

Title	The contested notion of "Curing" developmental disability in Ryōiku settings
Sub Title	
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Publisher	Centre for Advanced Research on Logic and Sensibility The Global Centers of Excellence Program, Keio University
Publication year	2012
Jtitle	CARLS series of advanced study of logic and sensibility Vol.5, (2011.) ,p.259- 264
JaLC DOI	
Abstract	
Notes	I. Study of Logic and Sensibility Part 4 : Philosophy and Anthoropology
Genre	Research Paper
URL	https://koara.lib.keio.ac.jp/xoonips/modules/xoonips/detail.php?koara_id=KO12002001-20120224-0259

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The Contested Notion of “Curing” Developmental Disability in *Ryōiku* Settings

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I. Introduction

In recent years, educational and welfare policies for children with *hattatsu shōgai*¹ in Japan have been emphasizing the importance of early diagnosis and intervention. The mandatory physical checkup for 3-year olds has been instrumental as one of the primary opportunities for screening, as well as the pre-enrollment checkup in elementary schools. 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 to help them better adapt to their preschools or elementary schools. *Ryōiku* programs vary greatly; some are run by children’s hospitals or clinics, while others are run by private or non-profit organizations. Some meet weekly, while others enforce a more intensive commitment or involve overnight stays. Their approaches are similarly diverse, but for the most part, the programs consist of social activities and individualized

¹. The Japanese term *hattatsu shōgai* may be translated as “developmental disability.” The term is generally used to indicate learning disability, ADD/ADHD, autism spectrum disorder and other pervasive developmental disorders that are caused by congenital brain defects and are not accompanied by intellectual disabilities.

learning exercises, and are implemented in ways that are informed by practices in ABA (applied behavior analysis), social skill training, TEACCH and play therapy, among other clinical methods of intervention.

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 after-school program run by a non-profit organization. Although the three programs varied in many ways and attracted children from different backgrounds, there were also a lot in common; they were tailored for children between the ages of 4 to 12, maintained a student-staff ratio of roughly 3:1 or lower, had a strong emphasis on social training, were organized by clinical psychologists and child therapists, and were deliberately distancing themselves from the idea of “curing” the disability.

II. The Contested Notion of “Cure”

Curing *hattatsu shōgai*, when defined as the complete elimination of its symptoms, is considered to be a rather controversial issue among professionals in the field of *ryōiku*. Throughout my fieldwork, I was taught both explicitly and implicitly by the staff members that cure (or *chiryō*) is not the goal of their program, and that it is quite inappropriate to question its efficacy in those terms. At the same time, however, the programs were usually designed to help children achieve what they couldn’t and to facilitate a positive change in their developmental trajectory, and in that sense, it can be said that the program administrators were negotiating the thin line between “care” and “cure”.

In the following, I discuss why the notion of cure is met with such ambivalence and what is made possible by avoiding this idea in the field of *ryōiku*.

1. Resistance to ableist ideology

One of the main factors shaping this negative attitude towards the cure of *hattatsu shōgai* is *ryōiku*’s unique distance with the existing educational system. While *ryōiku* is often seen as aligning with and supplementing the

public educational system to the extent that there are courses and symposiums offered for school teachers to learn from the latest *ryōiku* practices, it is also an alternative space where children are encouraged to learn through nontraditional methods and to build their self-esteem in a more liberal environment. While staffs from *ryōiku* programs often maintain close communication with parents and schools to provide all-round care for individual children, they also see their program as a unique place that offers a critical alternative to the way learning is imposed in the public educational system.

For instance, in one of the programs, the process of trial and error was considered to be an integral part of the learning experience. The staff members quietly observed as one of the children struggled with a task and waited without intervening until he figured it out on his own, when finally they stepped in, praised him and told him how much he'd accomplished. This, the staff told me, was an example of the kind of education that cannot be done in schools where a teacher oversees a large class and hastily spoon-feeds them with knowledge in order to cover the standardized curricula.

At another program, the staff members asked each child of his/her intention to participate in an activity, and it was permissible to sit at the corner and do other things as long as they communicate those intentions. There was a child with selective mutism in the program, and in her case, the staff approached her and she would reply yes or no by slapping his hand in a certain way. The encouragement of such alternative means of communication was creating a place for her to express herself and take part in social activities in ways that are unthinkable within public schools.

Rather than focusing solely on the children's adaptability to the existing educational system, *ryōiku* programs place particular importance in fostering a space where children can experiment and learn in a less structured way, and express themselves and interact with others more freely. In this sense, although they prepare children for school, they 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 staffs and administrators that I met during the course of my fieldwork were critical of the ableist ideology, which views disability as a deviance from normalcy and brings on the imperative to train children to overcome their differences and to behave as “normal” as they can. (Linton 1998) To them, the idea of curing *hattatsu shōgai* seems to come too close to embrac-

ing this ableist ideology, which would exploit the heart of *ryōiku* practices.

2. Cultural notions of embodying illness/disability

Another factor to consider is the way in which *hattatsu shōgai* is seen as an embodied trait, or an inseparable part of selfhood. During staff meetings, the program staffs made various comments about individual children, many of which went beyond conventional remarks on performance and progress touching upon the children's cognitive perception of their own bodies and the ways they interface with the environment. "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, alluding to how each child is perceiving the reality in ways that may be different from others, and thus not immediately apparent to the observer. Their narratives were based on the premise that children with *hattatsu shōgai* experience the environment in a different way, and that the disability is manifested precisely in their unique cognition of themselves and the world around them. In essence, *hattatsu shōgai* is seen as deeply embedded in and inseparable from the individual's body and personhood, in a way that is perhaps close to "jibyō" (constantly present illness) and "taishitsu" (inborn weaknesses of constitution) as described by Ohnuki-Tierney (1984). She argues that although Japanese culture provides various means to deal with these 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." (Ibid.: 73) The idea of curing *hattatsu shōgai* evokes the former image of eliminating a foreign pathogen that is inhibiting the child's true individuality, but what the *ryōiku* programs seem to be aiming for is precisely the latter: to help children learn how to embody their disability and to cope with it in a way that they can feel comfortable about themselves while fulfilling their academic and social responsibilities.

3. Dealing with parental stigma

The third issue concerns the politics of parental care and responsibility. Raising a child with *hattatsu shōgai* is different from raising a child with con-

genital physical or intellectual disabilities, in that the child’s behavior and inability to comply to certain rules or directions tend to be mistaken for a sign of irresponsible child-rearing practice and lack of discipline by the parents, because the disability is usually not visibly identifiable. Parents have been among the most vocal activists advocating for awareness towards *hattatsu shōgai*, and this for a reason, because they often share bitter episodes of being wrongfully accused of their child’s behavior.

This social stigma is historically deep-seated, for there is a long genealogy of scholarships and popular representations that have been instrumental in producing and reproducing the parent-blaming (and more prominently, mother-blaming) discourse. The “refrigerator mother theory” (Bettelheim 1967) blamed the mothers as the primary cause of their children’s autism, and its Japanese counterpart, the notion of *bogenbyō* (illnesses caused by the mother)(Kyutoku 1979), has criticized how industrialization has negatively shifted the lifestyle of Japanese women, making them ‘narcissistic’ and lacking in ‘child-rearing instinct’. (Lock 1987) Not surprisingly, similar discourses persist even today. Sankei News, a newspaper with nationwide circulation, did a series in 2010 on “oyagaku”, or parental education. The series emphasized the importance of the parents’ role in supporting the healthy development of children, and stated that *hattatsu shōgai* can be prevented if the parents would reclaim the “traditional” Japanese childrearing ways. This article stirred much controversy within the online community of parents, not only because the claim was unsubstantiated, but also because it was read as a shameless revisitation of the *bogenbyō* idea. In this milieu, the notion of curing *hattatsu shōgai* becomes a highly sensitive issue, for it evokes the imagination that it is somehow possible to undo the disability through appropriate training and discipline, alluding to the problematic and stigmatizing conclusion that the disability in fact has to do with certain parenting techniques or the lack thereof.

Based on this historical context, the dominant discourse on *hattatsu shōgai* today leans far on the nature side in the nature vs. nurture debate, and the *ryōiku* programs that I worked at embraced this perspective. The understanding that the disability is caused by a congenital problem of brain function and has little to do with particular child-rearing practices, inherently defies the idea that it could be cured through nurture.

III. Conclusion

Curing *hattatsu shōgai* seems to be a much less problematic idea within the medical community. The causes, genetic heritability, prevention methods and environmental factors that affect the disability are common and increasingly popular topics of research. However, I have shown that those who are involved in the field of *ryōiku*, in contrast, have maintained an ambivalent position with regard to the notion of cure. I argue that this is because *ryōiku* programs constitute a unique space that brings together knowledge from the medical field, practices from clinical psychology, collaborative links with schools and parents, and ideas informed by historical and cultural understandings of the disability. As the nexus where these diverse political forces encounter and interface, and also as the place of learning and socialization, as well as identification and belonging, *ryōiku* sites provide an interesting terrain of disability politics.

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