The Superiority of “Individuals” in the German Family Perspective: From the Narratives of Japanese Mothers with Children with Diseases and Disabilities

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Abstract

This article is based on fieldwork in Germany. In particular, the data from a survey about “Eltern Netzwerk Japan” in Berlin, Germany is used. The “Eltern Netzwerk Japan” is attended by many young people who were diagnosed with some kind of disease or disability during childhood, and their families. What kind of daily life do they spend in Berlin? This article uses narratives to introduce how young people living with diseases and disabilities and their families in Germany engage in their lives and activities with others and society.

Keywords
Diseases and Disabilities, Family, Difficulties of Life, Life Stories, Germany

1 Awareness of issues

I have conducted a research study of patients who were diagnosed with any disease or disorder in childhood and their families. The main research subject at present is to describe the life course from “onset” to “present” of patients with Turner syndrome, which affects only female born children and their families through interviews, and then to clarify how to evaluate “until now” and how to talk about “future.”

The “Berlin: Association of Parents of Children with Autism and Developmental Disorders ”, or Eltern Netzwelk Japan, is hosted by a Japanese mother in Berlin, Germany, and many adolescents who have been diagnosed with some sort of disease or disorder in their childhood and their families participate. I wonder what their daily lives are like in Berlin[1]. In this article, I would like to introduce how adolescents living with diseases and disabilities and their families in Germany interact with others and society in their lives and activities using narratives.

2 Why Germany?

This article is based on fieldwork in Germany[2]. I selected Germany because the review of German cases would be instructive in reviewing and translating traditional views of the family in Japan. It can be inferred that this will be particularly pronounced when the environment surrounding diseases and children with disabilities is focused.

In Germany, disability-related laws were prepared after a clause was added to the basic law that “No person shall be permitted to receive disadvantageous treatment due to his/her disability” (Article 3, Paragraph 3, enforced in 1994). It is considered that as a result, the policy of measures for the disabled in Germany significantly changed from “assistance” to “expansion of the right of self-determination.” When the German welfare system is compared with the Japanese welfare system, it is evident that there are many differences. For example, in Japan, there are physical disability certificates, rehabilitation certificates, and mental disability health and welfare certificates as handbooks for different types of disabilities, but in Germany there is no equivalent to these, and only a disability certificate (Schwerbehindertenausweis) is issued. At first glance, it seems that individual support according to disability type is not sufficiently provided, but the background seems to be the idea of providing support to many disabled persons by setting a wide opening. In fact, the proportion of the disabled population in Germany is 10% of the total population[3], which is much higher than that in Japan[4].

The handling of expenses when responding to individual needs is different from that in Japan. For example, if it is recognized that the purchase of an iPad is necessary to meet the needs of a minor child diagnosed with autism, there may be some assistance from local governments to purchase one in Japan. In Germany, however, since being a minor means that it is extremely difficult to do wage labor, iPads are provided free of charge to the minor autistic child. The expenses are covered by long-term care insurance, and the parent's annual income, etc. are not considered.

Under this welfare system, I would like to clarify how mothers and fathers who have children with various diseases and disabilities, as well as persons with disabilities, constitute a group called a family, with reference to the stories of the persons concerned and their mothers.

3 About “Eltern Netzwerk Japan”

It was in February 2019 that I contacted the “Eltern Netzwerk Japan” and first visited them to conduct a survey. In February 2024, after the COVID-19 pandemic, I was able to have that opportunity again[5].

“Eltern Netzwerk Japan” is a flexible network formed in the summer of 2013 in Berlin centered on mothers of autistic children. Members are mostly autistic children and their mothers, but also children and families with other diseases or disabilities. Japanese women play a role as a contact for the association, partly because “An association created from the desire to have a place to talk about raising children and exchange information in Japanese during the daily living in a German-speaking region and having children attend a local school.” Approximately once a month, convenient members meet at a café, etc. in Berlin City within a reasonable scope to discuss various themes, such as support measures, school selection, and Japanese education.

In this article, I would like to introduce the contents of interviews with two Japanese mothers of children with diseases or disabilities who are members of the “Eltern Netzwerk Japan” in Berlin and think about the concept of “family” through their stories.

3.1 Case A

A (in her 40s) is the mother of a child with severe autism. The child is a young man aged 15 (at the time) and currently lives in a group home with social workers (Sozialarbeiter) and other supporters. In other words, the child lives a life completely separated from A.

As described above, in Berlin, Germany, if a child is diagnosed with disability (including one caused by disease), a notification such as “I am the social worker in charge of your child” will be sent from the Child Welfare Division of the ward office. In response, a meeting at the district office is basically conducted, but it is possible to casually request a home visit without sticking to these procedures. In many cases, the child is also present at the first interview to check what type of child the child is.

Social workers are familiar with administrative services related to disabled children, and provide advice in line with specific cases, such as where to contact and consult with when such problems arise. For example, when a family member wants to leave a child with someone, they can provide specific consultation where is appropriate for the situation and circumstances of the child's family.

Through these daily support and interactions with the social worker, A came to want to keep his child in a group home.

> In my case, my son (*Although his real name is mentioned in the narrative, he will be referred to as his son in this article.) has severe autism. So, when I was thinking about how to raise my son, a social worker told me about a group home (during a regular home visit). (*The author “Are you a little surprised?”) Hmm, I remember not being surprised. I did not hear about group homes all of a sudden (I heard from a social worker that group homes exist and that there are such cases.), so I understand that he can “live this way”.
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> ... My son was put into a group home when he was 10 years old. He moved to a totally different place from me and my husband. He lives separately. ... (After hearing that he was 10 years old) You may think it is early. But in Germany, when a child like a son is born, people think about how to become a family with someone other than their mother or father. The reason for this is that when I and my husband become worn out, it bothers me how to raise my son, and it bothers him even more than I do. It is not good that his future will be affected if I and my husband are no longer able to raise my son. ... (If it is in Japan) I wonder some people think that I am not working hard as a parent. It is wonderful to see my husband and I create an environment in which my son is comfortable. However, this is not the case, and looking for an environment or person (with the son or social worker) in which the son himself is likely to experience is another way of interacting as a parent. ... The reality is that I and my family cannot spend time with my son all the time. I

> age and my body deteriorates. After that, looking for a facility may be difficult in reality. ... For the quality of life of our family, the social worker thinks about how we should not blame ourselves for "abandoning the child" by ourselves, who is involved, and how to involve to our son in a considerably detailed manner. ... They said it was strange that parent's responsibilities would change just because they are parents of a child with a disability (Parents of children with disabilities should not have a greater responsibility for raising children than those without disabilities). ....

3.2 Case B

B (in his 40s) is the mother of a child with muscular dystrophy. The child is a young man aged 14 (at the time) who lives with B. B, who is a craft worker, thinks about her child's life while accepting his declining body.

> In the past, I was strong, so I put my son on my back, folded his wheelchair, and climbed stairs at the station. And then, what can you imagine being told by strangers passing by? (The author answered, "you are trying too hard, right?") No. They said, "The fact that a mother holds such a large child will distort the relationship between mother and child, making it impossible for the child to separate from parents. Do not do this." Then, I was thinking of moving up to the elevator, so I put my son in a wheelchair again, and while I was working to rebuild our organization, these stranger women said, "You should show your child in front of him that you are relying on others to help you climb the stairs, instead of walking up the stairs on your back." There was no elevator at that time. These stranger women approached a powerful person passing by and said, "This is what you should do!" ... And then, if you are stay at Berlin Station for even 30 minutes, you will see a stranger carrying my son up the stairs, a friend folding and carrying the wheelchair. I take this for granted (walking up and down for a welcome talk together in this way). Did you see that at the station? ... My son said that people around him help him when he is put in a wheelchair where the disability mark is. When I see not only the skills of a person with a disease or disability to seek help from themselves, but also the skills of people around them to be aware of the person with a disease or disability at a train station, I feel a little relieved that my son will live even if I die. Even in ... (when I compare Japan based on these experiences in Berlin), I think Japan is making real progress. I am not being sarcastic. For wheelchair transportation, where is the elevator, where is the corridor with a slope, and is it a barrier-free map? (* The author "Yes, it is") can be downloaded from the subway website, so there is no need to use (support with) a primitive method like Berlin. But it is difficult ... in the end, that make it possible (for persons with disease or disability) to live alone (there are aspects that are arranged), basically do it with their family or relatives! Of course, (because I used an airplane) CA took care of me a lot! ... Like my son, he cannot ascend the slope with the strength of his arms. This is the hallmark of muscular dystrophy. There is a slope, which is helpful, but I can teach my son to say "Help me (I need your hand because I am sick)," but there are many people in Berlin who respond "I understand," although, Berlin is more primitive. ...

4 Reflecting on interviews with mothers

When I look back on the interviews with A and B, I think that one of the characteristics we can read from their stories is that they have a view of family members that they do not leave the lives of their children with diseases or disabilities to their family members alone.

The idea of "not leaving the life of a child to the family alone" may be derived from the idea that child-rearing is not performed only by the family, but also performed in the community or society in the context of people and their relationships[6].

A's story is as follows: A and her husband have had their child in a group home since he was 10 years old, but this has not separated her family; rather, they are searching for and building an environment and life that are easy for each of them. B's story also showed B's position as an individual higher than B's position as a mother of a child with a disease in the eyes of those around her. In addition, sudden strangers pointed out to her that they were concerned that she would strongly assume the role of "mother of a sick child." And the importance of seeking support from those around her was suggested as a way to deal with it.

5 “Not leaving a child's life solely to the child's family”

Behind the stories of A and B, there seems to be a view of families or people in Germany, where children and parents are regarded and acknowledged as individuals, respectively. In this context, “family” in Germany does not necessarily refer to a household. It would be helpful to understand the German view of family by recognizing family as a group of individuals rather than family = household.

It would be common in Japan for administrative services to be provided to households. In Germany, however, administrative services are not always provided to households. At first glance, it seems that support aimed at family relief is not provided. However, we can think that discussion based on the above stories of A and B may lead to new knowledge.

In other words, when this is positioned in the context of the transition of life stages and the expansion of social space associated with it, it can be interpreted that in Germany, the persons who obtained the disability certificate as a child are expected to live in group homes in the future, and therefore they were given a preparatory period to live with supporters other than family members, for example, unspecified persons who live in the municipality or community from the moment. In this article, I will refer to the activity in Germany where a person with disabilities lives with help from people other than their family members as “family based in community”. It is important to note here that the term “sick and disabled persons living with an unspecified number of people” does not necessarily refer to a restrictive representation of those living in the same province or territory as the sick and disabled persons. We may think that, without being hung up on administrative regions or regions, the relationship that individuals connect with others and build is regarded as “family”.

It is possible to understand that the idea of “family based in community” not only enhances the quality of life of persons with diseases or disabilities, but also enhances the quality of life of the family in the sense that the life of the family is respected as an individual life. For example, in a group home at the edge of Berlin in former East Germany, I was able to get a glimpse of the situation.

5.1 Implementation of group home in former East Germanys

In this group home, there are many young people who have completely left their parents and reside for a long time, like A’s child. This group home is characterized by a variety of considerations and practices that make it possible for disabled children to live with their "community-based families" and to build their autonomy and independence, so that parents and families who have left their children do not feel or feel that they have "abandoned" their children.

In *Markt*[7] (Markt as market in English) hosted by a group home, adolescents living in the group home enjoy a busy weekend, selling potatoes grown together with the local residents, French fries made from the potatoes, and playing music instruments[8].

Many facilities for people with disabilities in Japan also value contact with local residents. However, there are many events planned once a year and once a half year, and there are almost no facilities where, as I encountered in a group home in Berlin, a variety of people gather at the end of each week, which is an opportunity to interact integrated into daily life.

Even in such places, we can see a view of family and human being that is different from that in Japan, and it can be interpreted that, so to speak, “family based in community” has a persistent influence.

6 Instead of summarizing

Reading the two narratives described in this article from the perspective of “family based in community” not only touches on the reality of children and families with diseases and disabilities, but also provides an important viewpoint in considering how parents should live with their children's disabilities and how they should live with their own disabilities.

This is because “family based in community” does not come across as family = household, and in this sense, it also has a function not to cause isolation of the household from the community. I would like to mention this.

At a Marukt sponsored by a group home, a young man presented me with a “platform “ to use when taking things from high places. The young man had severe autism, and the younger adolescent in the same group home reportedly cared for him on a regular basis. He offered me the platform, but I did not know what to make of it, so I was only able to thank him. The young people and people involved in the group home looked at them with a smile and said, “It's a whim.” I was short, and this was especially true in Germany, so I tried to think that I had been given a platform to use as an item to raise my gaze, and the young man who was looking at me became infuriated.

The young man offered me a platform as a “chair.” The young man had no choice but to offer me a platform as I joined for the first time, because some regulars in Markt had fixed chairs that they used daily.

The act of the young man who thought that I, who was shorter than him, was his younger brother seemed to have arisen from his wish to serve someone else. Thus, acceptance of disability may also be done in association with others. This is just based on my experience with adolescents, but it seems to be done only when there is not only “approval from others” that “I want to be recognized for myself even though I have a disability”, but also “approach to others” that “I want to not only receive help but also help others even though I have a disability”. Adolescents have an aspect of being cared for by the author on a daily basis, but their feelings may have meant that their family had come to be new = they wanted to take care of the author. I hope it will be useful for understanding children.

At the end of this paper, new questions are being asked, such as why the idea that child care is not just a family issue is not replaced by community-based care, and why is it expressed using a "family" narrative rather than a human rights logic. These questions are also connected to the question of whether this article is actually reinforcing the Japanese view of the family, which this paper attempts to relativize. I would like to leave this as a future topic.

Notes

1) It is located in the northeast part of Germany, a country considered to be a high-welfare state. It is a city with a population of about 3.6 million.

2) The field work has been ongoing since February 2019. Since the survey started before the COVID-19 pandemic, the field work was done while accepting various changes. In addition, when I visited Germany in February 2024, it was reported that GDP would overtake Japan. Thus, the field work in Germany at the time of conversion was very suggestive.

3) Federal Statistical Office Germany. 2007. Lebenslagen der behinderten Menschen Ergebnis des Mikrozensus 2005. p.1268.

4) These circumstances led to the application and issuance of the above-mentioned Certificate for Persons with Disabilities (Schwerbehindertenausweis). In Germany, unlike in Japan, almost all applicants are issued with disability certificates. Since almost all applicants can receive a certificate for persons with disabilities, a kind of “what type ” is important here. It should be noted, however, that this does not mean that these are subdivided into small categories.

5) Again, this study has been ongoing since February 2019. During the COVID-19 pandemic, I was unable to visit the site, but I have continued to visit the site by communicating with each other.

6) It is conceivable that there may be a difference in the concrete contents of "What and to what extent" between former West Germany and former East Germany, but in general, this is the way of thinking. More detailed differences between former West Germany and former East Germany will be handled as a future issue.

7) Of course, Markt is also held in group homes in former West Germany. However, Markt, a group home in former East Germany, seems to be viewed as a rich and lively event by persons in charge of group homes in former West Germany.

8) As the participants said, in this event, the adolescents and people involved in the group home, the local residents, and the parents and families of the adolescents are also involved, but instead of taking a position of “as a party,” “as a local resident,” or “as a parent/family,” each individual overlaps to create one event.

References

Gabriele Vogt, 2018, Population Aging and International Health-Caregiver Migration to Japan, Springer.

Cabinet Office, 2006, “Summary of International Comparative Surveys on Promotion of Social Participation of Persons with Disabilities, etc.”

Reference URL

Eltern Netzwerk Japan Berlin, Accessed on 2024/12/27　（https://enj-berlin.com）

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【編集後記】『現象と秩序』第 22 号をお届けします．今回も充実の 9mm背表紙です．

第 1 論文は，ろう者の合理的配慮に関する考察であると同時に，多様な人生経歴を歩んできたろう者にかんするライフストーリー研究でもあります．「バケツ事件」，「手話サークル」等々の「小見出し」を見て下さい．それだけでも，筆者のインタビューが相互信頼に基づく充実したものであったことがわかると思います．味読すべき内容が書かれています．

第 2 論文は，日本人が羊羹（色）とどのような「ヒト‐モノ‐概念関係」を歴史文化的に取り結んで来たのかということに関するコーパス研究です．「羊羹色」はくすんでいることに意味があり，その結果「羊羹色」という色表現は「羊羹色に黄ばんで」と時間の経過をも含んで用いられています．本論文は文化研究の可能性を拡げる論文であるといえるでしょう．

第 3 論文は，是非オンライン版をカラーでご覧になってください．「きもち翻訳」がどんな風に「オノマトペ」を利用しているのか，「つむおと（みんなとつむぐ音楽会）」がお寺をどんな風にリラックスした空間に変えているのか，一目でわかると思います．著者の南摩周さんは，新進気鋭の人類学者であると共に文化領域における実践活動家でもあります．彼女の実践がおもしろそうだ，とお感じになったら，どうぞメール連絡をしてみてください．関東でも関西でも活動していらっしゃいます．

スペースが尽きかけています．あとは，1 行ずつの紹介とします．第 4 論文は，身体変工への嫌悪感という新しい切り口からのイレズミ論です．第 5 論文は，「生成 AI のハルシネーション」に関する実験研究です．第 6 論文は，イギリスの障害児者家族に関するフィールドワーク論文です．いずれも，新時代を切り拓く意欲に満ちた本誌らしい論文ですので，どうぞ，読んでの感想を企画編集室にお寄せ下さい．おまちしております．（Y.K.）

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