

Session A-1 Family Care 1

Suffering and Love between Genders: A Narrative Analysis of Autistic Children's Parents

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1. Introduction

The issue of autism has caused wide public concern across the world. The incidence of autism has increased rapidly in Taiwan in recent years; however, little is known about families' experiences of autism. Autism has a huge impact on family life and the caring responsibilities of parents. Moreover, the impact of autism on parents is gendered both in terms of experience and the meaning of parenthood.

This article studies the gendered suffering and meaning associated with illness and parenthood among parents of autistic children in Taiwan. Using narrative analysis, this article discusses how parents interpret the meaning of autism and their parenthood with regard to their caring responsibilities. Moreover, the uniqueness of autism in Taiwan is emphasized.

2. Autism and Autistic Patients in Taiwan

Autism is a neurodevelopmental disorder characterized by impaired social functioning and communication skills, and by abnormality in unusual behaviors and interests. The disorder often lasts into adulthood and its symptoms can affect every aspect of a patient's life. Autism is also known as autism spectrum disorder (ASD); as it is a spectrum disorder, this means it includes different types of symptoms and degrees of severity, so every autistic child may behave totally differently. The patients have no visible abnormality and some are talented in certain areas; however, some may also have some degree of intellectual disability. Autism still remains a mysterious disorder in the field of medical research. Its cause, diagnostic criteria, and treatment are under heated discussion (Mash & Wolfe, 2009; Chiu et al., 2011).

The most curious thing about autism is that it is becoming increasingly prevalent all over the world. A growing body of data suggests that the reported cases of autism have increased rapidly in the US¹ and in Taiwan. The data from the Department of Statistics, Ministry of the Interior show that the number of autism cases in Taiwan was 13,580 in 2013, a significant increase from 2001 when there were 2,550 cases.² Moreover, autistic children comprised approximately one-tenth of disadvantaged students in general schools.³ While it is difficult to understand why the number of cases has increased, the data remind us that it is important to understand the experience of autistic patients and their families.

3. Literature Review

There is a vast number of social science studies on autism. However, the literature often overlooks the families' experiences of autism including how the social context impacts on their experience. I will review three parts of relevant literatures in this chapter and highlight their contributions and limitations.

3-1. The Medical Context of Autism

Why does a variation in social communication or restricted interests become a medical problem called "autism"? Several social science studies discuss how the "medicalized" view of autism began; i.e., they have examined how the concept of "autism" emerged and how its meaning has changed over time (Nadesan 2005; Feinstein 2010).

On the other hand, due to the limited knowledge about autism, the parenting experience of autistic children's parents has also been constructed by an "uncertainty in medicine" (Fielding 1999; Chang 2009). As previously mentioned, the etiology, diagnosis, and treatment of autism are still open to debate, and the medical procedure of autism is full of uncertainty. Medical professionals often find it difficult to offer clear answers to parents about whether their children have autism or not, what therapy is best for their children, and to what extent we can say that children have "recovered" from autism (Soong 2009).

This article does not intend to discuss the issue of "medicalization" and "uncertainty in medicine" in detail; nonetheless, it seems these concepts are important in order to understand the blurred boundaries of autism in the narratives of autistic children's parents.

3-2. Caring for Autistic Children

Family is the basic care unit in peoples' daily life. When a family member is ill, the family often acts as a single unit to make medical choices (Chang 2009). As is often the case with the families of autistic children, parents assume the primary caregiver role. Because the obvious symptoms of autism tend to emerge in toddlerhood, other family members, and in particular parents, have to take care of the children and make all the medical decisions. How do parents deal with their children's autism? How does autism affect families? In this section, I will review three specific themes within the literature in order to seek answers to these questions.

3-2-1. "User-Professional Relationship" and "Stress and Coping" in Autistic Families

Fan-Tzu Tseng's (2008, 2010) studies regarding children with "developmental delays" in Taiwan are some of the most relevant and inspiring research for this article. Tseng argued that the parents of children with developmental delays act as "logisticians" who do not accept medical services passively; rather, they place much effort into the carework and learn new skills in the process. Tseng's articles provide many insights into caring for children with "developmental delays"; however, they mainly focus on the topic of "user-professional relationship," and overlook the suffering of the parents and the meaning of illness. Moreover, as Tseng covered all kinds of developmentally delays in children, the uniqueness of autism was not mentioned in these articles.

There is also a great deal of literature which discusses parents' stress and coping strategies. Researchers investigate how autistic children's parents deal with the stress of the carework, and the coping strategies they employ (Li & Lo 2010; Hsieh & Lo 2010; Chen et al. 2009). As Tseng highlights, these articles focus on a passive parenting style, which neglect the positive actions performed by parents.

This article uses narrative analysis to broaden the scope of the issue, including families' experiences of autism. To avoid the limitations of "user-professional relationship" studies and the passive approach adopted by "stress and coping" studies, I aim to understand parents' suffering and their love towards their children.

3-2-2. Social Suffering: Caring for Autistic Children

How does autism affect families? Many social science researchers, such as David E. Gray, have focused on the illness and parenting experience in autistic families. Gray (1994, 2002) analyzed the stress and stigma of autistic children's parents in Australia. He found out that the most stressful problems for the parents included a lack of normal language, disruptive and violent behavior, inappropriate eating and toileting, and inappropriate sexual expression. Although autistic children's parents may share similar stigma as the parents of children with other disabilities, the low visibility of an autistic person's disability makes them experience a different type of stigma. The parents suffer from what Goffman called "courtesy stigma"; moreover, parents, and especially mothers, have to bear the stigma of "irresponsible parents." Though many parents would like to "pass" as a "normal" family, they are unable to prevent their children from a wide range of social activities and therefore fail to "pass."

Woodgate, Ateah, and Secco's (2008) research on autistic children's parents in Canada showed similar results. Autistic children and their parents seem to "live in a world of their own." Parents feel isolated from the social world as a result of a lack of social awareness about autism, the full schedule

for recovering courses, lack of support from other family members and extended family, and low accessibility to medical and educational systems. Fletcher et al. (2012) also highlighted female primary caregivers experience considerable “costs,” including financial and work costs, costs to the health of family, social costs, and costs to overall family life.

The parents are not only anxious about the development of their children, but they are also tortured by various pressure derived by autism. I use the concept of “social suffering” developed by Arthur Kleinman to analyze the parents’ suffering experience, and I argue that this concept can offer new insights into the issue. Kleinman (1997: 320-321) considered suffering is “social,” which means that suffering is a “transpersonal engagement,” “societal construction,” and “professional discourse.” The concept of “social suffering” draws attention to how the social context constructs the experience of suffering. Using this concept, I will analyze the suffering experience in the narrative of parents within the framework of the social context, and discuss the effects of gender.

3-2-3. The Gendered Nature of the Caregiving Role

Most social science studies on autistic children’s parents only focus on the mothers. These studies briefly mention that the mothers are usually the main caregivers of autistic children, and quickly jump into their research questions. Furthermore, it is difficult to recruit the fathers as subjects because they are often busy with their work and are reluctant to discuss issues pertaining to their autistic children. It is reasonable for these studies to focus solely on the mothers’ experience, and they indeed contribute to broadening our understanding regarding the situation of autistic families. However, these studies tend to bypass the issue of gender, or take the gendered nature of the caregiving role for granted.

Some researchers critically analyze the gender differences in the caring responsibilities among parents with autistic children. Traustadottir’s (1991) study discussed gender issues in relation to parents of children with disabilities. She argued that “the primary role of the father is to be a supporter,” namely to provide financial support and be supportive of the mother’s dedication (pp. 220-221). Moreover, she suggested that families of children with disabilities are more likely to follow the traditional pattern of family life with “a breadwinning husband and a full-time wife and mother” (p.225). Gray’s (2003) article about the parents of children with high functioning autism also indicated the gender differences in the caregiving role, and noted that the most striking difference is the differing personal impact of their child’s illness. The fathers reported that their children’s condition did not significantly affect them. In contrast, the mothers claimed that their children’s autism severely affected their emotional wellbeing and their careers.

This article investigates the gendered nature of caring responsibilities for autistic children in Taiwan. Due to limited research data and lack of space, this article focuses more on the mothers of autistic children; however, it aims to place motherhood into the context of gender relations. In addition to suffering, the role of the caregiver has a positive side; i.e., the happiness that comes with loving their children. Using a narrative analysis, I will discuss both parents' suffering and their love towards their children.

3-3. Narrative

Narrative can refer to the process of making a story, or the result of the process (Polkinghorne 1988). Illness narratives are an important topic in narrative studies. Hyden (1997) pointed out that narrative is one of the most powerful forms for expressing suffering associated with illness, and patients' narratives give voice to suffering outside the domain of the biomedical voice. Narratives offer an opportunity to fit the illness disruption into a new framework of life history, and reconstruct a state of coherence and interrelatedness.

However, the researchers often pay less attention to the narratives of the caregivers. While the illness affects the patients, it also has a considerable impact on their caregivers, such as the parents of autistic children. The narratives told by parents are about their suffering as well as the meaning of parenthood. I call these narratives "illness-parenthood narratives," and I argue that this concept can help us understand the care experience of autistic children's parents.

Gray (2001) also looked at the experiences of parents' with autistic children through narrative analysis. Gray's studies showed three types of illness narratives told by parents; he argued that all these narratives are presented as attempts to reconcile with the moral dimension of the illness experience and link to the cultural "master narrative" of science, politics, and faith. They are described as the narratives of "accommodation," "resistance," and "transcendence."

While Gray's article shed light on how parents with autistic children deal with autism, it does not delve into the meaning of parenthood or the gender difference in the narratives. Landsman's (2008: 108-142) narrative analysis of mothers with "imperfect" babies, including those with intellectual disabilities, cerebral palsy, autism etc., offered some thoughts on the issue of parenthood and gender. Landsman showed that mother's motherhood and personhood of the babies were denied by American culture, so the mother's narrative was "performative." The narrative asserted full motherhood and personhood by claiming the desired ending of the children's future attainment. Landsman also suggested that "mothers' lived experience of their child's disability is itself structured by the story they tell (p.141)," which indicated the dynamic interaction between experience and narrative.

In addition, Gill and Liamputtong's (2011) research on mothers of children with Asperger's syndrome deals with the concept of "the paradox of motherhood." Motherhood provides women with a sense of reward and fulfillment, but it is also physically and emotionally demanding and limits their personal identity and careers. Furthermore, given the social expectation that mothers should feel happy and satisfied with their role, it is difficult for mother to express negative feelings about mothering. These paradoxical feelings would be more evident for women with a disabled child due to the heavy demand for care. Mothers of autistic children are anxious that they do not do enough for their children or fail to live up to the "ideal" image of motherhood. They often mask their stress, anger, frustration, and fatigue in public and with friends, pretending they can handle all the problems.

Nevertheless, Landsman's as well as Gill and Liamputtong's studies also treat motherhood as an isolated concept, and fail to analyze it within a framework of gender relations. The goal of this article is to explore the gendered narratives of autistic children's parents, and investigate the issue of autism and parenthood in the context of Taiwan. Narrative analysis is one of the best approaches to study the level of experience, meaning, and their interaction in the context of social structure and temporal dimensions. Through narrative analysis, this article aims to discuss the gendered suffering and meaning of parenthood and illness with parents of autistic children.

4. Research Questions and Research Methods

This article studies the gendered suffering and meaning of illness and parenthood in autistic children's parents in Taiwan. Using narrative analysis, this article focuses on two research questions. First, it examines the gendered social suffering experience of the parents of autistic children. I treat my research data as the parents' "illness-parenthood narratives," and investigate the social suffering contained in the narratives. Second, it studies the meaning of the illness on the role of parenthood. Due to data and space limitations in this paper, I focus on the mothers' narratives, examining how the mothers interpret the meaning of illness as well as parenthood through the typology of narratives.

The research data were mainly collected from in-depth interviews with parents and from parents' postings on online forums. I conducted the interviews with the parents of autistic children from four families; they were recruited as key interviewees by snowball sampling.⁴ One of the parents' online forums is a discussion board on "Babyhome.com,"⁵ the other is a private ASD parents' supporting group on Facebook. In both online forums, there are considerably more postings by mothers than by fathers.

5. Gendered Social Suffering

Taking care of mentally or physically challenged children takes an immense amount of time and effort, and the parents of autistic children tend to suffer more because of the unique autism context. Autism is a disorder full of “uncertainty in medicine,” and autistic children’s parents face several ambiguous situations in the process of seeking diagnosis and treatment. On the other hand, it is not easy to find appropriate schools or recovering courses for autistic children. As a lack of medical and educational resources is an additional burden for the parents, I argue that the suffering experience is “social.”

Further, these factors also widen the gender difference in the division of caring responsibilities. In my data, the division of work in autistic families in Taiwan is similar to previous research. Mothers usually assume more caring responsibilities than fathers, and fathers are either supportive or indifferent towards their children. Caring for a child with autism is so challenging that it may totally change the life plan of the main caregiver; the responsibility of care often falls on the mothers’ shoulders.

Most autistic children’s families are two-parent nuclear families or three-generation families.⁶ Many mothers have their own jobs and the paternal grandparents take care of the children before the mothers discover that their children have autism. However, it is nearly impossible for mothers to balance a career and caring responsibilities. The mothers need to take their children to several recovery courses, deal with issues pertaining to their children’s behavior at school or in public, and teach daily living skills to their children.

The care is so demanding that many mothers give up their jobs and become fulltime housewives. For example, Ting’s mother quit her job when she discovered that Ting had autism. She thought that Ting’s grandparents could not give him the special education he needed, so she assumed the role as her child’s primary caregiver. She arranged all kinds of recovering courses for Ting, and both she and Ting were exhausted by the full course schedule. As Ting’s father was the breadwinner, he was seldom with Ting.

Some mothers continue working while also acting as the primary caregiver. Thus, they have to simultaneously manage their work in the workplace and carework at home. Some mothers work for financial reasons, but others look for employment due to the emotional burden of the experience. Sam’s mother is a part-time teacher at a night school; the class schedule is flexible so that she can handle both work and care. Sam’s mother commented:

I had to take care of him at every moment, which almost drove me crazy! I couldn't bear to be with him all the time, so I found a job. [...] I choose to look for a job not for the money, but because it give me an emotional outlet.

The other reason that Sam's mother was able to take on a job was because of the support she received from Sam's father. Sam's father is a fulltime government officer. He shares almost half of the carework, and he agrees that his wife should pursue her career. However, I find that Sam's mother still assumes slightly more caring responsibilities than her husband;⁷ she noted she is lucky that Sam's father is "willing to help." The use of the word "willing" suggests that she assumes that Sam's father has a choice as to whether or not he helps with the caring responsibilities; however, she does not have the right to choose. Moreover, the use of the word "help" reveals that the role of Sam's father in carework is an assistant rather than the primary caregiver.

The gender differences are more evident in most autistic families. Many mothers feel content if their husband can be the "supporters" in carework; the work of the supporter often only includes "paying for the pricy recovering courses" and "driving the child and mother to the courses." In some special cases where the fathers are the main caregivers, it is often because the mothers are unable to take on this responsibility.⁸

Gender differences also exist in the context of the extended family. While extended family members on the mothers' side offer to help in the carework,⁹ autistic families seldom receive help or support from the father's extended family. The latter is because the families are indifferent to their difficulties or they discourage them from seeking treatment. As gender differences in extended families may be unique to Taiwan, further research is required on this issue.

The gender differences regarding suffering relates to both physical and emotional challenges. There are two kinds of social discourses against autism, and the mothers are more likely to be blamed by these discourses. They include two contradictory viewpoints about the boundaries between normality and abnormality: "autism is NOT a disease, but merely a result of poor parenting," and "autism IS a serious disease that is incurable." Both of these viewpoints hold negative attitudes regarding autism and autistic families.

Historically, some medical researchers thought that autism was caused by parent's coldness towards their children, and especially their mothers. This theory was called "refrigerator mother theory," and has now been widely discarded (Feinstein 2010). However, the tendency to blame mothers for their children's misbehavior still exists. Many interviewees and on online postings noted that people accuse them of spoiling their children; they also stated that people do not believe their

child “has autism.” As the medicalization of autism has only recently begun in Taiwan, community awareness and understanding about autism is low. The elderly are more likely have prejudices against autism due to lack of medical knowledge. For example, one mother posted the following on Babyhome:

My in-laws still think my child is “okay.” Although my son has a moderate disability card, they just regard the diagnosis as an excuse that I don't take good care of my son.¹⁰

This discourses of “autism is NOT a disease” tends to consider the children to be “normal” and criticizes the parent’s parenting style. On the other hand, the contradictory discourse of “autism IS a serious disease” also coexists. “Autism” itself is often considered as a terrible and incurable disorder, and autistic children may be deemed useless and not worthy to live due to the illness. Autism is a spectrum disorder; however, if the child receives the label of autism, he or she is often considered as “a child with special needs permanently.” Sam is a child with autism and attention deficit hyperactivity disorder (ADHD). When I asked Sam’s parents how they explain Sam’s illness to others, Sam’s mother said that she would just mention ADHD to acquaintances. She does not mention that Sam has autism until they know each other well. She said the reason she makes this decision is that ADHD sounds “ordinary;” however, an autistic child tends to be regarded as “special.”

Autism is considered to be a serious disorder, and autistic families are often regarded as unfortunate families. Furthermore, illness is a sign of “karma” according to the traditional religion in Taiwan; this means that misfortune is caused by bad deeds performed by an individual or their relatives in a past life. For example, one Daoist priest told Andy’s mother that Andy’s autism resulted from Andy’s grandfather killing too many dogs. In autistic families, the child’s illness may be seen as evidence of their parent’s karma.

These two social discourses against autism are contradictory; however, they coexist and significantly impact autistic families. The parents of autistic children have to respond to these discourses and search for the meaning of the illness in order to support themselves. Thus, the parents develop the “illness-parenthood narrative.” The mothers of autistic children often take on the majority of caring responsibilities, and they suffer from more negative social discourses than the fathers. As the narrative and experience interact with each other (Landsman, 2008), the mothers tend to develop the narratives to a greater extent than the fathers. In the next paragraph, I show that mothers create two kinds of “illness-parenthood narratives.”

6. The Mothers’ “Illness-Parenthood Narrative”

The way mothers interpret the meaning of autism and parenthood is related to the public opinion of autism. Mothers create a “narrative of acceptance” and a “narrative of progress” as response to two negative social discourses against autism respectively.

A “narrative of acceptance” is to accept that the children have autism, and to think the children need special medical and educational resources. Because there is no evidence of disability in an autistic child's physical appearance, their mothers have always considered them as “normal.” When mothers discover that their children are “abnormal” and “have autism,” the news is shocking. Due to the pressure of the “golden period” of therapy, mothers of autistic children have no time to waste. Many mothers adopt a “narrative of acceptance”; consequently, they accept the children’s illness as well as their identity as a mother of an autistic child. They also emphasize the importance of not caring about what other people think. For example, when mothers discuss how they explain their child’s autism to others, they said:

You don't have to think too much. As long as you accept the way your child is, you aren't afraid of others' opinions.¹¹

When we really accept our children, what relatives and friends think no longer matters.¹²

Moreover, when mothers adopt a “narrative of acceptance,” this does not mean they passively accept medical explanations. Rather, they actively create this narrative to struggle against the social discourse of “autism is NOT a disease.”

It is important to note that the mothers encounter this kind of discourse not only in the public sphere, but also within their families. The grandparents often do not believe that the children have autism and need to seek treatment, especially the paternal grandparents. In some families, the children’s father also doubts the diagnosis. In these families, the mothers are the primary caregivers; they try to persuade their husbands to accept the children’s illness and explain their need for special resources, however, this often does not work. These mothers feel frustrated and have no choice but to stick to a “narrative of acceptance.”

However, autistic children are not in the “sick role” in the short-term. The disability of the children may be long-term, and the challenge in illness and parenting for the mothers exist on a daily basis. How do the mothers interpret their motherhood, and motivate themselves to continue? They create the second “illness-parenthood” narrative, a “narrative of progress.”

A “narrative of progress” follows a “narrative of acceptance”; the former is against the discourse of “autism IS a serious disease.” As the children grow up, the gap between the development

of autistic children and their peers is more evident, and others may doubt the ability of the autistic children. The mothers use a “narrative of progress” to argue that the development of their children does fall behind, but they can catch up with their peers. While a “narrative of progress” admits the children’s disability, it emphasizes that the disability is not permanent. As quoted by various mothers:

My child is 2.5 years old, and he was recently diagnosed with autism. But I think he keeps progressing. When he bumps into his head, he can say “never mind” or just say “ohh,” which makes me see endless hope [for my son].¹³

My husband and I see a little hope for my child. He is receiving treatment now. I believe he will progress more and more, and catch up the level of other children.¹⁴

The mothers with a “narrative of progress” believe their children are likely to grow out of the symptoms of autism with their help. Hope of progress enables parents to devote themselves to their children without feeling any regret. One mother explained:

The reason why I left my job without pay was to “avoid any regret.” As long as I have tried my best to help [my child], I will feel relieved no matter the outcome, and I won’t feel that I owe her. However, if I don’t help her as much as I can, I will definitely regret it in the future.¹⁵

As some children with autism are considered to have better outcomes than other children with disabilities, mothers of autistic children are more likely to develop a “narrative of progress.” However, endless hope also comes with frustration. Ming’s mother commented that the development of autistic children is like a bottomless pit, because you never know their limit. Sometimes it makes her feel very frustrated; she believes that it may be easier to care for a child with intellectual disabilities.

On the other hand, a “narrative of progress” emphasizes the strength of the children. Some mothers are proud of their children’s talents, like their ability to swim or play a musical instrument, and some value the kind-hearted nature of their children despite their lack of social skills. For some high-functioning autistic patients, the boundaries of normality and abnormality are blurred, and the mothers may challenge these boundaries. For example, one mother with an autistic son wrote the following on her blog: “I like my child’s stubbornness. If his stubbornness is not harmful to his health and doesn’t break any laws, I don’t think he should be the same as others.”¹⁶

Moreover, some mothers view autism as a special gift. Ming's mother said the experience of taking care of Ming makes her a better mother. Andy's mother, a Christian, also considered Andy as one of God's treasures. Through this narrative, autism is reinterpreted in a positive way.

The reasons why mothers create these narratives is to defend themselves against the negative social discourses of autism, and to look for meaning in order to continue to face life's daily challenges. Most of the mothers' narratives mention the "narrative of acceptance" and "narrative of progress." These two kinds of narratives are not exclusive, but they are often mixed together. The mothers choose one or both of them depending on what kinds of social discourses they encounter.

Moreover, this is not to say that fathers lack an "illness-parenthood narrative"; rather, they may create other narratives. For example, Andy's father knows Andy's symptoms of autism well, but he said he did not really "believe" Andy had autism till now. If Andy's father was the main caregiver, without a "narrative of acceptance," he may not be motivated to deal with Andy's autism.

The "illness-parenthood narrative" is about parental suffering and love. By adopting a "narrative of acceptance" and "narrative of progress," the mothers of children with autism intend to persuade others that they are responsible mothers. Through the narrative, they explain they were not responsible for the illness, and they are doing their best to seek treatment for the children. Many mothers worry they are "unfit mothers," and the mothers of children the disabilities are more anxious about this. Due to the blurred boundaries of autism, autistic children may be not considered as ill and they may have the opportunity to develop. This places greater pressure and more resources on their mothers, which leads to the construction of an "illness-parenthood narrative." These two narratives help the mothers to prove that they are indeed good mothers.

7. Conclusion

Using narrative analysis, this article examined the effects of gender on experiences, and the meaning of illness and parenthood among autistic children's parents in Taiwan. This article demonstrates that the parents' suffering experience is constructed by the social context, and their experience is gendered. Mothers are the main caregivers and suffer from more social discourses against autism. In order to support themselves and justify their motherhood, the mothers develop "narratives of acceptance" and "narratives of progress."

This article deeply investigated the meaning of illness and parenthood among parents of autistic children, and discussed the interaction between experience and the meaning of caregiving. It captured the negative, positive and ambivalent side of caregiving, and highlights the social context of Taiwan, such as family structure, family relationship, and the social discourses against autism. Moreover, the

uniqueness of autism can provide new dimensions for caregiving and gender studies. The finding of this article illustrates that mothers of autistic children not only experience gender inequality with regards to caring responsibilities; they also tell stories, which leads them to feel empowered and fulfilled.

This article has several limitations that need to be addressed. The narratives of fathers are required in order to analyze the data further. Due to space limitations, this article does not address the issue of social class and the severity of autism. Autism is a special case in social science studies and a neurodevelopment disorder effecting people around the world. Thus, there is a need to further explore the experiences of autistic families.

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Notes

¹ For example, see <http://www.cdc.gov/ncbddd/autism/data.html>.

² The data are from Ministry of the Interior. Retrieved from <http://www.moi.gov.tw/stat/index.aspx>.

³ The data are from Special Education Transmit Net. Retrieved from <http://www.set.edu.tw>.

⁴ Four autistic families were included in this research: Andy's mother and father were interviewed separately, Sam's parents were interviewed at the same time, and I interviewed Ting's and Ming's mother. Andy, Sam, Ting, and Ming are all boys aged 9-18. All the families belong to the middle class.

⁵ <http://www.babyhome.com.tw/>

⁶ A "three-generation family" refers to autistic children and their parents who live with the children's paternal grandparents.

⁷ For example, when we discussed the difficulties of caregiving, Sam's father said that his wife spends more time with Sam, and she has more negative experiences about being with Sam in public.

⁸ For example, a posting written by a father, who is the main caregiver, noted that his wife has serious emotional problems, which prevents her from being able to care of their children. It was posted on 01/2013 on Babyhome.com.

⁹ All of the four families I interviewed mentioned this point.

¹⁰ It was posted on 08/2013 on Babyhome.com.

¹¹ This is quoted from an interview with Andy's mother.

¹² This is a passage from a Facebook group posting on 08/2014.

¹³ This is a passage from a Facebook group posting on 09/2014.

¹⁴ This is a passage from a Babyhome posting on 12/2013.

¹⁵ This is a passage from a Babyhome posting on 7/2012.

¹⁶ <http://helpasperger.blogspot.tw/2014/06/qal.html>

Regional Variation in Policy Implementation Regarding Out-of-Home Care for Children in Japan

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1. Introduction

Japan has the lowest foster care rate of all developed OECD countries. This is usually explained in Western academia with reference to Japanese culture. Kendrick et al (2011, p6) write that ‘traditional views of the family in Japan have led to the predominance of residential over foster care.’ Others, such as Bamba, emphasise tradition and the importance of ‘culturally embedded beliefs and practices’ (2010, p12). Thoburn and Ainsworth (2014) suggest that small houses and concerns over bringing a stranger into the family may be contributing factors.

Recently these ‘Japanese culture’ arguments have been challenged. Goldfarb argues that ‘there are many reasons for contemporary welfare practices, and the notion that Japanese people are unwilling to care for unrelated children is not a central factor... the culturalist explanations for welfare practices... [are] both insufficient and misleading’ (2012, p25). Taking a wider perspective, Kasza argues that ‘culture has minimal explanatory power in relation to Japan’s welfare programs’ (2006, chapter 4). Critically, homogenising cultural explanations cannot explain the regional variation in out-of-home care policy implementation. Japanese ‘cultural’ explanations for the foster care rate would lead us to hypothesise a fairly uniform foster care rate across the country. Indeed in other policy areas involving children, particularly that of compulsory education, policy implementation is highly standardised. The national foster care rate is 14.8 per cent, yet it varies from 5 per cent in Kanazawa City and Sakai City, to 44.3 per cent in Niigata prefecture (MHLW, 2014, p24). The regional variation suggests that, unless the children’s needs vary respectively across regions, the out-of-home care system is not centred on the child, and that there may be a ‘postcode lottery’ issue around equality of service provision.

This paper examines regional variation in policy implementation by examining some case studies of children entering care, as understood by the gatekeepers to the alternative care system.

2. Context

As in other countries, abuse and neglect form the bulk of cases of children entering care in Japan. There are also many cases linked to poverty, with some admitted into care exclusively for this reason.¹ Children entering care come from all backgrounds, but they are disproportionately from families with lower socio-economic statuses, divorces, single parents, young pregnancies,² and those involved in organised crime, hostess work, or the sex trade.

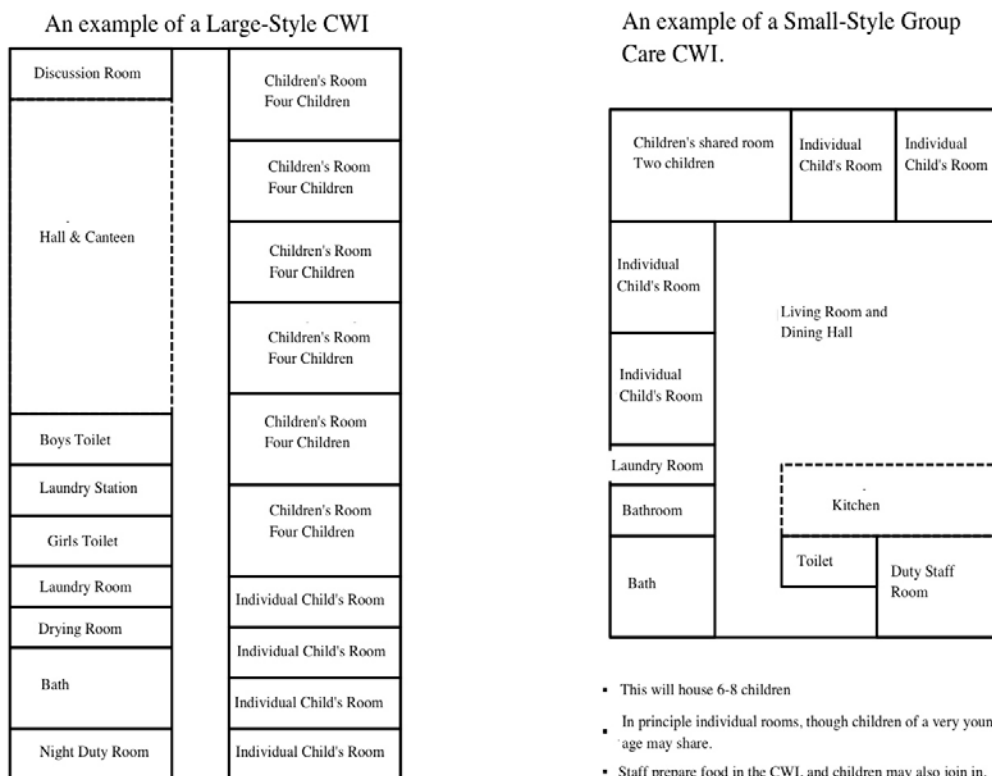
Japan places 19 children per 10,000 children into care. This is half the rate of Italy, the next lowest country (Ainsworth and Thoburn, 2014, p3). 85 per cent of these children enter institutional

care.³ The average size of child welfare institution (CWI) is 50 to 80 children, sometimes in large dormitories with 12 children per room, sometimes in ‘unit’ homes of 6-12 children. More institutions house over 150 children than those that house fewer than 20 children. Babies and infants up to two years old are housed in Baby and Infant Welfare Institutions (BIWI). These average 27 babies and infants, though much larger institutions, including one run by the Japanese Red Cross that houses 70 babies and infants, are not unusual. The institutions are paid a set amount per baby, infant, or child cared for, which has created an incentive for them to keep children in institutional care. The use of BIWIs goes against guidance from the United Nations, World Health Organisation, and the World Bank (Mulheir and Browne, 2007; UNICEF & World Bank, 2003, p9-10, p31-32; WHO, 2010).

Figure 1: Examples of Different Institutional Care in Japan (MHLW, 2012, p8) translated

(参考) Types of CWI

Translated from the original



- This will house over 20 children
- In principle shared rooms, though older children may have individual rooms
- Food is prepared in the kitchen and eaten in the dining hall.

- This will house 6-8 children
- In principle individual rooms, though children of a very young age may share.
- Staff prepare food in the CWI, and children may also join in.

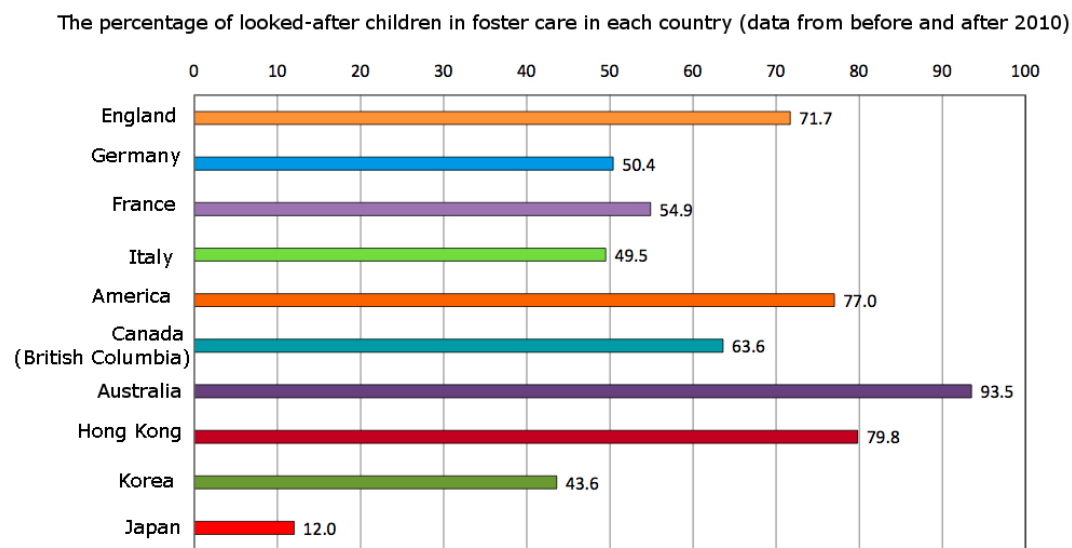
There are three kinds of foster care in Japan: kinship foster care, fostering with a view to adopt, and foster care, which has a subcategory of specialist foster care. In addition to this, the Ministry of Health, Labour and Welfare (MHLW) recently created a new category of foster care called ‘family homes.’ These are run by a foster ‘couple’ with one additional helper, and care for up to six children. Some of these homes are run by experienced foster carers, often supported by a natal

child, others are run by ex staff from institutions, who are not in a relationship and hire multiple part time carers. The UN guidelines for alternative care of children, article 29 c (iii), states that fostering occurs ‘in the domestic environment of a family’ (2010). Under this definition, some family homes would be considered foster care, others would not.

Figure 2: Foster Care Rates in Other Countries (MHLW, 2013, p23) translated

(Reference) Foster care rates in other countries

○ As systems are different it is not possible to compare easily and directly. However, Japan’s residential care to foster care rate of 9:1, in comparison with the foster care rate of over 50% (approximately) in the majority of major Western countries shows the high dependence on institutions in Japan.



※ The principal investigator of the study 'International comparative study of foster care rates in looked-after children' was Kaihara Hisayo of Tokyo Seitoku University's Faculty of Children. (Research as part of the 2011 Health Sciences Research study 'The characteristics of standard care packages of children in social style care: A study of treatment support mechanisms of the foster carers of abused children in private homes.'

※ The Japanese foster care rate of 12.0% is from March 2011.

※ The concept of 'foster care' is understood differently in different countries

MHLW 2013 March *shakaiteki yougo no genjyou ni tsuite (sankoushiryou)* p23

Japan recognises its outlier status regarding foster care rate, as demonstrated by figure two, which is taken from an MHLW report. The Japanese government has taken steps to increase foster care rates by setting a target of having one-third of children in care in foster care, including family homes, by 2029. It has also set a target of having one-third of children in group homes (smaller residential care), and one-third in institutional care of no more than 45 children. There has been little practical advice from the MHLW on how to achieve these targets, though one MHLW report highlighted the work of Oita prefecture and Fukuoka city, which have both increased their foster care rates, as potentially replicable models. The MHLW has asked each prefecture and designated city to create a 5-15 year plan by 2015 (MHLW, 2014, p58). The delegation of responsibility for creating and implementing policy change to local authorities contributes to regional variation. Proactive authorities have significant space to create and implement new policies and practices. Conversely, authorities that do not wish to change face minimal pressure to do so.

The MHLW has created a new role within BIWI and CWI, a foster care specialist worker. This person has to support foster carers, promote foster care, and identify children in the institution

who can be moved to foster care. Each institution is paid five to six million yen per year for providing this service. The MHLW's plans suggest a new role for BIWI and CWI as a local hub for care support, though funding incentives do not support this vision, and no training has been created for the institutions' staff on how to provide this service. Of the fifteen specialists I have met, two are pro-actively creating their own job role. One is supporting foster carers in her area, and the other is facilitating placement changes of babies and infants into foster care. The first one has a director who does not micromanage, which gives her space to be proactive; the second has a director who believes that foster care is better for this age group. In their own words, the other specialists have no clear idea of what they should be doing, or how they should be doing it.

The final change the MHLW has introduced is a small policy amendment shortly after the 2011 earthquake and tsunami, which saw full foster care payments being extended to uncles and aunts.⁴ This change was separate from other policy change, and fits into what Campbell terms the 'artifactual' type of policy making, 'in which circumstances... introduce a period of dynamic policy making that includes otherwise unpredictable welfare initiatives' (cited in Kasza, 2006, p152).

3. Methodology

Child welfare laws, policies, and policy guidance are uniform across Japan. The variance in foster care rate suggests that either children's needs, or policy implementation, vary significantly across regions. This research is being conducted at the local authority level, in child guidance centres (CGCs), to investigate how policy is implemented in different regions. The CGC works alongside the prefectural or city hall office to create policy, and is where policy becomes practice.

The CGCs in Japan operate as gatekeepers to the care system. The term gatekeeping 'refers to systematic assessment with the goal of matching services to individual needs' (Gudbrandsson 2004, p15). In reality, many countries struggle with the 'systematic assessment' aspect of this and Japan is no different. There is very little evidence⁵ on which to base placement decisions in Japan. This increases the importance of how each individual CGC, and indeed caseworker, understands foster care and institutional care.

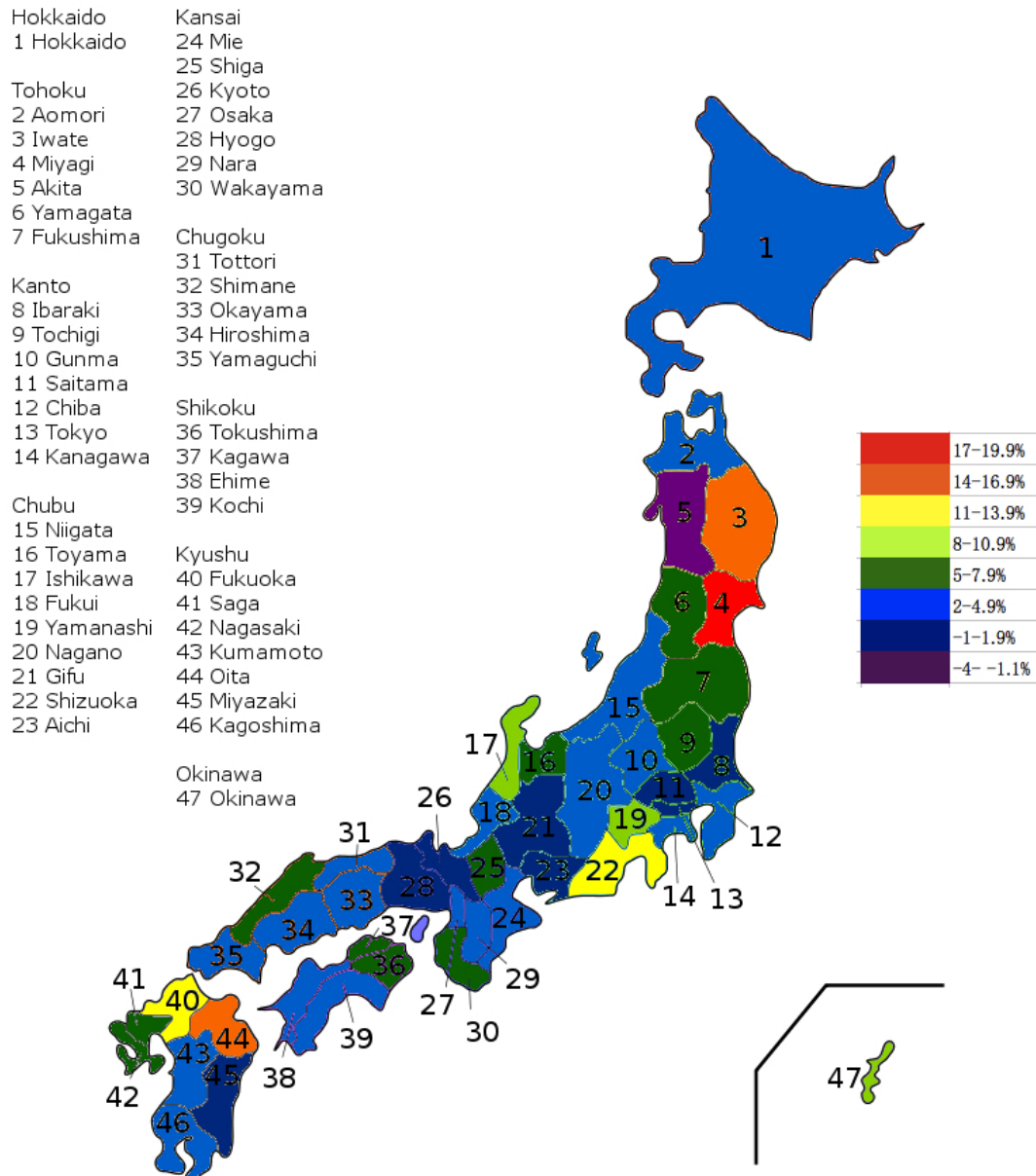
Initially CGCs were set up in every prefecture and major city to provide temporary accommodation and care for children in need following the Pacific War (Goodman, 2000, p35-6). Their role has become more complex over time, and they now provide services that in the US are provided by eight different bodies; child protection service, children's advocacy centre, juvenile court, children's hospital, community health centre, board of mental retardation / developmental difficulties, board of education, child guidance clinic (Tsuzaki 2009, p169). Despite this array of services, and in line with public servants in other areas, the majority of staff and managers are rotated between other public offices on average every three years (Goodman 2000, p37), though there is regional variation in this.⁶ Each caseworker has an average of 107 new cases per year (Goldfarb, 2012, p102, footnote). There is regional variation with caseload but initial analysis suggests no correlation to foster care rate.

To understand changes in the alternative care system, I am using Pierson's later work on path dependency. This couples the concept with gradual change, as opposed to critical junctures (2004, p82-91). Path dependency states that the further an institution progresses down a path the larger the costs of exiting it become. Large set up costs, the increasing effectiveness that comes with learning, increased coordination, and adaptive expectations (Pierson 2000, p254) can result in a system that is highly resistant to change. Where multiple systems interlock path dependency is strengthened (Pierson 2000, p255).

The alternative care system is built around BIWIs and CWIs. With no structural changes, a new role has been placed on CGCs: to provide a significant quantity of foster care with sufficient support. With out-of-home care, the CGCs effectively act as service regulators for institutional care, and service providers for foster care. The MHLW is investigating this 'service versus provider' issue in a research committee, and is seeking to learn from best policy and practice from abroad.⁷ Staff have limited training for this foster provider role; indeed, around half of the caseworkers have no social welfare or social work training at all.⁸

There are 47 prefecture and large municipalities, 20 cities with designated status, and 2 additional cities that run their own CGCs. Figure three shows the change in foster care rates between 2005 and 2011 for the 47 prefectures. All of these 69 local authorities (LAs) operate in a slightly different context, in terms of the needs of the children entering care, and perhaps more significantly in terms of the quality and quantity of current institutional care facilities.

Figure 3: Percentage change between 2005 and 2011 in the percentage of looked-after children that each prefecture places into foster care (Data from MHLW, 2014)



Despite their critical role in the child welfare system, this is the first research to be conducted into policy implementation in CGCs. It is the first research of any kind using ethnographic research methods involving CGCs. There is nothing published in English or Japanese about regional variation in the alternative care system for children in Japan and the ‘postcode lottery’ concept has been entirely absent from debates in this field.⁹ This research will be based on fieldwork conducted in CGCs in three research sites: one with a high foster care that has seen high growth in its foster care rate in recent years where I have conducted six months of fieldwork, one with medium foster care rate that has seen medium growth where I will soon begin two months of fieldwork, and one with low foster care rate that has seen low growth in foster care where I have conducted two and a

half months of fieldwork. Places names have been randomly generated. This paper is drawn from experiences in the first two research sites.

4. Taniko City and Ishizan Prefecture

Taniko city has seen considerable growth in foster care rates over the last ten years, and now has one of the highest rates of any LA. There is one CGC in the city, three CWI, with a total capacity of 274, and two BIWI, with a total capacity of 65. The temporary care institution can care for 40 children. The CGC serves a child population of around 250,000, and places around the national average rate of children into care. Ishizan Prefecture has a low foster care rate, and has only seen a small incremental increase over the last ten years. There are two CGCs in the prefecture, and research was carried out in the larger of these. There are eleven CWI, with a total capacity of 570 children (though the prefectural office has limited this to 546 children), and one BIWI with a capacity of 40 (limited to 39 by the prefectural office). The temporary care facility can care for 24 children though the CGC limits this to 12-14 in order to provide higher quality care. The second CGC's temporary care can care for 10 children, and is limited internally to 8. The two CGCs cover a child population of around 400,000, and place a little over the national average rate of children into care.

Table 1: Summary of the CGC and the area they are located in

	Taniko City	Ishizan Prefecture
Child Population	250,000	400,000
Children in Care per 10,000	18	23
CGC	1	2
Foster Care caseworkers	6	2 + 1
CWI	3	11
CWI capacity	274	570 (546)
BIWI	2	1
BIWI capacity	65	40 (39)
Temporary Care Capacity	40	24 (12) + 10 (8)

These figures do not include other institutions such as for those who have left school, have issues with the law and are below the age of consent, or those requiring therapeutic residential care with a greater focus on mental or physical health issues. Looking at data on why children entered care, the background of children entering care appears to be broadly similar between the two areas.

The organisation of foster care support is quite distinct between the two CGCs. In Taniko there is one mid-level manager in charge of a team of five social workers who work exclusively on foster care. They are responsible for recruiting, training, and certifying foster carers, as well as assessment and support work post placement, and take the lead in matching children with foster carers. There are five banks of desks in this CGC, who directly work with children potentially in need of out-of-home care. Each bank of desks has 9-11 social workers. Three banks of desks work

on cases divided by area. The fourth bank works exclusively on emergency response to abuse claims and includes the first lawyer to be working full time at a CGC in the country. Less serious reports of abuse are initially outsourced to an NPO, who refer them back to the centre where appropriate. The final bank of desks includes the six staff responsible for foster carers, and two staff members responsible for the institutional facilities. Each foster care social worker works with between ten and twenty families. If a child comes in via an emergency response to abuse, the case is initially handled by the emergency desk, before being passed to a caseworker based on area, supported by a foster care or institutional care social worker when relevant. Taniko has a well-developed NPO network that has worked closely with the CGC for over a decade. This network, coupled with a large and active foster care association, provides alternative sources of support for the CGC and children in foster care. Three of the key senior management have been at the CGC for 33, 18, and 13 years.

In Ishizan there are three banks of social workers that work with children potentially needing out-of-home care. Each bank has around nine social workers. Two of the banks are made up of social workers, each responsible for an area. These social workers are also assigned one institution each to supervise. The third provides support staff, and the caseworkers for foster care, family homes, BIWI and institutions for children with disabilities. There are two foster care caseworkers, one full time public bureaucrat, who is also responsible for the mental health of all the children in care, and one is a first year staff member on an annual contract. The CGCs in Ishizan are a part of larger support centres. These work with children, women, and people with mental or physical disabilities. The centres deal with more consultations relating to children with disabilities than they do with children in need of out-of-home care. Two of the senior management have significant experience in CGCs (one for over a decade). The CGC I did fieldwork in is in an area that does not have a relevant NPO of any significant size or capability. They recently outsourced foster carer recruitment and training to a local welfare group that also runs a BIWI and a CWI. The social workers are aware of the conflict of interest there, in outsourcing recruitment and training of an alternative care provider to the institutions to the institutions, but at the time they saw limited alternative service providers. The outsourcing of foster care service provision to institutional care facilities is not unusual: In 2013 33 CWI and 12 BIWI were running some foster care services (MHLW, 2014, p34)

Both areas are operating with tight budgets where national political pressure means that it is hard to increase the numbers of public bureaucrats. Taniko has managed to do this to a degree, in part due to a windfall from the privatisation of public nurseries, and has reallocated money within the centre to prioritise foster care. There are concerns within the Taniko CGC about the potential of approaching a capacity ceiling in providing good quality, supported foster care. In both centres the staff have sought creative solutions to the problem of being the provider of foster care. In outsourcing part of the foster care process to an institution there is a danger that Ishizan is starting to lose the ability to shape what foster care is. At a recent recruitment event, the director of the

welfare institution group that now recruits and trains foster carers stated that ‘one third of children in out-of-home care have no way of going back to their natal parents. The foster care system is for these children.’ This long-term fostering is different from the CGC’s broader understanding of foster care and demonstrates how constructions of what foster carer is are being contested.

The Ishizan CGC also expressed concerns about losing capacity to do effective matching, as they will become more removed from the recruitment and training which had provided a good opportunity to get to know new foster carers. The CGC turning to an institution to support foster care is indicative of a vacuum in foster care provision that the MHLW has yet to address. There are two NPO foster care service providers in Japan with the capacity to provide a significant scale of service: *Key Assets Japan*, which is a part of the Core Assets group, and *SOS kodomo no mura*, which is part of the SOS Children’s Villages.¹⁰ These two organisations are, as yet, providing only a very small percentage of foster care services in the country.

5. A Child Entering Care

The organisation of meetings from a child first coming to the attention of the CGC to the child being placed into care varies slightly between my research sites. In both CGCs there is an immediate meeting for individual abuse cases only when it is deemed potentially serious enough for an emergency removal. These meetings are attended by the caseworker(s) in question and senior management, and are relatively short, determining what is known, what needs to be known, the course of action and who will take it.

Next comes the *juri kaigi*, a meeting in which all the cases that the centre has dealt with that week are discussed. In Taniko this meeting is held once a week. It lasts about two and a half hours and everyone attends. Caseworkers leave after they have presented all their cases. The supervising caseworker provides a summary of each case, their initial course of action, and who will be involved in the case. There are internal protocols for different types of cases requiring particular divisions of the CGC to be involved. The senior and middle management sit through all these cases, and often question the caseworker, and sometimes challenge or change the suggested course of action. Through these questions and challenges, over time the caseworkers start to adjust their suggested plans. Temporary care staff comment on the case where the child has already been taken into temporary care. More time is spent on more complex cases. Taniko also holds weekly meetings to report on the current situation of every child in temporary care. In Ishizan the *juri kaigi* are held more frequently and follow a similar format. Here only the caseworkers directly involved in each meeting attend. The senior management, particularly one manager who has over ten years of experience in CGC in his career, also ask questions. In general, the meetings are shorter in Ishizan than Taniko, with a time limit of 3 minutes set for the caseworker to present their information, followed by the one minute for the psychologists and the temporary care staff respectively.

The *juri kaigi* results in an initial care direction. There is variation between area, caseworker, and even case, regarding how much is decided at this stage. A short case study, of one of the more

detailed cases from Taniko, gives insight into how this decision-making process begins.

A 19 year-old lady comes to the CGC. She is working in 'delivery health', a part of the sex trade, and wants her child to enter care for 6-12 months to enable her to go to work in a 'soapland' (a brothel), in a different prefecture. She believes this will be safer and will allow her to save 1 million yen. The mother was abused as a child. The child is under two and has thus been placed into a BIWI for temporary care. The mother wants the child back in 6-12 months, and is wary of foster care, preferring a placement in a BIWI. The CGC is concerned about the mother disappearing as they only have one contact number. The caseworker convinced the mother that after 6 months they could start looking for foster care, by stressing the difference between adoption and foster care, and stressing the developmental benefits for the child.

Here a lot of decisions have had to be taken relatively early. The window for gaining parental consent was very limited. Critically, the caseworker got the mother to 'not oppose' the foster care placement. Since the 2011 MHLW foster care guidelines, parental consent has been redefined as a lack of informed opposition rather than as active consent.¹¹

For cases that need continued support the CGCs hold a *hantei kaigi*. This meeting serves as an interim consultation. In Ishizan this is a formal meeting and sets a clear direction for the case, which very often follows that set out in the *juri kaigi*. In Taniko this meeting is much less formal and its purpose is merely to provide a space for the caseworker to express their thoughts and ask for help or advice.

For cases deemed serious enough – for example to consider a child being placed into care, the CGC considering referring a case to court, or to address issues a child in care is having – CGCs have an *Enjo hōshin kaigi*, a care plan meeting. These last a lot longer than the preliminary meetings. Taniko summarises this information on two sides of A4, including details on the chronology of events, a family tree, information on abuse, medical reports, police involvement, caseworker opinions, psychologist's summary, with supplementary information often attached. The form used by Ishizan is one side of A4, with similar categories. More of the managers attend these meetings in Taniko than in Ishizan.

The supervising caseworker presents the facts of the case and the family situation, after which the psychologist gives a report on the child. This provides IQ and any recognised diagnoses (such as autism or ADHD), before touching on behavioural or attachment issues. Staff from the temporary care then provide information on the child, focusing on educational level and development, and on behaviour with other children and with staff. With a baby or infant the caseworker liaises with the BIWI and relays this information. In Taniko, CWI staff also occasionally attended meetings when the child in question is in their care. The caseworker then provides their suggested care-plan, before the floor is opened for questions. Where an institution is the preferred placement the nature of the child's needs and the institutions that would best suit the child are discussed. Children can be placed outside the local authority and Taniko often uses this option. Ishizan currently has one child placed out of the prefecture, in the nationally run institution that cares for children with most complex

needs.

In Ishizan the vast majority of cases follow the initial direction suggested by the caseworker in the *juri kaigi*. In Taniko there is a lot more debate and discussion in these meetings, and fewer cases follow the caseworkers' initially suggested care plan.

I have attended meetings covering over 2,000 children's cases. This paper next presents two case studies in order to understand how the placement decisions are made, what this shows us about the systems and interests that surround these decisions, and how this contributes to regional variation. To protect individual's anonymity, details have been changed and names changed.

6. Yoshi & Hiro

Several years ago one of the Ishizan prefectural CGCs faced two cases in quick succession that the social workers, management, and temporary care workers all describe as involving children displaying very similar behaviours and with very similar needs. One child was placed into foster care, and the other into an institution for children with severe mental health issues.

Yoshi entered care at around 7 years old. He had been locked in a room his whole life, and had seen his younger sister die from malnutrition in the same room. After her death doctors found she had been so hungry that she had eaten her hair. Both children, and the sister to an even more total degree, had been deprived of almost all stimulation. The father stated later that he wanted to 'keep their hearts pure'. The doctor said that it was impossible to say for sure that there had been abuse. He stated that the daughter might have had a pre-existing medical condition that inhibited weight gain. The police investigated and the mother spoke in great detail about what had happened in a way as to distance herself from blame. Ultimately, due to a lack of certainty over apportion of blame and the doctor's report, the police did not arrest or charge either parent.

When Yoshi entered care he had an IQ of around 50 and his mental age was approximately half his age. CGC staff said that he spoke 'like a robot' with no emotion and repeated words and phrases. Lack of exercise had stunted his growth and his teeth were all rotten. After a period in hospital to treat him for undiagnosed but suspected attachment disorder, Yoshi was placed in an institution for children with special developmental needs. The CGC wanted to see how he developed there, to see if the environment made a significant improvement to his state. They believed that this would show that his condition was in part the result of his environment and not just the result of pre-existing medical issues. If this was indeed the case, the CGC planned to move Yoshi to foster care if possible. Yoshi's IQ has increased by over 30 points in a few years, demonstrating in their eyes that his initially low IQ was due to his environment and not a pre-existing condition. Despite this, the CGC is wary about moving him to foster care as doing so requires parental consent.

The lack of a police charge meant that the CGC placed Yoshi into care on the grounds of his developmental issues, not abuse.¹² Parental consent meant that Yoshi was not removed through the court, though this would have only given the CGC the power to keep him from home for up to two years. The mother, now divorced, holds sole parental rights. Police believe that the father controlled

her to a degree. The CGC does not doubt this, but said that she has not expressed regret or remorse, and spoke instead about how it was good she could now finish her education and learn to drive. The mother, who is now in a new relationship in a new town, has recently started asking for Yoshi to be returned home. Legally, the CGC has to comply once she can demonstrate that her current environment is suitable for the child. The CGC fears that any attempt to move Yoshi to foster care would catalyse his mother to remove him from care altogether. The CGC is thus forced into a holding pattern to try to maintain the status quo, as they believe this is in the best interest of the child given the situation.

Hiro also entered care around the age of 7, a few months after Yoshi. There is less evidence of what abuse he suffered, though it is clear he was locked in a room without any stimulation for a significant period, or periods, of time. His mother remarried when Hiro was young. The stepfather adopted Hiro. Hiro had had his left thighbone broken whilst at home. When Hiro was taken into care he had the mental age of a 1 year old and an IQ of just over 40. His teeth were all rotten and he was indiscriminately affectionate with all adults. Like Yoshi, Hiro came across 'robot-like, alien-like' and staff noted other behavioural similarities. Despite there being less evidence of precisely what had occurred, as the parents said as little as they could, the doctor ruled that the issues with Hiro were the result of environment rather than pre-existing medical conditions, and formally diagnosed Hiro with attachment disorder. He underwent the same treatment in hospital for this as Yoshi had.

The emphasis placed by the doctor on the impact of the environment on Hiro led one caseworker to suggest trying a family environment, to see how this impacted on his condition. After just a little over three years in foster care the CGC caseworker described Hiro as 'a normal kid' and stated that though 'child specialists like those working here may be able to notice he is a little different, to the average person who meets him now, he just seems like a normal kid.' The mother and step/adoptive father are living with their new children. They still hold parental rights for Hiro but have given no indication of wanting to remove him from care. The two cases are summarised in Table two.

Table 2: A summary of the two cases

	Yoshi	Hiro
Gender	Male	Male
Age entered care	7	7
Abuse history	Extreme and sustained lack of stimulation, neglect, locked inside a room, witnessed sister starved to death, stunted growth, rotten teeth	Lack of stimulation for period(s?), neglect, broken thighbone, stunted growth, rotten teeth
CGC notes	IQ around 50 Spoke 'like a robot'	IQ just over 40 Spoke 'like a robot, like an alien'
Family History	Natal Parents	Mother remarried when Hiro was an infant. Step-father adopted Hiro
Doctors assessment	Yoshi's condition and younger sister's death from malnutrition may be result of pre-existing condition not environment	Issues are the result of environment, not pre-existing condition. Diagnosis of attachment disorder
Police involvement	Investigation but no charge. Believe father more responsible	None
Medical treatment	Treated in hospital for attachment disorder – no formal diagnosis	Treated in hospital for attachment disorder – had formal diagnosis
Given reason for placement	Developmental issues	Abuse
Court involvement	None	None
Foster carer availability	Unclear	Yes
Case worker's decision	Specialist institution, consider move to foster care later	Foster care
Placement	Specialist institution	Foster care
Parental consent	Yes	Yes
Development post placement	Substantial. IQ has increased by about 30 points in 3-4 years	Very substantial. Hiro is now described as 'like a normal kid'
Parental rights	Mother	Mother & step/adoptive father
Current state of parental involvement	Parents divorced. Mother in new relationship and asking for Yoshi to be returned	Living with new children from their relationship. Not asking for Hiro to be returned
CGC's ideal course of action	Move Yoshi to long-term foster care. Do not return to mother	Keep Hiro with his foster carers long term. Do not return home
CGC's pragmatic best course of action	Leave Yoshi in the institution and hope that the mother does not push for his return	Keep Hiro with his foster carers and hope that parents remain disinterested

7. Discussion and Analysis

The outline of the cases given above shows the importance of the respective doctors' decisions on the different placement types made. The individual caseworker's belief that a problem caused by environmental issues could best be treated with a better environment is also central to understanding why the placements varied, but what do these two cases show us about gatekeepers' decision processes, and the impact this has on regional variation of foster care rates around the country? Two key themes emerge from the analysis of these cases; how CGCs understand and manage risk, and how CGCs create and comply with expectations around role performance. How these concepts are understood varies across regions, and this contributes to regional variation in

policy implementation.

All placements into care are to some degree a gamble. Not placing a child into care is also a risk. The 'systematic assessment' (Gudbrandsson, 2004, p15) aspect of gatekeeping is not a science, and how risk is understood and managed by gatekeepers is central to how they conduct this assessment. The basic standpoint for the Ishizan CGC is that institutional care is more of a known quantity than foster care. Caseworkers are familiar with the different institutions, the staff members, and the children in the institutions. Whilst the CWI may not offer the best possible care, it is generally considered to be safe and stable. Where abuse in a specific institution occurs, the CGC can stop placing children into that CWI for a period and use other CWIs. Foster care is much less of a known quantity, and as such, is perceived as more risky. A placement into foster care is seen as having the potential to go much better than a placement into a CWI, but also as having the potential to go much worse.

The relationship between the CGC and foster carers in Taniko is very different from Ishizan. In Taniko there are six caseworkers who work solely on foster care. The CGC has a very close relationship with the foster care association and the head of the CGC personally interviews all foster carers before they are registered. Senior managers and all the foster care staff know a lot of the foster carers personally through attending foster care association meetings and NPO events. In Ishizan the two foster care workers are the only people who know the foster carers. The foster care association has almost no relationship with the foster carers and refuses to host foster care salons as they sometimes led to arguments. The foster carers have set up their own smaller local organisations to fill this vacuum. The new organisations are indirectly connected to the CGC through a CWI foster care specialist worker. The vast majority of caseworkers have no clear idea of who the vast majority of the foster carers are.

In Ishizan a caseworker will sometimes come and ask the main foster care caseworker if there is a family available for a child they are working with, and often be told that there isn't. This is resolved before any placement decision meetings have taken place. In Taniko the discussion happens in meetings, and the different potential foster carers are discussed by staff who have met them and know them to a degree. There are still often cases where foster care would be the preferential placement, but there are no suitable foster carers. This discussion serves to reduce the individual caseworker's feeling of responsibility for taking the risk of placing a child into foster care. Where these discussions happen in front of other caseworkers, as in Taniko's *juri kaigi*, it also serves to educate other caseworkers about when foster care is to be preferred.

The importance of risk is compounded by the gravity of what is at stake. A child's future depends on the decision of the CGC. How the CGC as a whole understands this risk varies by region. Some CGCs appear to consider the risk of inaction, of simply doing what has always been done and using an institution, to be bigger than the risk of inaction. Here individual leaders can shape frameworks, as can particular events. Where there has been abuse, or a death in care, the CGC becomes more wary of this type of care. Where abuse occurs in the institution the CGC is one degree

removed from it, the staff and head of the institution are held accountable.¹³ Where abuse occurs in foster care the CGC is directly responsible. It has recruited, trained, and trusted the foster carer with a child, as well as being responsible for the support and ongoing assessment. In outsourcing practical responsibility for care provision to an institution, the CGC also outsources moral responsibility.

The outsourcing of responsibility can be seen most clearly in Tokyo. An infant placed into foster care died, and it was strongly suspected that the foster carer was responsible for the death. The natal parent successfully sued the Tokyo metropolitan government for placing her child into an unsafe environment, and the CGCs came under intense focus for their failings. Since this case, and uniquely in Japan, all children under one year old in Tokyo are now placed into BIWIs. There are deaths every year in BIWIs nationwide, usually from natural causes. Responsibility for the cases that are not unpreventable natural deaths is, in practice, laid at the BIWI's door, not the CGCs. Conversely, in other areas some CGC heads are extremely concerned about research showing the detrimental effect of institutionalising 0-3 year olds, and thus see institutional placements at this age as carrying greater risk than a placement into foster care.

The availability of foster care is often the first reason given in Japan in explaining the low foster care rate. Hiro could be placed into foster care only because at that moment his current foster carers were available. Availability can be broken down into quantity and quality. The quantity of foster care depends on both historical use of foster care and the CGCs determination to recruit. Niigata, which has the highest foster care rate in Japan, has traditionally had a very high foster care rate, particularly of kinship foster carers. It also has very few CWI. Excluding Tohoku, which the MHLW considers separately from other regions due to the massive impact of the 2011 earthquake and tsunami, Fukuoka City has increased foster care the most in the last decade, moving from 6.9 per cent in 2004 to 31.5 per cent in 2012 (MHLW, 2014, p25).

In Taniko there was a critical juncture just over a decade ago when the CWIs were nearly full, and a policy decision was made to allocate resources to promote foster care rather than building or taking on another institution. The head of the CGC said that one of the central reasons that this has been successful so far was a concerted decision to focus on recruitment, and the dedicating of resources to this task. Ishizan has never had a point where the CWIs in their area were nearly full, and felt that this lack of stimulus was one reason why this promotion of foster care has not historically been on their agenda. I will examine the relationship between foster care rates and capacity of institutional provision in each region in a separate paper.

Areas that have significantly increased foster care rates serve to demonstrate that whilst the availability of foster carers does vary by region this is not a fixed commodity. Local policy planning and budgeting has a great impact on availability, which in turn contributes to regional variation in foster care rates. It seems probable, from the two case studies conducted so far, that supply and demand for places in care mediates this local policy planning process.

The threshold for 'quality' of foster carers also varies considerably by region. The national standards for registering as a foster carer in Japan are very low. Anyone who is healthy, financially

stable, not a known criminal (this is taken on trust and not checked with the police), and completes the short training course, can register as a foster carer. This means that the CGCs have a lot of foster carers registered who they believe they cannot actually place children with. Between 1960 and 2010 60 to 80 per cent of registered foster carers do not have children placed with them (Miwa, forthcoming, p26). This local decision, in the lieu of trusted national standards, creates regional variation in the quality and quantity of trusted foster carers.

The fear of 'what goes on behind closed doors' is a particular concern of government officials who are wary of foster care. Again this, 'quality' issue, is understood differently across different regions. According to Ishizan CGC staff, the foster care family that Hiro was placed with 'live way out in the countryside, and have the support of the whole community. It is the kind of little town where if a kid is being naughty in town other adults will tell them off.' The fact that this family, and indeed community, conform to an idealised traditional image, changed how the CGC assessed the risk of placing a child with them. The foster care family home is more open and transparent than the more typical modern nuclear family household. This serves to reduce CGC fears of abuse within the foster care household. In addition to this, the CGC cannot provide all foster carers with the degree of support that they would like to, and here the CGC believes that the community will take on this role. Different CGCs value different qualities in foster carers, though both Taniko and Ishizan value this type of foster carer highly.

The idea to place Hiro into foster care came from one caseworker, who felt that given that his condition had been caused by his environment, it could perhaps be improved by a better environment. Here, foster care was seen as a better environment for the child, whereas for Yoshi, the specialist institution was seen as being able to offer a more specialist level of care. Yet, if we look at the where the children were when they entered care, there is very little difference between them. There were differences: Hiro's IQ is slightly lower, and Yoshi suffered seeing his sister starve to death, yet the children presented with very similar behaviours, and were indeed treated the same way for attachment disorders.

Caseworkers in both CGCs tried to draw on their experiences, and often spoke of 'types of cases' and children as being similar to previous cases. In Taniko this knowledge is more communal. Wider participation in meetings means that caseworkers learn about more cases, and the management having been in place long-term means that they have more experience to draw upon. In Ishizan caseworkers draw more closely on cases they have been directly involved in. Returning to Yoshi and Hiro, the CGC assesses Hiro's outcomes as significantly better than Yoshi's. The mid-level manager in Ishizan expressed regret that in hindsight, having seen how well Hiro did in foster care, she had not advocated for foster care for Yoshi. She saw the two children as having been of one 'type', and wished she could apply what she had learned from Hiro's case to Yoshi's, which had come earlier. She qualified this by saying that it was 'lucky' how well Hiro and his foster care family had clicked, and that had he been placed into another foster care family he may have been abused. Likewise, she felt that whilst Hiro had developed more than Yoshi had, it was possible that if Yoshi

had been placed in foster care it could have gone very badly and caused further harm to him.

The regret expressed that Yoshi was not placed into foster care demonstrates how the beliefs around foster care can change within a CGC. In explaining the increased foster care rate, the head of the Taniko CGC strongly emphasised the importance of the changing frameworks of how caseworkers think about foster care. He described how caseworkers seeing better than expected results from foster care placements has led them to be more proactive in pressing for foster care placements, both with the natal parents and within planning meetings. Yet in Ishizan, the success of Hiro's placement has been largely attributed to luck with the matching process, and the successful experience has not been 'shared' to caseworkers not directly involved in the case.

The capability of the CGC to provide good quality foster care is also important in how they assess risk, as is the belief that the staff have in their ability to provide this service. Staff in Taniko know that if they place a child into foster care there will be a relatively experienced foster care caseworker attached to the case providing support. There are also NPOs and a strong and active foster care association, with local subgroups, providing alternative sources of support. In addition, the fact that caseworkers are encouraged by the management to attempt foster care placements, serves to reduce the caseworker's feeling of individual responsibility for any future potential problems. In Ishizan the CGC is able to provide less support, and there is also no support from NPOs and minimal support from foster care groups. One foster care specialist worker in a CWI is very active, and the CGC are grateful for the support she is offering foster carers. Workers here are not pushed by management to consider foster care.

The practice framework of different CGCs impacts greatly on how risk is understood and evaluated. The structures of the Taniko CGC facilitate knowledge accumulation and management attitudes promote shared practice learning. The broad participation in meetings helps to create an office environment that facilitates learning. Regional variation in the organisation of the CGC, from the organisation of caseworkers to the organisation of meetings, contributes to regional variation in policy implementation.

In Yoshi's case, the Ishizan CGC faces a further risk, of the mother removing him from care and him returning to a very high-risk environment. This illustrates a fundamental issue that CGCs face in supporting children facing abuse or neglect: how to create expectations for role performance, and what to do when these are not fulfilled.

When placing Yoshi into care, the CGC believed that his parent's would never ask for him to be returned to them. It is possible that the doctor and police believed the same, and with the focus primarily on getting the child into care, this may have contributed to them not stating that what occurred was abuse. The CGC, and perhaps the police, felt bound by the opinions of the 'expert', the high status doctor. The CGC would have found it hard to state abuse was the reason for entering care when the police had been unwilling to state abuse had occurred. Given that the parents consented to the placement, it seemed to make little difference at the time.

When a case is first taken into the CGC they have several potential courses of action. The

cases are initially processed under article 27 of the Child Welfare Act. The first option open to the CGC is to require the guardian to sign an agreement that they won't carry on the behaviour that led the child to be referred to the CGC. This is an agreement under law, however there are no penalties for not complying, aside potentially from the child being removed from the guardian, and no way for the CGC to enforce this contract. This is aimed at shaping parental behaviour. The second course of action is for the family to have continued support and guidance from the CGC, or bodies that the CGC recommends. This can include home help, visits from other government welfare offices, or telephone consultations. The third option is to place the child into the alternative care system, or one of the array of institutions for children with mental or physical disabilities that sit outside the alternative care system. The final option under article 27 is to refer the case to the court for the behaviour of the child to be investigated.

There are three options for a CGC if they take a family to the family court: They can use article 28 of the Child Welfare Act, apply for temporary suspension of parental rights, or apply for parental rights to be cut. Article 28 allows CGCs to place children into care (foster care or institutional care) for up to two years without parental consent. Temporary suspension of parental rights removes all parental rights from the legal guardian, which in Japan are split into different categories (right to determine healthcare, education, etc.), and gives these rights to the head of the relevant CGC. The cutting of parental rights is extraordinarily rare. Between 2003 and 2012 the courts ruled to suspend or cut parental rights in between 7 to 32 cases per year nationwide (Supreme Court, 2012, p3).

The Ishizan CGC suggested that it would be easier to apply pressure on the mother to dissuade her from trying to have Yoshi returned to her if the case had been labelled as abuse rather than as developmental issues. She would have to meet a higher threshold, in the CGC's eyes, for the environment having improved enough for Yoshi to be returned home. Here the temporary nature of this suspension, or enforced placement into care, still suggests that the goal is family reunification, if the family are resolve their issues. In reality many children who enter care under article 28 or suspension of rights will be in care until the age out of the system. The system is structured around guardians 'knowing their place' and conforming to this role of staying away. Where, as is Yoshi's case, the guardian does not comply it is challenging for the CGC to prevent the child being returned to the family.

The fact that the CGC is unable to call on more concrete legal measures indicates the power relationship underpinning child welfare in Japan. One CGC head described the role of the CGC in the child welfare system in the following terms:

Imagine a piece of dough, rolled out flat to cut cookies from. This star cookie cutter is the police. They cut away their role. This circle cutter is the school. They cut away their responsibilities. Then we have cookie cutters for healthcare, institutional care, foster carers, mental health support and so on. The CGC has to take care of all the dough that

is left. Everything that isn't covered in someone else's remit is covered by us.

The CGC has a legal remit, but minimal systems for ensuring others comply with their work. It is not just parents that are given roles in the hope that they choose to conform to them: police, doctors, and schools are all given roles with little ability to ensure that they conform. All citizens have a legal obligation to report suspected abuse,¹⁴ but many doctors still see patients more as customers, and many school teachers are wary of disrupting their relationship with the parents. In a case conference in Taniko, a seven year old with gonorrhoea and chlamydia, diseases that her father also later tested positive for, was taken into care. The management noted that it was unusual for a doctor to report cases like this, and that doctors tend to believe parents, particularly of middle and upper socio-economic status, when they offer more palatable, if medically impossible reasons such as sharing a bath.¹⁵

The CGCs also lack support from the judiciary (Human Rights Watch, 2014). In recent years more cases are being taken to courts under 'article 28' or seeking suspension of parental rights, though these make up a fraction of all cases. Where a parent refuses to allow a child to be placed in care it is very hard for a CGC to force them, unless the abuse or neglect is over a threshold that they believe the local family court will recognise. The Taniko and Ishizan CGCs use family courts very differently. Taniko has a full time lawyer and has found that as it files more cases the courts increase their expertise in this field and are relatively more accommodating though still with local discrepancies between judges. Ishizan refers far fewer cases to the courts. In both CGCs experience, courts are more likely to recognise physical or sexual abuse than neglect or psychological abuse.

The CGC feels that the threshold of abuse needed to get a court ruling is high, and even in extreme cases such as Yoshi or Hiro's, they usually try to work to gain parental consent to prevent having to comply to a court ruling not in their favour. This gives the parents some influence over the placement type. The majority of parents initially prefer institutional care to foster care, as it is seen as less of a threat to their construction of their role as parents.¹⁶ The CGC's primary concern is to ensure that the child can enter care. How far they push for parental consent for foster care, which is at times seen as jeopardising the parental consent for entering care, varies between regions. The case study presented in section five indicates how the attitude towards gaining this consent has changed in Taniko. Here the whole framework of how foster care is understood has changed in the last decade. In Ishizan, where an awareness that perhaps steps should be taken to increase foster care rates has only come in the last few years, and even then largely from a caseworker and mid-management level position, there is less incentive to take the risk of attempting to persuade the parent to agree to foster care at the possible risk of losing the consent for the child entering care.

The result of this lack of legal support results in many cases like Yoshi's, where the CGC does not believe the current placement is still the best option for the child, but they are unwilling to suggest placement change as it risks the child's placement in care. The CGC has to hope that all the other actors conform to the roles the CGC assigns to them. How the CGC manages this, and how

the local external actors understand their role varies between Ishizan and Taniko. This in turn impacts on how policy is implemented.

8. Conclusion

This research, into the least studied part of an understudied system, gives insight into how the alternative childcare system is organised and implemented in Japan. Recent policy aimed at increasing the foster care rate shows a slight move towards policy convergence when Japan is considered in the international context. Yet this policy convergence on an international level is leading to greater policy divergence on a local level in Japan. The two case studies presented in this paper demonstrate some of the reasons why this regional variation in policy implementation is so pronounced in this field.

The two key themes to emerge from the analysis are how risk is understood and managed differently by CGCs in different regions, and how CGCs can influence external actors to perform the roles that the CGC, and legislation, assigns them. There is significant variance between Ishizan and Taniko in how these two discourses are understood, and this contributes significantly to regional variation.

Creating local solutions to local issues has many benefits, but the regional variation in out-of-home care practice suggests that the weakness of central policy and structural issues have led to children entering care via a postcode lottery. The nature and quality of care varies between local authorities, and this variance has a huge impact on the lives of the children who enter care. Whilst in education, concerns about vocal parents keep the national threshold high and uniform, in the alternative care system the children and their guardians are largely without voice. Political consciousness is starting to grow on this issue: Hosono, a presidential candidate for the Democratic Party of Japan, raised the 'serious state of alternative care' during a recent press conference in Tokyo (FCCJ, 2015). The MHLW foster care guidelines (2011) mark a change in attitude in the bureaucracy to alternative care. The publication of a Human Rights Watch report on the state of the alternative care system in 2014 has led to a second transition point, here with regard to political awareness of this issue. It is hoped that this paper will bring an increased awareness of the importance of equal access to care to the debate currently gaining momentum about the quality of care.

Further research is needed into all aspects of the alternative care of children in Japan, with a particular focus on the continued use of baby and infant welfare institutions, the situation of care-leavers, and the mechanisms by which institutions and organisations project power to protect their interest.

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Notes

¹ Placing children into care exclusively due to poverty is considered bad practice by international bodies including the UN, however the reality of the benefits system in Japan, particularly for single parents, means that the CGCs are often left with no choice but to remove the child.

² The youngest case I have seen during my fieldwork is an 11 year old mother with a 13 year old father

³ The percentage of children in institutional care is actually higher than this. The Ministry of Health, Labour, and Welfare figures exclude children in the first phase of care, institutional temporary care, as well as excluding some other institution types that are commonly included in residential care figures worldwide. If we factor in 'temporary' care, where children have been known to stay for two years before being placed into foster or institutional care, the percentage in institutional care rises to approximately 88 per cent.

⁴ Previously uncles and aunts, like grandparents, were registered as kinship foster carers. Kinship foster carers are paid the allowance for the child, but are not paid the personal allowance (72,000 yen per month for the first child, and 36,000 yen per month after this point). Uncles and aunts can now register as foster carers, and thus receive the child allowance and the personal allowance.

⁵ 'There is no data on ... the number of regular adoptions by foster parents of children they had raised from a young age, or data on which adoptions were conducted based on kinship relationships between adopter and adoptee. There are also no breakdowns demarcating special adoption cases of children from children's homes, foster care, or infant adoption, and no separation between adoption cases in which stepparents adopt their spouse's child, and cases in which both parents adopt the child.' (Goldfarb, 2012, p22) See also Goodman and Neary, 'There exists no comprehensive study detailing the life outcomes of care-leavers in Japan' (1996)

⁶ There is a CGC where the caseworkers stay for about 8 years, whilst management rotates every 2-3 years. Data on this is, as far as I am aware, only available by word of mouth.

⁷ As yet, and this may just be something I have not yet found as opposed to it not being discussed, I have not heard of any moves towards creating a third party independent assessment body, such as OFSTED in the UK, to assess these new care providers. The importance of such a body is stressed by, among many, Mulheir and Browne in their WHO report on deinstitutionalisation of care provision (2007).

⁸ There is (at least) one CGC where every single staff member is a specialist in welfare, though this is rare enough that the CGC is famous for this.

⁹ At the 2014 National Foster Carer Association's annual conference the MHLW bureaucrat mentioned briefly that the regional variation may be something the MHLW needs to consider more. This was the first time I have seen or heard this issue commented on, and came a few months after I had met some MHLW bureaucrats and outlined my research to them.

¹⁰ Japan is one of only two countries, the other being Columbia, that has classified the SOS children's village as foster care, rather than as residential care. Some practitioners in Japan do not see this village as foster care.

¹¹ The parents still have to be told about the placement into foster care. Where a child is in institutional care, and the parents have gone missing and are not contactable, the child cannot be moved to foster care. This is true even where the parents have been missing for over a decade.

¹² The CGC does not need a police report to place a child into care under the category of abuse. It seems here that the fact that the police did not charge the parents made it hard for the CGC to do so, that is, had the police not been involved Yoshi would have been placed into care under the category of abuse.

¹³ Though in reality almost nothing is done to those committing abuse, an apology, sometimes temporary suspension, and very occasionally a resignation, is usually the most a CGC can hope for from the member of staff who committed the abuse

¹⁴ This was amended from an obligation to report known abuse to suspected abuse following the 2002 'Kishiwada incident', where a child who was known to a CGC died from abuse.

¹⁵ The head of the Taniko CGC had referred to legal guidelines in the US on the transmission of sexual diseases with regard to STDs being found in children, and noted that doctor's in Japan are not taught the same things as are held to be true in the US.

¹⁶ There are cases where the parent will only grant permission for the child to enter foster care, and

refuse institutional care. These cases are infrequent and all that I have come across so far have been from parents who were themselves in institutional care.