatives generate the need for a diagnostic label to allocate special resources to those in need. In a sense, Sugiyama’s definition of the disability serves to underscore the need for psychiatrists to be aware of the world outside the clinics and hospitals, to frame the diagnostician’s task with consideration to the opportunities and consequences that the biomedical diagnosis entails. The need-based diagnostic model, for Sugiyama is what psychiatry should truly strive to attain: “Although there are big-name psychiatrists who remonstrate against the ‘prevalence’ of hattatsu shōgai, hattatsu shōgai is not a trend. It only attests to the fact that child psychiatry, and psychiatry as well, is returning to what it ought to be” (Sugiyama 2007:5).

## **On visibility and numbers**

Thus far, I have discussed the controversies and debates surrounding the question of whether and why hattatsu shōgai cases are increasing in Japan. The increase is felt and imagined by all, in the sense that more and more children are receiving diagnoses and treatment (and adults as well, in more recent cases). However, due to the emergence of the disability over a relatively short period of time, and to the lack of a consensus on whether these children have always been present at the same rate (in the sense of their clinical presentation), the interrogation of this question uncovers, as I have described, the various positionalities and beliefs held by various individual and community stakeholders.

The process of counting a population is never politically neutral; this is particularly true when the population concerns a minority group that would be the recipient of special education, social welfare, and other resources imparted by the nation-state. In the case of hattatsu shōgai, we are counting children who are to be socialized as future members of the society, making the stakes even higher. Although the investigation of data may seem to be an objective pursuit of scientific knowledge that stands clear of subjective interpretation, meaning-making and prejudice, the stakes set in play by these sets of discourses are such that disinterested evaluation is rare, if not impossible. Taking a census requires the creation of labels and boundaries. For an analogous example of the politics of numbers and demographics, we might look at the classification of ethnicity in the American census. Porter, in discussing the creation of categories in census taking, points out the social imperatives behind the process: “The German category, *Angestellte*, a name for salaried



employees outside the public sector, was invented at the time of Bismarck's social insurance laws so that these respectable types would not be classed with wage workers, nor represented by socialist unions. The American "professional" arose early in the twentieth century to distinguish men of knowledge committed to an ideal of service from business managers. French statisticians formed the cadre as part of economic planning in the 1930s and 1940s" (Porter 1995:42). The categorization of hattatsu shōgai as a quantifiable population is, similarly, a way of marking and distinguishing a certain group from the mainstream population, as well as from the existing categories of disability, ensuring that group's existence and presence in the political landscape of governance. Once it comes to be represented by the seemingly neutral abstraction of numbers, the category gains validity and legitimacy. Social statistics evoke powerful and often provocative imagery regarding the categories and characteristics making a society's constitutive demographics. When MEXT first announced the result of its survey, revealing that 6.3% of children enrolled in regular classrooms are suspected of having hattatsu shōgai, various stakeholders ceased upon the figure as attestation of the fact that the category exists. The survey was based on the teachers' impression of what they thought about their students, which is far from a reliable source, given that the teachers (particularly at the time when the survey was taken) were not at all trained in identifying these disabilities in children. Nevertheless, once the percentage was printed on MEXT's official publication and was released for circulation, its reliability has rarely been questioned. The release of these numbers marked the moment at which children with hattatsu shōgai became a salient, quantifiable and visible population.

Inevitably following the MEXT moment came the question of whether hattatsu shōgai's numbers are increasing. Is the figure of 6.3% transitioning? And if so, why? One aspect of this question concerns how hattatsu shōgai gained recognition, understanding and awareness among the general public over a very short period of time. For the function of publicity is never unrelated from the ways in which a discursive category takes formation. Hacking writes:

People of these kinds can become aware that they are classified as such. They can make tacit or even explicit choices, adapt or adopt ways of living so as to fit or get away from the very classification that may be applied to them. These very choices, adaptations or adoptions have consequences for the very group, for the kind of people that is invoked. [...] I have called this phenomenon the looping effect of human kinds.”  
[Hacking 2003:34]

Looping effect, in other words, is the process by which the classification of a population influences the very ways in which those classified behave and engage with their classification, which could trigger qualitative/quantitative shifts in the population itself. I believe such an effect is behind the question of hattatsu shōgai's increase. In the case of hattatsu shōgai, the classification has not only affected those who had already received diagnosis, but it has in fact become instrumental in recruiting new members into the community, as exemplified by the increasing number of parents bringing their children into the clinics and counseling rooms asking for a hattatsu shōgai diagnosis, as well as adults who come to seek diagnosis. The enlargement of the population has, in turn, led to yet more visibility, less stigma, and the mobilization of political forces to institutionalize services and treatments, which then loops back to the increasing availability of the diagnosis.

Putting this explanation aside, asking the question of whether hattatsu shōgai is increasing and why remains interesting from an anthropological perspective, for the investigation reveals not only the beliefs of the respondents regarding the idea of hattatsu shōgai itself, but also the ways in which respondents engage with labels, numbers and statistics. Regardless of stakeholders' interests and political standpoints, the frequency rate of the disability is treated as an item of established and unwavering "scientific knowledge" which, as such, merits attention. It is precisely for this reason that I feel it is all the more important to ethnographically portray the confusions, controversies and debates behind the numbers.

### **On a final note**

During the earlier stages of my fieldwork, I was primarily involved with a non-profit advocacy group working on behalf of dyslexic children. As I have defined previously, dyslexia is a form of learning disability, which constitutes one of the three major disabilities within the category of hattatsu shōgai. However, almost all of the children that I was encountering seemed to have symptoms overlapping with ADHD and autism spectrum disorder, and most were diagnosed accordingly. On one occasion, when I was having lunch with a child psychiatrist and the leader of the organization, I asked the question of why there are so few (if any) children with learning disability and that alone. Both women responded that learning disabilities are simply more difficult to identify; those who are hyperactive or socially awkward tend to stand out in class, whereas those with learning disability tend to be overlooked as simply not academically inclined or competitive. So the answer is, yes; of

course there are children with just LD out there, but they tend to struggle on their own without realizing their disability, and thus their cases tend not to come up as often in clinical settings. Unconvinced, I had repeated the question paraphrasing my point: “But I sometimes wonder if those children (who have LD and that alone) really exist, or if they are just in our imagination; you know, I’m wondering if the category of LD is really useful in reflecting the reality.” The two women stared at me blankly, and I realized that my point had not come across. I awkwardly changed the topic of the conversation.

During this dialogue, I was associating LD with the idea of the “native” in anthropology. The notion of the “native” as the representative of a monolithic culture and the sublime bearer of pristine knowledge, untainted by modernity or civilization, has long been present in the anthropological imagination. However, the realization that the “native” in fact encompasses individuals with diverse backgrounds, positions and interests, and that the distinction between “native” and “non-native” is not as clear-cut as had been believed, led to the deconstruction of the concept and the reflexive re-examination of how the imagery of the “native” had been produced, reproduced and circulated (Narayan 1993). I had wondered, then, that perhaps learning disability is also an empty category in the same sense. I don’t mean to argue that LD is “constructed” or that it is not real. The experiences of children with LD are certainly real, I wouldn’t deny the struggles and sufferings of the children that I have gotten to know. What I meant to articulate during that lunch was that, the more I got to know children with hattatsu shōgai, the more was I beginning to feel that the categories and schemes that are consolidating them, or setting them apart, are not only arbitrary but also illusory, in the sense that they are based on a clinical imaginary (Castoriadis

1998). The children were coming from different class/family backgrounds, had different experiences in school, and were living with symptoms that more or less overlapped with others'. But their reactions to those experiences were diverse, as were their methods of coping and their personal views of the disability. In essence, once I got to know the children as individuals, they seemed too heterogeneous and unique to be reduced to one category: not only was the label of LD failing to capture the messiness of reality, but it was also postulating a clinical picture, an ephemeral image of a "typical" child with LD whom, I had become convinced, does not exist.

As my fieldwork progressed, I did get to meet people with the diagnosis of learning disability alone. That uncanny feeling that I had towards classificatory labels during the early stages of my fieldwork disappeared with time and, in my interaction with informants and with academics, I learned to speak of LD and hattatsu shōgai as substantial, real, entities. However, when seeing the people of my field represented in numbers and percentages, and when revisiting the question of increase and causality, I sometimes feel the recurrence of that strange feeling, particularly in realizing that such social statistics are not mere representations but are political tools instrumental in presenting a particular image of the population in order to bring about actual legislative and bureaucratic changes that affect the community.

## CHAPTER VI: EPILOGUE

### **The question**

One evening, during my fieldwork, I was sitting at a dining bar with several of my informants, with whom I had just attended a self-help meeting. We were chatting about random things over a few drinks when one of them asked me how I became interested in my topic of research. “You don’t have hattatsu shōgai, do you? Do you have siblings or family members who do?” I said I that do not. “I’m just wondering how you see ‘us’ then. Do you pity ‘us’? (kawaiisō dato omou?)” This question struck me, and left me in silence for a moment. I had written numerous funding applications discussing the rationale and contribution of my project in academic terms, but he was obviously asking for my personal motivation and background to engage in this project. All eyes were on me, and I explained that I had never thought of looking down on those with hattatsu shōgai; I had grown up feeling different and alienated in the Japanese school being a returnee student who had spent a significant part of childhood abroad, and I was trying to relate to them through that experience. “But being a returnee is a privilege. You learned to speak English, and can write about us in English. Don’t you think that’s a bit different from having hattatsu shōgai?” Another young man said. Before I tried to reply, someone else

broke the tension by turning the conversation to a harmless joke about an English speech given by a common acquaintance. Everyone laughed, and I found myself relieved for being off the hook.

These questions from my informants pointed out my “outsider” status in multiple ways. First, I do not have the disability myself and thus my responsibility in telling their stories seemed questionable: Was I going to write a sympathetic and pitiful ethnography? Second, I am positioned to write these stories from an academic perspective my informants, as objects of study. Thirdly, my dissertation, the most important product of my work, will be written in a language that is not easily accessible to my informants, drawing on a skill that they ironically associate with the story I told them in the attempt to establish a link with their experiences. In all of these ways, I was constantly reminded that I was not one of “them”.

### **The notion of tōjisha**

The politics of membership and entitlement is a particularly salient aspect of communities based on disability status, for it brings up the notion of “tōjisha”. Literally translated as “those who are concerned (with a particular problem or a category of belonging/an agent),” the term “tōjisha,” by definition, refers to individuals who are stakeholders of a particular issue and thus have first-hand experience based on that attribution. For example, one may call him/herself a tōjisha based on residency when that area has been affected by natural disasters or is contested for various political reasons. One may also be a tōjisha for being a survivor of abuse and domestic violence, or for belonging

to a certain minority population based on his or her gender, sexuality, class, and ethnicity. In a broader sense, one may be a *tōjisha* for being subject to certain governmental or institutional policies and sanctions, as well as for taking part in a controversial legal case. In short, being a *tōjisha* is an attestation of having “insider” status in a particular group, either by self-claim or through labeling by others.

The concept of *tōjisha* was established as part of the disability rights movement in Japan. According to Nakanishi and Ueno (2003), this process can be understood as a movement against professionalism and paternalism in the medical field. It embodies the will to recover the rights of the disabled and to take back the power that had been monopolized by the medical experts to define, categorize and grade the degree of disability, and to draw up rehabilitation plans to treat individuals based on a normative and corrective philosophy. In reviewing the genealogy of the *tōjisha* discourse, Nakanishi and Ueno point out that it can be traced back to a particular incident in 1970 when a mother in Kanagawa prefecture killed her two-year old daughter with cerebral palsy out of desperation and despair in raising the child, because she was denied admission to residential treatment programs and her husband was not cooperative in taking care of the daughter. Mothers under similar circumstances petitioned for reduced sentence and their movement gained public sympathy, which led to the probation of the mother. Despite this public sentiment, however, “Aoi Shiba no Kai”, an advocacy group organized by those with cerebral palsy, reacted to this incident by filing a complaint to the court stating that the mother had violated the child’s basic human right by taking her life. They argued that, by framing the mother as a victim of the social structure that prioritizes labor and productivity, that same social structure views



people with CP as second-class citizens – citizens whose existence is not valued within the society. To reduce the sentence of this mother on this basis would also serve to reinforce the subjugation of people with severe disabilities, threatening the most basic of their human rights. This statement had a tremendous effect on the public discourse regarding disability, and it also established a standard for other disability rights movements to follow. The impact that a group of disabled individuals stood up for their own right and claimed that they were not docile subjects of welfare and charity, but are active participants and agents of the society, became a critical stepping stone in defining the notion of tōjisha.

Another issue of contestation for the early disability rights movement in Japan was the eugenics movement. The statement by the “Aoi Shiba no Kai” was being released at a time in which the national government was initiating various social programs in the attempt to build a welfare state, but such programs were seen as a pressure on state finances, and prenatal “prevention” of disability was emphasized as a countermeasure. The presence of eugenic ideas in Japanese population control dates back to 1920s (Robertson 2002), but it was in the 1970s that the disability rights movement first made a visible reaction to intervene with the policy. In 1972, the revised Eugenic Protection Act including a new clause on fetuses was submitted to the national diet, and in 1977, the Ministry of Health and Welfare began a new national program to screen newborn babies for five congenital metabolic diseases. The petition against the new policies, and particularly the new Eugenic Protection Act, brought together various disability rights organizations throughout the nation. A collective identity was established, as representatives of the larger tōjisha community began to work collaboratively across regional and ideological differences.

Not incidentally, the 1970s was also a time in which the independent living movement that originated in California slowly began to gain roots in Japan as well as in many other countries in the world. In 1970, the Fuchū Metropolitan Medical Center of Severe Motor and Intellectual Disabilities, located in a rural area in Tokyo, was accused of violating the rights of its residents. Allegations included such atrocities as the conduct of experimental “treatments” on those with cerebral palsy, experiments involving lobotomies and the cutting of muscles. Female residents were being subjected to forced sterilization; their heads were shaved and they were bathed by male staff. The protest against such abuse continued for two years, ending with an agreement under which the Tokyo metropolitan government was to provide private rooms for each resident. A program was launched whereby staff members would be sent to the homes those who chose to live independently. Such movements eventually spread across the nation and led to the establishment of the first independent living center (ILC) in Japan in 1986, which was staffed and run largely through the participation of those who had gained experience at independent living centers in the US. Inheriting the spirit of US independent living movements, the Tokyo-based initiative emphasized self-determination and the active community participation of disabled people, instituting their shift from being the receiver of personal assistance to the being the providers of their own collective care. Thus the disabled were able to take charge in designing and implementing a local system to meet their own individual and collective needs. In the following decades, similar movements initiated by the tōjisha community brought about various positive changes in the social and welfare policies. Most importantly, the Tokyo disability rights movement empowered the disability community, helping to shift the

perception of welfare from that of a benefit that was begrudgingly provided for the weak, to a right that ought to be guaranteed for all members of the society.

It was in this context of collective social action that the term “tōjisha” came to be widely used to connote solidarity of people with disabilities; it was the banner under which people came together and fought against the paternalism that permeated the society. The collective identity of tōjisha functions to interrupt a structure privileging the knowledge of “expert” professionals – i.e. doctors, scholars, and others – to one that provides a channel for the dissemination of a different type of knowledge, one which focuses on the lived experience of disabled individuals. By reclaiming the knowledge and voice of the oppressed and the discriminated, the notion of tōjisha became a key, mobilizing concept in Japanese disability rights movement since the 1970s, defining and shaping the identity and agency of the disabled population as a collective group.

While tōjisha has done much to lead the disability rights movement in Japan, it has also been an object of critical inquiry, particularly with regard to its exclusive nature and its failure to account for the diversity and complexity by which membership to the community is granted and claimed. Tanaka, a scholar of social welfare, argues that there were three significant moments in which the concept of tōjisha had been contested in the history of Japanese disability activism (Tanaka 2005). The first moment came with the reaction against the Eugenics Protection Act during the 1970s, when disability rights movement encountered the women's liberation movement, which was at its height in advocating for reproductive rights. When disability rights activists were working for the agenda to resist the negative signification of disability and to advocate for the equal right to life of newborn

babies, feminists were claiming reproductive rights of women including the individual choice to have abortions. This was a critical encounter that shook the foundational belief of the movement that their mission was first and foremost to reclaim the right to self-determination, by entailing the realization that their right to self-determination as a tōjisha was in direct conflict with the same right advocated by the feminists.

The process of defining tōjisha-ness as the embodiment of self-determination marks the second contestable moment underscored by Tanaka. In focusing on the agency of disabled individuals themselves, the movement actually took on the some of the problematics of an ableist ideology, which resulted in the exclusion of those with severe intellectual disabilities and mental illnesses. Those who were deemed incapable of making decisions on their own were at times faced with life-threatening conditions when left to make those decisions based on their own will.

Finally, as Tanaka points out, although the disability rights movement emphasized the collective identity that tōjisha represents, striving to shift the experience of disability from the personal sphere to the political sphere, many of the policy changes the movement mobilized behind had the result, in effect, of reducing and confining the experience of disability and its management to the private sphere. This occurred primarily through the design of a commercial welfare system where each individual actively selects and acquires the necessary resources and services based on one's condition; what was considered to be a positive change – one aligned with the ideology of self-determination – produced the concomitant side effect of concealing the social aspect of disability.

A similar critique of the limitations of the *tōjisha* concept is lodged, although in more abstract terms, by Toyoda (1998): the notion of *tōjisha* inevitably draws a clear boundary between those who belong to the category and those who do not, thereby rendering invisible the population that does not identify with either group, or that falls out of the dichotomous categorization. *Tōjisha* has also been depicted as describing a homogenous group of people with common interests, masking the diverse experiences and needs of a population that is, in reality, constituent of a range of different types and degrees of disability. Furthermore, it has failed to account for disabled people who are ethnically or sexually underrepresented, at times even creating a discriminatory environment within the *tōjisha* group. While these issues have been minimized as the cost of establishing a monolithic, unified voice representing a minority group, it has become increasingly necessary to postulate an alternative mode of membership and identification in order to push for a more liberating and empowering society for all. Toyoda argues that, by dismantling the imaginary entity of *tōjisha*-ness and the notion of uniformity and exclusiveness of disability experience that it seeks to address, we can carve out the true *tōjisha*-ness where each and every member of the society, disabled or not, engages with the issue with an equal sense of obligation and commitment to civil participation. In other words, Toyoda posits the question of how every member of the society can be equally held accountable for resolving issues of discrimination and exclusion, rather than rendering that responsibility to narrowly-defined *tōjisha* groups.

Returning to the original comments made by my informants, I had felt that I was being told, implicitly, that one had to be either a *tōjisha* or a *tōjisha* family member to be engaged in a project like mine. I was neither, and I began to sound apologetic when

confiding the nature of my research and my relationship to the community. If I were a *tōjisha* even in the broad sense of the term, my commitment to the field would have gone unquestioned. If not, I should at least have a professional commitment to the community and my research should yield tangible and visible contributions. I felt that my credibility, and thus my entitlement to the research, was at stake. Frustrated by the inability to legitimize my presence in the field, I often found myself trying to beguile my identity as an anthropologist by being completely immersed in the work as an aide or a staff member of an organization. More than once, upon finishing the day with a sense of accomplishment for having finished editing a newsletter for a parents' organization, or having received positive feedback from the school principal for my achievement as an aide, I would suddenly remember that this was not my "real" job.

The fact that I am not a *tōjisha* of the community – that I was unable to claim insider status – was particularly significant for me, as my fieldwork took place during the time when a number of books were published by *tōjishas* of *hattatsu shōgai* or their family members (Izumi 2005; Ayaya and Kumagaya 2008; Koumori 2007; Niki and Fujiie 2004). Such studies were inspired by a movement called "*tōjishagaku* (*tojisha*-ology/*tojisha* studies)," initiated by Bethel no Ie, an independent living home of individuals with schizophrenia in Hokkaido<sup>39</sup> (Urakawa Bethel no Ie 2005). *Tōjishagaku* is a practice to describe the experience of illness from the *tōjisha*'s perspective; individuals give names to their illness, describe their symptoms in lay terms, and come up with coping strategies through group

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<sup>39</sup> For an ethnographic study of Bethel no Ie, see Karen Nakamura (2007).

discussion. It is an attempt to resist the authoritative and paternalistic representation of the patient by the professionals of clinical psychiatry and to retrieve the subjective voice of the patient, while shedding light on the personal perspectives of illness experience and suffering. Tōjishagaku has grown to be a highly influential and inspiring practice for communities with various illnesses and disabilities, including hattatsu shōgai. While this movement has had the positive effect of enabling individuals to speak of their illness/disability without having to resort to strictly medical discourse, it has also reinforced the politics of entitlement to story-telling by excluding and disqualifying the non-tōjishas. The questions of what a non-tōjisha can write about and how they might contribute to the field, therefore, stayed with me throughout the duration of my fieldwork, leaving me at somewhat of a loss when I embarked on the write-up stage.

## **Encounters**

During the post-fieldwork phase of this project, while I remained in Japan to write, several notable incidents and encounters served to help broaden my perspective. First, I became involved in an interdisciplinary research project comparing the social phenomenon of hikikomori in Japan and France. Hikikomori, literally translated as “shut-in/drawn,” refers to the condition where individuals withdraw from social contact, shutting themselves in their rooms for a prolonged length of time (more than three months, according to the official definition by MHLW).<sup>40</sup> I was initially invited to this project because it was

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<sup>40</sup> For more information on the definition of hikikomori, see Horiguchi (2013).

suspected that hattatsu shōgai may be relevant to hikikomori, but the project provided me the opportunity to conduct interviews with former hikikomoris, school counselors and others involved in the community, as well as to interact with anthropologists who had conducted extensive fieldwork in these communities. My most memorable experience occurred when I was participating as a translator in a group interview of former hikikomoris by several French scholars. Prompted by the French scholars, the former hikikomoris gave eloquent accounts regarding the identity and stigma of being a former hikikomori, citing their childhood, family, school life and career, and including their thoughts on society and culture. Although, in many ways, the issues and concerns of tojishas and parents of hikikomori differ significantly from those of hattatsu shōgai (Teruyama and Horiguchi 2012), I realized that there were several critical similarities. These included, most notably, the discomfort and the sense of alienation and isolation they feel as members of Japanese society. Many hikikomoris recounted that there was no particular reason for their withdrawal, apart from perhaps a seemingly trivial incident in school or at home that hurt them or made them “tired of it.” A small setback, however, led to more than a couple of lost years, and when they finally managed to emerge from their rooms and find support in self-help groups, they found themselves unable to get back on track in life. The job market had been hard on those without higher education or vocational training and they were left unable to explain what they had been doing during those years. Many complained that there was no second chance in Japanese society; once off track, it was very difficult to find a way back to the mainstream work force, and they struggled to carve out a living without resorting to disability status or welfare. Finances were definitely an issue, but what they considered to be more problematic were the social and moral preconceptions defining “success.” Many



individuals who I met in the hikikomori community were surprisingly outspoken and critical – in ways that those with hattatsu shōgai were not – about the status quo of Japanese society. The issues the hikikomori pointed out, however, powerfully resonated with the situations with which individuals with hattatsu shōgai were likewise coming to terms.

I also became involved in another interdisciplinary research group, which focused on minorities within Japanese schools. Here I met scholars researching students with Filipino roots, read books on Zainichi Korean public school teachers, and formed a small sub-group with fellow disability scholars on public school teachers with disabilities. Participating in this research group gave me a perspective on other minorities in public education (among both students and teachers). Together with other disability scholars, I interviewed several public elementary and middle school teachers with impaired vision. During one interview, we had asked the teacher how he thought of himself as a role model for students with the same disability. He replied that, in his time spent as a teacher at a regular school (rather than a special support school for students with disability), he had only met one or two students with the same disability as himself and that his relationship with those students weren't very different from those with other students. Then, after a short pause, he said:

It's not so much about visual disability per se. All my students would go on to lead their own lives, and at one point or another, they would go through rough times. They would feel defeated and incapable, as if they are all alone in this battle that they are destined to lose. I want for them to remember me then, how I stood in front of them and taught as a professional teacher with my disability. I want them to think, 'well, he managed somehow, there's no reason for me not to pull it off.' That's what teachers are for. I teach all kinds of students, coming from different backgrounds, and some with hattatsu shōgai too. I want for them to see me as a role model in that sense.

His words struck me deeply. I had interviewed many teachers up until this point, but I had presented myself as a researcher of hattatsu shōgai, and the conversation had rarely left the topic of dealing with children specifically with hattatsu shōgai. It was the first time that I had heard a teacher frame the disability in a much larger context, as one of the many stumbling blocks in life that one could encounter, and speak of the power of education in those terms. It was his words that prompted me to return to the field notes I had taken while working as a school aide, and to reconsider the implications of my experience there.

The final incident has to do with my own family. During the second year of my write-up phase, a relative in my extended family was diagnosed with schizophrenia. I accompanied her to a local clinic and the visit became my first experience on the patients' side in a psychiatry clinic. Patients with schizophrenia are entitled to receive full coverage of medical expenses upon application to the local welfare office, but my relatives dreaded going to the office and postponed it for some time, despite their incurring expenses. They clung to the possibility of her condition being temporary, hoping for her quick recovery, despite the doctor having clarified that recovery would require some time and an up-hill battle. When her mother finally went to the welfare office, she had felt shameful and distraught at facing the arrogant attitude of the woman who processed her papers; she feared that the woman would read the diagnosis too loud, as we were sitting within earshot of several people we recognized from town. Everyone in the family lowered their voices when talking about her condition, or the medication that she was taking, for fear that our neighbors would hear us. There were even tears shed over the narrowed prospect of her marriage. I felt as if the stigma of having a mental disorder was piercing my extended family. I was postponing

writing my dissertation, but all that my family was going through made me think more intently about my work. I remembered a time when I was working for a non-profit organization of hattatsu shōgai, and picking up the phone from a parent who screamed at me for having sent some documents in an envelope with the organization name printed on it:

It says ‘Japan Developmental Disability Network.’ What do you think our neighbors would think, seeing something like that lying in our mailbox? They would obviously learn that someone in our family has disability! We live in a tiny town and word of mouth gets around very quickly. Better be careful next time!

I had apologized profusely then, but, recalling that moment, I realized that I did not truly understand what was behind her anxiety and anger at that time. The real anticipation of stigma towards mental disorder forced me to reflect on the significance of my work in ways that I had not previously been able.

My relative’s condition was relatively mild, and she talked a lot about her symptoms – the voices she heard, what they were saying and who they were. She provided explanations and background stories so that I, her listener of choice, was able to make sense of the fragmented and irrational comments of the voices. I took careful notes, as if taking field notes. She sometimes asked me for my interpretation of the story. I had read in a self-help book that it was not advisable to discuss the content of hallucinations with schizophrenic patients, but I felt her pressing need to hash out the story and to be heard. I occasionally gave her comments, mostly contextualizing her story in her past experience and sometimes expressing reserved suspicions about the validity and legitimacy of the delusions that seemed so real to her. She seemed satisfied, nevertheless. Her psychiatrists did not listen to stories; they simply asked whether she was sleeping, eating and taking drugs as

prescribed. Although this is standard practice, she was deeply dissatisfied that she eventually began to make appointments with a clinical psychologist in the same clinic, which could not be covered by her medical insurance. Her parents ended up paying an expensive fee only to have her recount her entire life story to the psychologist who listened with an attentive attitude. By the time she finished telling the story, her condition improved substantially and she decided to enroll in a school to start her career afresh. All of her symptoms eventually receded and she successfully moved on with her life.

Storytelling was a form of treatment for my relative. She desperately looked for a receptive listener, and she found one in me, first, and then also the psychologist. Neither of us gave her much feedback, however, on her own, she eventually did begin to contextualize her illness within her own life story, beginning to make sense of the condition. Talk therapy seemed to provide an explanation of her condition in a way that biomedicine did not. She never identified with the label of “schizophrenic”; when we once, following her psychiatrist’s advice, took her to an inpatient ward of a large hospital, she adamantly refused to be admitted, seeing the other patients and claiming that she was “not one of them.” She went home with her family. Her insistence on telling her *own* story, resisting being reduced to one of the many patients of a particular illness and being treated accordingly, was compelling. This experience prompted me to revisit the narratives of my informants with a renewed perspective. The notion of story-telling being a form of resistance began to bear a new significance for me and, for the first time, I clearly saw the intricate ways in which my informants were variously negotiating the diagnostic label of hattatsu shōgai; depending on the occasion they might describe their identities both in terms of being “one of them” while

also being a unique individual. At the same time, I reflected on the mothers' desperate need to recount their stories of suffering. Staff members at ryōiku, leaders of non-profit organizations, and many others sat down to listen as their words spilled out. Storytelling was indeed a form of treatment, of salvation, in the sense that it provided a way to interpret and make meaning out of the disorderliness of experience.

These encounters provided me with a new perspective on my research and shifted my positionality and investment in the field. I revisited the term "*ikinikusa*" (the difficulty of living), which was frequently brought up in characterizing the day-to-day experiences of individuals with hattatsu shōgai. "Ikiru" means "to live," but its connotation is more abstract and graver than to simply cope with daily necessities and to sustain a lifestyle. The term signifies the active choice of life over death. "Nikusa" is a suffix that means "the difficulty of/having trouble in." When I first encountered the word "*ikinikusa*" during fieldwork, I was somewhat taken aback by its turgidity, for hattatsu shōgai is not a life-threatening condition in itself. However, I eventually came to understand that the word refers to the difficulty of "being"; the ontological struggle of finding one's place in the family, school, community and society that one belongs to. In other words, the suffering of those with hattatsu shōgai is not coming from the specific symptoms per se, but from the ways in which they manifest as the inability to deal with various social imperatives, and the sense of hopelessness that such a process entails.

"*Ikinikusa*" is a keyword that ties together the experiences of different minorities that I had encountered or learned about in the phase after my fieldwork. It shifts our attention away from the specificity of each illness/disability and each form of marginality,

and portrays the existence of numerous individuals' feeling of displacement and not belonging, gasping for breathing space in this society. It also speaks to the larger significance of my project, beyond the community of hattatsu shōgai. A close look at how this particular disability is being conceptualized and understood in society, following its rather abrupt emergence into the public sphere, sheds light on the more general meaning of marginality, difference, and "ikinikusa" in Japan today.

### **Contextualizing the experience**

During the 70s and 80s, Japan established itself as an economic and technological superpower rivaling the US. Many domestic manufacturers grew to become multinational corporations headed up by some of the largest foreign investors in the world. The rapid expansion of the Japanese economy led to a steady increase in the size of the labor force; the unemployment rate remained very low while new graduates of every level of education were actively recruited into the workforce. With the shortage of labor, the wage level also increased, substantially improving the lifestyles of the average workers and producing the common parlance: "tomorrow will be better than today." All in all, the upsurge of the nation's power and international influence had created a social atmosphere of affluence and optimism, which culminated in the bubble economy during the late 80s to the early 90s. However, when the bubble economy burst in 1991, Japan was unprepared to cope with the consequences, and plunged into long-term recession. The suffering economy was accompanied by a rising unemployment rate, and the social atmosphere degenerated. On top of this, the neoliberal reform by the administration of Junichi Koizumi (2001-2006) in

early 2000s drastically shifted the nature of Japanese business practices, rendering many blue-collar manual laborers out of work or without job security; opportunity was likewise shrinking for new graduates. The widening disparity between the upper and lower classes became a pressing issue and resentment and frustration simmered.

The emergence of hattatsu shōgai coincided with the precise historical moment in which Japan was suffering from the long-lasting effects of the post-bubble recession. Recent publications in *nihonjin-ron* as well as Japanese sociology have described the present state of Japanese society as “impasse” and “hopelessness” (Furuichi 2011; Yamada 2007). The lives of the individuals I encountered during my fieldwork – both adults and children – are shaped and defined as much by this specific social landscape as by their disability.

Many of the young adults with hattatsu shōgai that I interviewed identify with the label of NEET (Not in Education, Employment or Training), a new group of youths who have come to be increasingly visible as the byproduct of the harsh employment situation. Having no place to go to, some have taken up a lifestyle similar to that of hikikomori; and among those who did not withdraw from social contact, many knew a friend who did. Of those fortunate enough to be working, very few have full-time jobs; more often, they work as “arubaito,” a part-time job with hourly pay, no job security, and little prospect of building a career or moving up the ladder to become full-time employees. The vast population of NEETs (estimated at 630,000, constituting sixteen percent of middle school graduates and nine percent of high school graduates, according to MHLW) and of those in non-regular employment (constituting one-third of all employment and particularly high among those under the age of 35) are identified as a major social problem, as their chance of holding down

full-time jobs decreases steadily with age, and they are at a high risk of becoming welfare recipients in the future. Furthermore, it has been pointed out that low wages lack of job security negatively affect the marriageability of these workers, particularly among males. Therefore, many end up ailing in poverty and isolation, unable to hold a positive vision for the future. Arguably, the dire situation in which young adults with hattatsu shōgai face does not pertain solely to those with the disability but is common among a significant proportion of the same generation. When considering their circumstances from political and economic perspectives, the disability recedes to the background, accounting for just one of several factors that might conspire to place young adults in positions of marginality. In fact, some with hattatsu shōgai see the disability as an asset, for at least it provides them disability welfare and special support.

School-aged children with hattatsu shōgai, on the other hand, are also subject to the current educational climate. During the 1980s, Japanese public education was applauded for its effectiveness in producing a highly efficient and capable workforce necessary for the nation's technocracy. Books were authored on the "secrets" of Japanese education, admiring its uniqueness and discussing its applicability to other countries (Lynn 1988; Lewis 1995; White 1988). However, more recently, the fact that Japan has been unable to recover from the economic downturn for nearly two decades has triggered the anxiety and a loss of confidence, leading people to question if perhaps there is something innately and deeply misguided in the way Japanese schools educate and prepare their students. The rising juvenile crime rate and the qualitative shift in the nature of delinquency, as I pointed out in the introductory chapter, added to the frustration. As discussed in the chapter on special



support education, MEXT has made a major shift in its policy in response to the very situation I am describing. They have endeavored to prioritize and nurture personal individuality in education. It is in this context that the emergence of hattatsu shōgai was seen as an opportunity to critically scrutinize the public education system, making visible the diversity of a student population that had previously been obscured by a veil of false uniformity; awareness of hattatsu shōgai helped mobilize the shift in educational ideology – from one in which productivity and efficiency had been over-emphasized to one in which individuality and creativity are valued. In this way, acknowledgement of students with hattatsu shōgai within the school setting had been – and continues to be – contingent upon a transitioning Japanese education system.

Taking a step back to look at the larger picture, Japan had, for a long time, seen itself as a development-oriented nation. Over a short span of 30 years, it had rebuilt itself from the aftermaths of the Second World War, an achievement upon which was founded a strong sense of national pride, and that had been equally applauded by the international community. So strongly rooted was Japanese identity and of achievement that, even after its downturn in the 1990s, the social climate remained fixated on the belief that perseverance (“ganbari”) and selfless commitment would yield results in the form of affluence, betterment in lifestyle, and emotional fulfillment, just as they had maintained in the earlier years of economic development. It took more than a decade into the recession for the society to gradually and collectively interrogate the assumption that continued upward development could lead Japan to restore the economic power and influence that it once enjoyed. Beginning at around the turn of the millennium, the social climate slowly shifted. Alternative lifestyle movements

– such as the “slow life” movement, which seeks to move away from the efficiency-driven mass consumer culture and to reconsider the value of a slower-paced, locally oriented, and nature-friendly lifestyle – began to gain popularity. The word “iyashi (healing/therapeutic/comforting)” a keyword signifying the general atmosphere permeating the society, was selected as one of the top ten buzz words of 1999. Treatment to pain, healing of wounds, and respite from the constant pressure to advance forward, were precisely what the society was seeking. One series of TV commercials for Regain, a popular energy drink, offers a compelling and eloquent mediation of the social climate representing this new era. In the late 80s, the commercial featured images of Japanese businessmen tirelessly working to pull off a contract or negotiation in a foreign country, accompanied by the copy, “can you fight for 24 hours? (nijyu yojikan tatakae masuka?)” The commercial went through several revisions in the years that followed, and in the late 1990s, it featured a soothing piano performance by Sakamoto Ryuichi, a prominent Japanese musician, with the copy, “this song, to all who are tired. (Kono kyoku o, subete no tsukarete iru hito e).” The powerful contrast speaks for the transformation of Japanese society over the course of those ten years.

The emergence of hattatsu shōgai coincided with this specific juncture in time. There has been a sense of resignation toward the understanding that hard work and perseverance – the values that had led Japan’s growth in the past – no longer seem to guarantee a “pay-off” of material gain. This resignation strangely traces the ways in which schoolchildren with hattatsu shōgai were portrayed in the popular media; they continue to try and try (ganbaru), but often in vain, until one day when they become tired and lose confidence in themselves.

It almost seems as if the present state of Japan is being imposed on the imagery of hattatsu shōgai. As I have discussed in the chapter on school, acknowledgement of the presence of students with the disability has entailed the necessity to set different goals, reconsider new modes of evaluation, and to redefine the meaning of achievement and success. This transition also seems to resonate with the larger ideological transformation that Japanese society is undergoing. It may be argued that hattatsu shōgai bears a peculiar symbolism in the present Japanese society. Just as hattatsu shōgai is a specific biomedical condition, defined by and treated in accordance to international diagnostic manuals, it carries, at the same time, an additional layer of significance by embodying the distress of the present Japanese society; the “ikinikusa (difficulty of living)” of those with the disability is not only a matter of personal perception and experience, it is unmistakably a trait of the society itself.

### **The universal and the specific**

Treating hattatsu shōgai in this way – as a disability of which the experience is contingent upon the unique sociocultural context of Japan – inevitably raises the question of universality and specificity. Is hattatsu shōgai a universal disability that can be observed and epidemiologically studied across cultural boundaries? What does it mean to locate it in the historical and cultural context? Moreover, what is the implication of writing an ethnographic study of a universal illness/disability in a local setting? In answering these questions, I would like to refer to Margaret Lock’s concept of “local biologies.” Lock defines this concept as a “way in which the embodied experience of physical sensations, including those of well-being, health, illness, and so on, is in part informed by the material

body, itself contingent on evolutionary, environmental, and individual variables” (Lock 2001:483). Lock theorizes the way in which the body is subjectively experienced as being informed by social processes, while these social processes are, simultaneously, a product of the biological reality of the symptom; In other words, the two processes are dialectically intertwined. Lock's ethnographic work on menopause in Japan and the U.S serves as an informative illustration of this point.

In *Encounters with Aging*, Lock explores how menopause is experienced by Japanese women, through symptoms such as stiff shoulders and headaches, as opposed to the hot flashes and night sweats experienced by women in the US. Doctors and patients in Japan speak of menopause as a symptom specific to pampered housewives who have nothing else to worry about. Thus it is treated not so much in association with the end of menstruation, as is the case in the US, but as a phase in life where the woman's social role changes significantly. In Japan the process is not treated with medication. Based on fieldwork conducted in the mid- to late-1980s, Lock cites specific notions of maturity, responsibility, and sense of loss, as experienced by the generation constituting her interviewees, in the context of the cultural values regulating women's overt expressions of complaints and resistance. Contextualizing Japanese women's narratives through national discourses of aging, Lock criticizes the (US) biomedical notion of menopause as a universal physiological process. Rather, she posits that the way in which menopause is experienced in Japan is a result of “local biologies” as well as local cultures, where material explanations given by Japanese doctors – such as estrogen-rich diets or differences in endocrine systems,–

are dialectically intertwined with sociocultural processes that define the ways in which knowledge regarding menopause is produced, received, and circulated.

Pointing out the sociocultural specificity of how biological conditions are experienced, however, touches upon the danger of reifying an Orientalizing ideology and repudiating any further considerations of its significance. Lock makes an important point about how experiences and narratives regarding a presumably “universal” condition, such as menopause, could affect the ways in which a group of people thinks about themselves and others. “It is tempting to Orientalize this discourse and dismiss it as anomalous,” she writes. “The danger, of course, is that the white Euro-American body remains the gold standard and the medical model of a universal menopause survives intact” (Lock 2001:486). If the Euro-American society casts an Orientalizing gaze on Japanese embodied experience, the Japanese society, on the other hand, strives to establish its own cultural particularity through deviation from the Euro-American norm:

In an era of struggles to create and recreate cultural identities and establish the grounds of cultural difference, the self-conscious possession of scientific knowledge, or, alternatively, its repudiation as inauthentic or culturally inappropriate, is explicitly made use of as an ideological tool to establish local power bases and authority. [Lock 1997:211].

In other words, the deviation from the “universal” experience of the body, which may operate as a cardinal point for assigning stigma and Otherness, could, at the same time, be utilized as a tool to establish a moral community based on that very difference (Goffman 1963; Yang 2006). In the case of menopause in Japan, while both the gynecologists and their patients espouse the view that some aspects of the menopausal experience are culturally contingent,

the gynecologists also express concern that they don't want to be thought of as old-fashioned or unscientific by rejecting the Euro-American biomedical standard. As Lock notes, the Japanese relationship to science and technology is historically intertwined with its ambivalent relationship to the “West,” most notably the United States. Experience of suffering, or even of death, becomes a contested terrain where confounding ideas about religion, nationality, individualism and altruism clash with one another (Lock 1995; Befu 1993, 2001).

Hattatsu shōgai, like menopause, is also considered to be a “universal” biomedical condition. Although there is not a comparable categorical term corresponding to hattatsu shōgai in English (for reasons I have discussed in the introduction), the disabilities that the category encompasses – LD, ADHD and ASD – are standardized diagnostic labels, constituent of symptoms believed to be the same throughout the world. However, the ways in which hattatsu shōgai is understood, experienced, and spoken about, are highly localized, as I have shown in the previous chapters. The entrance of hattatsu shōgai into public discourse was tainted with a stigmatized association with juvenile crimes, and its increasing visibility has led to the confounding debate over labels, numbers, and shifting forms of family and child-rearing practices. Hattatsu shōgai unraveled the notion of effort and achievement in the school setting, created a new identity among adult tojisha, and cultivated an entire industry around the practices of care and treatment. All these local social transformations and processes that the introduction of hattatsu shōgai entailed has, in turn, shaped the ways in which the disability is experienced, generating a unique discourse of suffering and struggle which is perhaps most prominently expressed through the rhetoric of “ikinikusa.”

The difference between menopause and hattatsu shōgai, on the other hand, lies in the fact that cultural specificity of the latter is denounced, or at least underplayed within popular discourse. While menopause is a temporal phenomenon that most women undergo, hattatsu shōgai represents a disability status associated with a specific population; those diagnosed are likely to live their entire lives with the label. Thus the identity of those with hattatsu shōgai is founded upon their distinction and exclusion from the mainstream Japanese population, and they associate themselves more closely with those with the same disability in other cultures and societies. In other words, the discourse on hattatsu shōgai is far from Orientalizing; those with the condition have been legitimized through references to universally standardized biomedical practices and Western modes of treatment and intervention. It is precisely because of a Western influence that the hattatsu shōgai movement has been able to productively and successfully critique the status quo and thereby initiate and facilitate political changes.

The dichotomy between the universal and the specific pertains not only to the disability itself, but also to how I envision the contribution of my work. I have explicitly tried to distance my work from the all too simplistic grand narrative of global disability rights activism, by carefully depicting the confounding debates and discussions that cannot be elucidated by a universalizing project that celebrates the liberation of individuals with disability in yet another culture. Rather, I have attempted to contextualize the story of hattatsu shōgai within its specific sociocultural and historical location and moment, in order to consider its impact in terms of the present Japanese society. I have done so, also, so as to situate my work at the interface between disability studies and anthropology. Disability

studies emerged in the 80s and flourished in the 90s, bringing together scholars in diverse disciplines and developing an important field that sheds light on the experiences and narratives of a minority group that had not previously been accounted for. However, the field is also geared towards activism and engagement, and had taken for granted the ethnocentric perspective that views local stories of disability experience as chapters of the global movement to fight for the rights of individuals with disabilities. I hope to have contributed to this disability scholarship without letting go of my identity as a Japan anthropologist, locating the story of hattatsu shōgai in the specificity of its time and space, and utilizing it as a means through which to view Japanese society and culture.

In fact, hattatsu shōgai provides a perspective on society in ways that other disabilities do not. The fact that the disability is not immediately identifiable from a lay perspective (not visible by way of a person's outward appearance), has led to the coining of the phrase "invisible disability (mienai shōgai)." Hattatsu shōgai's invisibility is at times considered to be an inconvenience, for it puts the weighty burden on individuals to "come out" in order to acquire special accommodation. Invisibility, though, also means that it is relatively easy to "pass" as able-bodied and to mix in with the crowd without constantly being marked as different. Hattatsu shōgai's diagnosis is also unstable, to a certain extent, such that the boundary between disability and personal character is often ambiguous, which has elicited the notion of being in the "spectrum." The concept of "spectrum" should be credited for having brought forth the awareness that the boundary between the "disabled" and able-bodied is blurrier than had previously been understood. These advances have been instrumental in avoiding the essentialization of hattatsu shōgai as yet another type of



disability to be single-handedly categorized and managed through the existing welfare system that had accounted for the existing disabilities (physical, intellectual and mental). The spectrum concept has elicited the realization that difference resides *within* the mainstream population, often in ambiguous forms that resist simplistic compartmentalization. In a sense, the emergence of hattatsu shōgai has shaken the myth that “the mainstream” constitutes a homogenous citizenry with universally comparable capabilities (Befu 2001).

### **Revisiting the question of tōjishaness**

Returning to where I began, I would like to reexamine the notion of being a “tōjisha.” The question that was directed at me in this regard had assumed there to be a clear boundary between those with hattatsu shōgai and those without it, using the term tōjisha to create an imaginary community of exclusivity and to presume that certain experiences are shared solely among its members. That boundary, however, is more precarious and arbitrary than it seems. In what Lennard Davis describes as the “dead-end of identity politics,” he critiques the formation of a collective minority identity based on disability status, arguing that the only way to learn from struggles of women, queers, and people of color – moving forward from the considerable achievements of identity-based politics – is to denounce the premise of exclusivity and victim status that defines membership within any one minority group. Davis argues that the present moment calls for “a critique of and a politics to discuss how all groups, based on physical traits or markings, are selected for disablement by a larger system of regulation and signification” (Davis 2002:29). Although admission to the tōjisha community of hattatsu shōgai depends on the possession of a diagnosis, what ties it together

is shared experience (of struggling and suffering). Experience is the irreducible grounds by which collective identity is formed and the claim for exclusivity is made. However, as I have shown, what those with hattatsu shōgai are going through is in fact contiguous with the lives of many others living in Japan today, and those experiences eloquently encapsulate the shared “ikinikusa” of the generation. Joan Scott writes that “experience is a subject’s history,” meaning that subjects are construed through experience, rather than the other way around (Scott 1991). Following Scott, I would argue that the subject position of tōjisha is not what generates a particular experience or narrative, but that shared experience is what entitles individuals to tōjishaness. In other words, tōjishaness is constitutive of all those experiencing the “difficulty of being” – including the hikikomoris, NEETs, and others who are made to feel different, isolated and not belonging – whose social survival is at stake. By dismantling the exclusivity currently undergirding the concept of tōjishaness, thus opening up the term to incorporate a broader range of experience, the story of hattatsu shōgai will become more public than ever, engaging a larger audience and thereby fostering a dialogue broad enough to speak both to and of the meaning of difference and diversity in Japanese society today.

### **On a final note**

In the aftermaths of the earthquake of March 11<sup>th</sup>, 2011, treatment of children with traumatic experiences of having lost their family and/or homes to the earthquake and tsunami became a topic of public concern. Many organizations concerning hattatsu shōgai extended their resources to the affected areas, sending teams of psychologists, psychiatrists and ryōiku

professionals to provide specialized support for children with hattatsu shōgai, but the scope of their projects were often enhanced to help many other children who had begun to exhibit mental issues caused by the devastating experience. NISE (National Institute of Special Needs Education) published a handbook for teachers teaching children in the affected areas (with a particular focus on children with hattatsu shōgai), listing some tips in interacting with children: “Tell them that the current situation is not going to last long, and help them feel secure.” “Children who have lost family members and homes are sensitive about loss. Be there for them, and talk to them.” “Give them a role and impart responsibility. Make them feel needed.” “Some children may blame themselves, saying things like ‘this all happened because I didn’t listen to mom and dad.’ They might even say, ‘If I could die...’ Do not reprimand them for saying these things; it is their way of balancing their emotions. Stay in touch with their feelings and let them slowly realize that that is not the case.” (NISE 2011:3-4) These tips are relevant to specific symptoms that may be more visible in children with hattatsu shōgai, but are also readily applicable to all children who have been affected with the disaster. Prior to the earthquake, Tohoku region was known to be one of the regions where the availability of resources and support systems for children with hattatsu shōgai are severely limited. “It’s so ‘behind’ that it’s like this blackhole on the map.” A member of the Japan Developmental Disabilities Network once said to me. “It’s where regional disparity is most visible.” In a way, therefore, the 2011 Earthquake had helped alleviate that regional disparity by triggering the flow of knowledge, funding and professional expertise to the area. At the same time, however, the specific circumstance of Tohoku has in fact extrapolated the notion of “ikinikusa” and distress of children with hattatsu shōgai to account for many children suffering from loss and depression. Not coincidentally, JDD-

Net also began a new project after the disaster promoting the training of “Parent Mentors” who are to become peer supporters/counselors within the community of parents (mostly mothers), shedding light on the frustration and anxiety of and lack of mental support for mothers raising children with hattatsu shōgai. “Empathy” is mentioned time and time again in emphasizing the importance of this project as well as the outreach programs to Tohoku region, as a keyword that ties together those going through similar experiences. It is here too, that we can see individuals and groups slowly coming together to share experiences of “ikinikusa” or difficulty of being, and mutually extending a helping hand.

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