

Difficulties disabled women in Japan face with regard to love, marriage, and reproduction

Naoko Kawaguchi*

* *Visiting researcher, Research Center for Ars Vivendi, Ritsumeikan University, Kyoto, Japan*

I. Introduction

This paper explores the difficulties faced by disabled women in Japan with regard to love, marriage, and reproduction.

The interviews analysed in this paper were conducted as part of the ongoing research by JSPS KAKENHI (Grants in aid for Scientific Research) on the Intersectional Approach for Structural Discrimination Against Disabled Women from 2016 to 2019.

The KAKENHI research project aims to investigate the overall pictures of the difficulties disabled women face and the intersectionalities in their difficulties, while this paper focused on personal spheres such as sexualities and reproduction.

The sex lives and sexualities of disabled women in Japan are hidden or invisible.

In the interviews, I was barely able to hear the words “sex” and “sexualities” overtly. Disabled women I interviewed intended to talk about their difficulties, not limited to the subjects such as sex lives and sexualities. Then I did not use the words ‘sex’ and ‘sexualities’ in the title of this paper, and this absence itself indicates the current situation of disabled women in Japan.

Nevertheless, I was able to obtain a lot of narratives involving subjects such as ‘love, marriage, and reproduction’. These narratives can provide useful insights regarding the sex lives and sexualities of disabled women in Japan.

II. Theoretical background of the research

II-1. The concept of intersectionality

This research utilises the concept of intersectionality, which means to view the matter as an intersection of gender, ‘race’ and other (age, poverty, disability, etc.) types of discrimination simultaneously; that is, issues are not analysed based only on one ground or separately.

“I began to use the term intersectionality to deal with the fact that many of our social justice problems, like racism and sexism, are often overlapping, creating multiple levels of social injustice.”
TED talk (Crenshaw and Dobson, 2016)

The concept was originated by Kimberle Crenshaw, an African American woman academic and lawyer in 1989 (Crenshaw,1989). Crenshaw tried to explain the case that a judge dismissed Emma DeGraffenreid's lawsuit against an employer who was practicing job discrimination against African American women. No African American women were hired but the court failed to see this double discrimination because African American men and white women were hired.

Crenshaw argued "that Black women can experience discrimination in ways that are both similar to and different from those experienced by white women and Black men" (Crenshaw 1989, p. 149).

Disabled women may face discrimination differently from disabled men or non-disabled women.

II— 2. Current legal system for intersectional discrimination in Japan

Currently, Japan lacks a comprehensive legal framework for addressing multiple/intersectional discriminations. It also lacks affirmative actions to avoid multiple/intersectional discriminations. (Asakura, 2016)

In 2013, an anti-discrimination act for people with disability was enacted in Japan; it was implemented in 2016, though it made no mention of the complexities/ intersectionalities of discrimination.

For gender equality, there is an employment law that prohibits gender discrimination in the workplace; however, there is no comprehensive anti-discrimination act to deal with gender discrimination.

III. The aim and procedure of the research.

A brief explanation of the research project 'Intersectional Approach for Structural Discrimination Against Disabled Women'

(HOMEPAGE <http://www.nabe-labo.jp/wwd/index.html> (2016~2019) is provided as follows.

<Aim>

This research aims to identify discrimination against disabled women not only within the dimensions of 'disability' and 'gender' but also within the interlocking of other positionalities.

At present, not enough data dealing with this have been collected in Japan. Thus, it is necessary to collect data related to disabled women's narratives before identifying any intersectional discriminations.

<Procedure >

This research project employed the 'snowball' sampling method for gathering the informants.

The research members approached potential informants for the research through Disabled People's Organizations, Service Users Groups, and various kinds of networks. Sometimes a woman who had been interviewed would kindly introduce the researchers to another disabled

woman. The researchers tried to find informants across a range of diverse impairments and age groups.

The interviews were conducted from December 2016 to March 2018, and the following steps were taken.

- Ask to fill in a profile sheet. For comparison reasons, some of the questions were taken from the official disability survey of the Japanese government. (Government Official Disability Survey https://www.mhlw.go.jp/toukei/list/seikatsu_chousa_h28.html)

This research tried to grasp not only disabled women's personal perspectives but also the socio-economic situations they faced.

- 2 to 4 researchers per person: Semi-structured interview
- 1 interview that lasted for about 2 to 3 hours

The researchers did not define discrimination or oppression against disabled women in advance.

As a disabled woman, decide what is hard or difficult in your life, what you consider a disadvantage, the points at which you thought that things had become worse, and the experiences that you find painful.

Researchers thus listened to the lived experiences from each disabled woman's perspective.

In KAKENHI Research, the interviews cover a wide range of topics related to disabled women's lives: life history, daily life, and social life (e.g. employment/social activities)

Ask when and how they feel disadvantaged compared to disabled men and non-disabled women.

Up till the present, the research members have interviewed a total of 25 disabled women (as of March 2018).

<Privacy and consent>

Before the interviews, the researchers received written consent from the interviewees. The privacy of interviewees should be protected when disseminating the results of the research. In addition, the interviewees were free to stop participating in the research at any time.

IV. Interview results

In this paper, I have extracted findings from the narratives of 12 disabled women whom I interviewed with regard to love, marriage, and reproduction.

IV-I. The Profiles of the 12 women

*** Impairment**

Main Impairment : Physical: 6 Visual : 2 Mental Health : 4

(Notes: Some of the women have multiple impairments. Besides 4 women with mental health problems, 4 other women had experienced mental health problems at one time in their lives, though

these conditions were not continuous.)

*** Age**

20s: 1 30s: 2 40s: 2 50s: 4 60s: 2 70s: 1

*** Onset of Impairment**

Childhood: 5 10s: 2 20s: 3 30s: 1 50s: 1

*** Employment Status**

General Employment (counted as a legal obligation of disabled people)	4
Sheltered Employment type A (guaranteed above the minimum wage)	1
Sheltered Employment type B (workshop; not guaranteed the minimum wage)	1
Teleworking	2
Other	4

IV—II. Love

• Body norms : Devaluation as a love interest

Disabled women feel that they are devalued as love interests because their bodies are ‘deviant’ compared to ‘normal’ bodies.

Appearance:

Some women with physical disabilities find it difficult to maintain a positive self-image regarding their bodies. A woman with mental health issues felt stressed when she had to maintain a tidy appearance.

‘I think that my appearance is bad.’ (Physical)

‘I think I am ugly. My body did not develop properly as a woman’s body should.’ (Physical)

‘Women receive more criticism and feel damaged than men if they are not clean and decent. I can go out only when I am well-groomed. But it is so hard for me to do so. Men can go out more easily.’ (Mental)

Dressing up or Being fashionable:

Disabled women feel that they are regarded as asexual beings. Thus, their daily circumstances have created barriers to their enjoyment of fashion compared to non-disabled women.

A woman talked about her experience in an institution for the physically disabled.

‘All the clothes were washed with a huge washing machine (like a concrete mixer), so it was

impossible to wash beautiful clothes. I did not want to have my hair cut by the staff of the institution. I went to a good hairdresser when my parents came.’ (Physical)

Another woman said that disabled women tend to give up on being fashionable, and she resisted that.

‘People may feel pity for a woman in pyjamas at a restaurant. People may feel it is a breach of manners for a non-disabled woman to do so. I never want to be looked at with pity. I want to maintain the average level of fashion for my age group.’ (Physical)

Another woman thought that people labelled her as disabled no matter what she wore.

‘Does anything change if I dress up? I thought it was meaningless.’ (Physical)

Denial of femininity and sexual existence

‘When human beings are divided into categories such as men and women, I do not feel I belong to these categories. From my perspective, human beings are categorised into men/women/disabled.’ (Physical)

‘I was never told “You are female. Be ladylike.” Rather, wasn’t I recognized as a woman? I was not treated as a woman.’ (Physical)

‘My parents told me, “You shouldn’t expect love or marriage.”’ (Physical)

Sometimes this denial of the femininity of disabled women intensified the desire for love or marriage, which is traditionally seen as the women’s *raison de’tre*, much more so than the same desire in non-disabled.

‘I wanted to marry even if it would last for only 3 days.’ (Physical)

• Affection, care support, and privacy

Practical problems emerged when disabled women who needed care and support from personal assistants (PAs) thought of love.

When they establish intimate relationships with their partners, finding ways to get appropriate care support will be a crucial matter. Disabled women do not want care support from their partners, but at the same time, they want to maintain their privacy. Disabled women find it difficult to satisfy both these needs.

‘I separated from my boyfriend when my disease worsened, and I started to require consistent care support every day. Our relationship changed, and it became unequal. I could not bear that. I didn’t want to be a burden to him.’ (Physical)

She added that she would have married him if she had not suffered from her disease.

‘I’m opposed to the connecting of affection with care support provision. If you regard care support

as an expression of affection, you will be so exhausted when you quarrel with your boyfriend.’
(Physical)

‘I want to forget my impairment when I am in a romantic relationship. I dream about dating without having to consider the accessibilities of trains or rest rooms.’ (Physical)

‘I never want to be cared for by my boyfriend. I want to have my PAs carry out my care support. Then, how these three persons (me, my boyfriend, and my PA) will be able to stay together . . . I have no idea.’ (Physical)

IV—III. Marriage

*** Marital status**

Single (No experience of marriage): 6 Married: 3 Divorced: 3

*** Children**

Have children: 5 (Divorced and raising the child by herself: 1; Divorced and raising the child with an ex-partner: 2) Have no children: 7

*** Experience of marriage 6**

Before or after the onset of impairment/ where she met her partner

Before the onset of impairment	2
After the onset of impairment / the University she graduated from	1
After the onset of impairment/social circle for people who have the same impairment	1
After the onset of impairment/matchmaking meeting for the general population	1
After the onset of impairment/matchmaking meeting for disabled people	1

In the interviews, out of 12 women, 5 talked about their experiences in matchmaking meetings they had attended. Two women married through matchmaking meetings. ‘Matchmaking meetings for disabled people’ are also held by some organizations; these are some of the main opportunities for disabled people to marry. Sometimes parents (mostly mothers) of the disabled people attend the matchmaking meetings.

However, rather than for disabled women, these meetings seem to be tailored towards the needs of disabled men (and their parents). For disabled women, this can lead to disempowering experiences.

Experience of matchmaking meetings 5

Got married 2

- Attended matchmaking meeting for the general population

‘A friend wanted to attend a matchmaking meeting with me. My husband and I became a couple

thanks to a meeting. He wanted to marry, so we met at the right time.’ (Mental Health)

→Before she got married, she told her potential groom about her mental disease, but she did not tell his family. His family learned about her disease when her mental condition started deteriorating, and this angered his family.

- Attended matchmaking meeting for disabled people.

Their parents also attended the matchmaking meeting.

‘Compared to the other attendees, my impairment was mild, so many men approached me asking for dates. I chose the man my mother recommended.’ (Physical)

→There were some families looking for a bride for their disabled son in order to have a grandchild = a successor for the family.

Disappointed 3

Three women who attended matchmaking meetings for disabled people were left disappointed.

‘I expected to meet someone nice. The man who asked me for a date was more severely impaired than I am. His mother (not he himself) said to me, “Please marry my son and take care of him.” I drew back in surprise.’ (Physical)

‘I once attended such a meeting with my friend. I could hear the male attendees whispering that women should be good at housework and cooking. So, we realised that this meeting was not for us. There was no space for finding a life partner. It was so disappointing.’ (Physical)

‘When I attended the meeting, I found myself being like a counsellor, and I listened to the worries of the male attendees. I want to meet a man who has no connection to the field of social care but who can look at me the way I am (not as a disabled person).’ (Physical)

Disabled women are expected to carry out housework and perform care roles, even though they have disabilities. On the other hand, because of their disabilities, disabled men are not expected to carry out housework and perform care roles.

- **Family members’ attitudes towards marriage**

Opposition:

Some women experienced opposition from their partner’s family.

‘His mother said that he may experience unnecessary hardships if he married a disabled woman like me.’ (Physical)

‘His family opposed our relationship when I told them that I could not have a child, even though he had the same impairment. He decided to break up.’ (Mental)

Promotion :

Sometimes the families of disabled people can be the promoters of marriage. Some parents of disabled men look for brides of their sons in order to produce grandchildren as successors for the

family and to honour their family names. Some parents of disabled women think that marriage can guarantee a lifelong financial and social security for their daughters.

However, these marriages may reinforce gender roles, with the women being expected to carry out the conventional gender role-related duties such as housework and care work for their husbands' families after marriage.

'I wanted to give birth at my parents' house [as same as non-disabled women], but I couldn't. My mother in law did not allow me to do so.' (Physical)

A woman was expected to live with her husband's parents, and not separately as a couple with her husband. Having disabilities was used for a reason to justify this decision. Her husband did not support her in housework or child-rearing not only because he had a disability but also because his mother allowed him to avoid fulfilling such roles. When she divorced him, she was unable to take her children with her.

IV—IV. Reproduction

Dealing with menstruation

Some women experienced hardships when they had to deal with menstruation.

'I began to experience the hardships of women soon after I got my first period. Some carers put a sanitary pad on me very carefully, but others put it on me roughly. When there was a leakage, the carers would put multiple layers of pads on me (instead of changing the pads more frequently). I felt uncomfortable, and it annoyed me very much. ...Moreover, a nurse in the institution asked me, "How about getting a hysterectomy done to stop the menstruation?"' (Physical)

She did not accept the nurse's recommendation, but there were some who followed the recommendation.

'Nurses in the hospital didn't care about how to deal with menstruation and continence care. No one taught me.' (Physical)

She could meet a woman with the same impairment to get information instead of the medical professionals in the hospital.

Access to sex education

'In the institution, no one taught me about menstruation, so I was so surprised when I got my first period. Then, I learned about menstruation, but there was no education about sexual intercourse or the function of pregnancy.' (Physical)

'My mother taught me about menstruation. For me it is not taboo, as I usually ask someone to help me deal with it. Regarding sexual intercourse and pregnancy, the special education high school provided this kind of education. I had to take this class alone from a male Physical Education teacher. He did nothing strange, and we just read the textbook, but I was so embarrassed.' (Physical)

Denial of sexual desire

‘I worry about my body in case I have sexual intercourse. But I cannot consult my doctor about such things.’ (Physical)

‘When the staff made rounds of the institutions, a girl with mild intellectual difficulties played with herself in bed. The next morning, it was known to everyone, and she was called amorous or nasty. Why didn’t the staff respect her privacy? I think that it was not right.’ (Physical) ‘I felt guilty about masturbating and worried that I was abnormal because of my strong sexual desire.’ (Physical)

Pregnancy

Disabled women talked about the barriers they faced when they tried to see gynecologists and receive appropriate care.

‘In addition to psychological barriers, there are physical barriers. We have to consider the accessibility of a lavatory, an inspection bench, and so on. We have to endure an unfamiliar person’s care. I don’t want to be touched by strangers.’ (Physical)

‘When I had a disease that effects the reproductive functions, I couldn’t receive appropriate care as a woman.’ (Physical)

Losing reproductive functions was a big matter for the women, even though physical care, such as hormone therapy, and psychological care were not available.

Medication and drugs

Some disabled women pointed out that the reduction or termination of medication during pregnancy could deteriorate one’s health condition heavily. (Physical, Mental)

The risk could spread to their expected babies and, thus, not remain limited within their own bodies. The women themselves and their family members worried about teratogenicity.

Parturition

Sometimes, it is difficult for disabled women to find hospitals where they can give birth.

‘First, I thought about giving birth at a maternity clinic nearby, but the clinic asked me to go to the university hospital.’

‘When I went to see a doctor about the pregnancy, the doctor didn’t say “Congratulations”. Instead, the doctor recommended an amniotic examination, as I was at high risk of having a disabled baby. It was disgusting that the doctor described disabled babies in such a negative way.’

‘When I went to the hospital to check whether I was pregnant, a doctor suggested that I should abort my baby because there was a possibility of my husband and I passing our impairments to the baby. I was so shocked, and I said that I would bring my baby into life at any risk.’

Respect and recognition for women who are not expected to have children

‘In fact, I physically cannot have babies. It is decided, and I have no choice.’ (Physical)

‘My health is my priority. I don’t want to sacrifice my health by giving birth.’ (Mental)

Some of the disabled women felt that it would be difficult for them to give birth because of their body conditions.

However, they are not free to overtly express these words , for fear of being devalued as they are unable to perform traditional gender norms.

Once disabled women are recognised as not being able to give birth, they have no access to gynecological care for issues such as sexual functioning and menopause.

Reproductive health rights should thus cover the lifelong health conditions of disabled women.

V. Consideration

The desire to have sex and to fall in love (experience relationships and intimacy) are inseparable. Self-satisfaction is related to a partner’s satisfaction. These are the points to be considered when analysing difficulties related to love, marriage, and reproduction.

The ‘arrows of consequences’ are drawn as follows.

Difficulties in carrying out the dominant gender roles ⇒ Difficulties in finding Love ⇒ Difficulties in satisfying one’s sexual desires (in the narrowest sense possible).

V—I. Difficulties in developing gender identities and sexualities

Disabled women find it difficult to establish gender identities because the disadvantages and difficulties of having disabilities are too heavy for them, and this affects their self-identity as disabled women.

How disabled women face difficulties:

Difficulties to carry out dominant gender roles

+ (Plus)

an environment where disabled women have to face the people who do not accept their impairments and exclude alternative gender roles

||(Equal)

Instability of self-identity as a woman

Finding it hard to live

Disabled women have the difficulties in establishing gender identities and sexualities. This does not mean that disabled women do not experience gender discrimination as I’ve described in this paper. On the contrary, gender discrimination against disabled women is overlooked and not properly

addressed.

V--II. Disabled women as subjects with rights who resist discrimination.

It should be noted that disabled women were not merely the subjects of discrimination. They tried to find ways to survive despite their discriminatory circumstances.

• The existence of role models

‘I’ve met disabled women who have the same impairment that as me, who have created families and raised children.’ (Physical)

‘I’ve met disabled women (disabled for congenital reasons or through accident) who are cool, fashionably having manicured nails as well as accessories. I want to be like them’ (Physical)

• United as residents

‘I asked a friend who can walk to go to a washstand and wash my dress.’

‘When the institution tried to bring in male carers for assisting with the bathing, the female residents united to resist this move. We could stop that.’

• Networking as mothers

‘I could make myself understood to the other mothers and build social support networks. We share common ground as mothers.’

‘My children are a major source of my energy.’

• Existence of persons who understand and support them

‘When the nurse suggested that I undergo a hysterectomy done, I consulted a female staff member I could trust. She said that I shouldn’t do it, as I may meet someone in the future.’

‘I met a PA who understood my sexual desire. I began to collect information and contact organizations.’

In the end, this paper describes some of the difficulties disabled women face with regard to love, marriage, and reproduction. The survival strategies of disabled women and the identification of intersectional discriminations require further analysis.

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