2023
Summary of Research Papers 09

A Study on Discrimination Experiences and Human Rights Promotion in Sexual and Reproductive Areas of Women with Severe Disabilities

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1. Research Background and Necessity

Persons with disabilities are still regarded as asexual and incapable in Korean society. As such, their autonomy is denied, and their sexual and reproductive activities are controlled. Also, not only the information and education needed to realize their sexual and reproductive health and rights but also the rights to access and use medical and welfare services are not guaranteed. Though many have posed a problem about the sexual and reproductive health and rights of women with disabilities until now, their grounds for raising the problem have been very limited. In particular, in the case of women with severe disabilities who have difficulties expressing their own opinions, their autonomy and rights to self-determination have been even further excluded, thereby remaining

1) This result is partially extracted from "Kim, Dong-sik, Kim, Young-taek, Tong, Cheyon, & Na, Young-jung (2022). *Experience of Discrimination against Women with Severe Disabilities in the Area of Sexual and Reproductive Health and Suggestions for Improving their Human Rights*. Seoul: Korean Women's Development Institute." For specific content, refer to the full research report.

left out of government policies.

Therefore, it is necessary to examine the policy directions of the international community for ensuring the sexual and reproductive health and rights of persons with disabilities and to identify the current situations of women with severe disabilities in such areas in Korean society.

2. Research Purposes and Methods

This study has the following two purposes: The first is to examine the policy directions of the international community for ensuring the sexual and reproductive health and rights of persons with disabilities and derive implications from the results of the examination. Regarding sexual and reproductive issues women with severe disabilities experience in their life-course ranging from the first to last menstruation, the second purpose is to identify the current situations of various types of discrimination against them and violation of human rights arising from the types and characteristics of disabilities they have, and prejudices against and stereotypes of persons with disabilities in Korean society. For the first purpose, we reviewed general comments of the Committee on the Rights of Persons with Disabilities, Nairobi Principles on Abortion, Prenatal Testing, and Disability announced by the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of Discrimination against Women, and the guidelines issued by the World Health Organization. From the review, we attempted to find the policy directions and implications of the international community for ensuring the sexual and reproductive health and rights of persons with disabilities. For the second purpose, we conducted an in-depth interview with 30

persons with severe disabilities or with difficulties of communication among the persons with developmental, auditory, and physical disabilities who are heavily restricted in accessing and using information, and goods and services.

3. Research Findings

1) Policy directions of the international community for ensuring the sexual and reproductive health and rights of persons with disabilities

(1) General comments of the Committee on the Rights of Persons with Disabilities

The general comments of the Committee on the Rights of Persons with Disabilities (CRPD), one of the UN Human Rights Treaty Bodies, provide a very important guideline for establishing legal and institutional directions for promoting the human rights of persons with disabilities in the overall area of sexual and reproductive health. Some of the general comments are directly and indirectly related to the area of sexual and reproductive health. For example, General Comment No. 1 (2014) of the CRPD deals with “equal recognition before the law.” Particularly, 8 of the General Comment No. 1 stipulates that “all persons with disabilities have full legal capacity,” making it clear that persons with disabilities are non-discriminative, equal beings to persons without disabilities (National Human Rights Commission of the Republic of Korea, 2020:4-5). The denial of legal capacity to persons with disabilities means depriving them of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, and rights related to autonomy. Of the General Comment No. 1. 9 clarifies that

support in decision-making to protect all rights, including rights related to autonomy of persons with disabilities and their freedom from abuse and ill-treatment should not be a means of limiting the rights of persons with disabilities to enjoy in the area of sexual and reproductive health (National Human Rights Commission of the Republic of Korea, 2020:11-12). This comment too stresses that persons with disabilities should be recognized as equal to persons without disabilities before the law, and that decision-making support should serve as a means of providing a necessary support for persons with disabilities. Next, the General Comment No. 2 (2014) addresses “accessibility.” In particular, 40 of the General Comment No. 2 states that not only physical and geographical accessibility to medical services for the sexual and reproductive health and rights of persons with disabilities, all information and communication pertaining to the provision of healthcare should also be accessible through various means of communication, including sign language, Braille, and alternative script. It also emphasized that the gender dimension of accessibility should also be taken into account when providing healthcare (National Human Rights Commission of the Republic of Korea, 2020:35-36). This is to say, women with disabilities should be accessible to medical care facilities using the most suitable means of transport to promote their sexual and reproductive health depending on the type and degree of their disabilities. It also means that information should be provided in the most appropriate mode, means, and formats for them to sufficiently understand and to be autonomous for themselves, the General Comment No.3 (2016) focuses on “women and girls with disabilities.” This comment pays attention to stereotyping related to disability and gender. For instance, 38 of the General Comment No.3 stresses that “wrongful stereotyping related to disability and gender

is a form of discrimination" against women and girls with disabilities. Taking note of eugenic stereotypes that assume women with disabilities will give birth to children with disabilities, 39 of the General Comment No.3 states that these stereotypes may lead to discourage or prevent women with disabilities from realizing their motherhood (National Human Rights Commission of the Republic of Korea, 2020:52). This is an example of multiple discrimination women with disabilities face in the area of sexual and reproductive health. 40 of the General Comment No.3 introduces stereotypes that assume women with disabilities are asexual or hypersexual. Persons with disabilities are often misunderstood as being asexual, but the comment warns that this misunderstanding may lead to ideas that their access to information and services is not necessary about all aspects of sexual and reproductive health, including comprehensive education (National Human Rights Commission of the Republic of Korea, 2020:53). In addition, this comment includes healthcare facilities and equipment unfriendly to persons with disabilities, prejudices and stereotypes of healthcare workers and staff against persons with disabilities, and restrictions on the access of women with disabilities to medical care and services related to sexual and reproductive health (National Human Rights Commission of the Republic of Korea, 2020:53). The General Comment No.5 addresses "the right to live independently and be included in the community," and the General Comment No.6 "equality and non-discrimination."Both comments include sexual and reproductive health. The General Comment No.5 clearly states that just as the necessities of life are indispensable for persons with disabilities to live independently, so is sexual and reproductive health essential for them (National Human Rights Commission of the Republic of Korea, 2020:97). The General Comment

No.6 emphasizes that all forms of discrimination against persons with disabilities that infringes on their rights to sexual and reproductive health should be prohibited as mentioned in the General Comment No.3.

(2) Nairobi Principles on Abortion, Prenatal Testing, and Disability jointly announced by the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of Discrimination against Women

Concerned about the situation in which sexual and reproductive health and rights of women, including women with disabilities, were not still ensured or to the contrary went backward, the UN Committee on the Rights of Persons with Disabilities together with the Committee on the Elimination of Discrimination against Women announced a joint statement in 2018. The statement urged that the government authorities faithfully implement their obligations from various aspects to ensure women's sexual and reproductive health and rights, including safe and legal abortions (refer to Women with Disabilities Empathy. The Nairobi Principles on Abortion, Prenatal Testing, and Disability. Translated version in Korean). Focusing on abortion, experts in sexual and reproductive rights belonging to the two committees presented the basic principles for the problem of awareness of the intersection of women and disability in Nairobi, Kenya, in October of the same year. The principles begin with the recognition that "human rights" apply to everyone on an equal basis. This is to say, human rights are on a non-discriminative, equal basis regardless of gender, disability, or degree of disability. This includes the autonomy and self-determination of all persons, making it a principle that all persons respect and protect these rights. Of the principles, the third principle states about women. In

particular, women have the right to decide whether to become pregnant and whether to continue a pregnancy, and their right to access all information available must be ensured to make their decisions based on the most reliable ground. Next, the fourth principle points out that discriminative and negative stereotypes of disabilities in our society can affect decisions of persons with disabilities on sexual and reproductive health and rights and on their future as well. The principle clarifies that laws, policies, and practices advocating non-discrimination and equality for persons with disabilities should be supported. Pointing out that intersectional discrimination against women and disability is unethical and violation of human rights, the subsequent principles reaffirm that women with disabilities should be able to understand, use, and access high quality counseling and services equally to women without disabilities. The principles also point out that to do so, i) the voices of persons with disabilities should be listened to, ii) their needs should be reflected in all aspects of information, goods and services related to sexual and reproductive health, and iii) providers of information, goods and services should have education to better understand the intersectional and complex nature of gender and disability.

(3) Implications from the policies of the international community on the sexual and reproductive health and rights of persons with disabilities

In order to examine the policy directions of the international community for ensuring the sexual and reproductive health and rights of persons with disabilities, we reviewed general comments of the Committee on the Rights of Persons with Disabilities (CRPD), the Nairobi Principles jointly announced by the CRDP and the Committee

on the Elimination of Discrimination against Women, and guidelines issued by WHO & UN Population Fund (UNFPA), UN Department of Economic and Social Affairs (UN DESA), and European Disability Forum. To sum up, the policies of the international community emphasize that equally to persons without disabilities, persons with disabilities have agency of enjoying rights to sexual desire and pleasure, reproductive rights to plan, safely deliver and raise children, and rights to be free from health risks in that process. An important implication from the policies is that the denial of these rights originated from our misunderstanding of and prejudices against persons with disabilities, stigmatized laws and policies, and long-held practices and norms, hence these points must be recognized and be cautious about. In this regard, the international community points out as the most fundamental origin of the problems that our society has no integrative perspective on gender and disability. In general, sensitivity to gender and sensitivity to disability, respectively, are understood as individualized definitions and concepts. However, the relations of the two cannot be separated for women with disabilities. As such, the international community points out that women with disabilities should be looked at from an integrative perspective of combining the two into one.

To have such an integrative perspective on gender and disability, the international community also points out that Korean society needs to make efforts to thoroughly understand not only the needs of persons with disabilities but also those of their parents, families, and diverse supporting organizations. This guideline of the international community presents a big implication on Korean society, because the persons directly concerned, their supporters and advocates in fact have often been excluded from policies on persons with disabilities. Another big

implication can be derived from the guideline of the international community that it is necessary to closely examine whether the current laws, policies, and social norms and practices act as barriers to promoting the sexual and reproductive health of women with disabilities and practicing their rights. Here it is necessary to clearly recognize that establishing a database and conducting research on persons with disabilities in this process—which was relatively lacking compared to that on persons without disabilities— will lay a very important foundation for specifying the goal of the international community to ensure sexual and reproductive health and rights of persons with disabilities. Simply approaching persons with disabilities from the same gender perspective as on persons without disabilities will definitely have limitations because i) diverse laws on sexual and reproductive health and rights and all forms of information, goods and services based on the laws should be available for persons with disabilities regardless of the type or degree of disabilities they have, ii) physical, economic, and socio-psychological accesses should also be possible for them, iii) they should be sufficiently and properly accepted and understood considering the characteristics of their disabilities and circumstances, and iv) high quality goods and services should be provided for them. As stressed earlier, it is necessary to recognize that an integrative perspective on gender and disability and approach based on this perspective are the most fundamental basis for achieving non-discrimination and equality in the area of sexual and reproductive health, and furthermore promoting their human rights.

2) Current situations of discrimination against persons with severe disabilities and violation of their human rights in sexual and reproductive areas.

(1) Sexuality education

According to the result of conducting the in-depth interview with persons with severe disabilities, many of them pointed out in the area of sexuality education that sexuality education during their child and adolescent periods was perfunctory. In particular, even if they received sexuality education, the education was generally centered on the prevention of crimes, including sexual abuse. Due to this, physical, psychological, and emotional changes, sexual curiosity or rights during the child and adolescent periods were not included in the sexuality education they received. In many cases, sexuality education did not take into account the characteristics of disabilities nor provided accurate information. Or it was difficult to understand the information taught. Ultimately, this became an important factor for forming wrong perceptions and knowledge of sex or attitude toward sex.

(2) First menstruation and management of menstrual health

Like persons without disabilities, women with severe disabilities usually became aware of monthly periods and learned how to deal with them from their parents, siblings, and teachers when they experienced the first menstrual period. However, the information providers, including parents and teachers, had negative perceptions of the first monthly period that women with disabilities experienced. Due to their negative perceptions, many women with disabilities too negatively perceived menstruation, and learned social norms about monthly periods. Of the

interview participants, women with physical disabilities and brain lesions often experienced acute pain from their unfitting sanitary pads or discomfort from the oozing menstrual blood.

(3) Masturbation and sexual desire

Women with severe disabilities were aware of masturbation, but they could not masturbate due to the devices unfitting their disability types. Even if that was the case with them, they could not ask for assistance from their activity supporters. Many of the interviewed women perceived persons with disabilities as sexually unattractive and asexual without having a sexual desire. This perception was partially what they learned from the prejudices and stereotypes of their parents, family members, and acquaintances who were their closest persons without disabilities.

(4) Contraception and sexual relations

In some cases, forced sterilization operation or abortion was determined by their parents regardless of the will of persons with disabilities. Also, some interview participants recognized the physical body of persons with disabilities as infertile because they were not pregnant even if they had not avoided pregnancy. In other cases, they prevented conception with a purpose of blocking out the potential genetic inheritance of disabilities. The interview participants who could not control their body due to disabilities said that it was difficult to refuse sexual intercourse when their spouse or partner requested it, and in this process they had to endure the situation where their sexual intentions were not respected and the pain arising from their disabilities.

(5) Dating and marriage

Persons with severe disabilities themselves were highly desirous of dating and marriage, but worried attention from their family and people around them made it difficult to maintain their relationships with dating partners or led them to lose initiative in the bilateral relationships. This is to say, such attention impacts the sexual autonomy and rights to self-determination of women with disabilities. In some situations, their right to decide on planning for having children was ignored due to the stereotypes of parents about children with disabilities.

(6) Pregnancy and abortion

One of the difficulties the interview participants expressed most was access to contraception. Many persons with physical disabilities and brain lesions had difficulties visiting pharmacies to buy pregnancy test kits when they had to. Also, in some cases, the interview participants doubted their reproductive potentials and femininity due to their disabilities. A majority of those who had ever experienced pregnancy were not congratulated from their family or healthcare workers, and many were instead recommended to have an abortion.

(7) Delivery and childbirth

Even in a disability-friendly obstetrics and gynecology (ob-gyn) clinic, medical equipment and environment that did not consider the physical and disability characteristics of persons with disabilities worked as a main factor for inconveniencing their use of medical services. The problem of communication with healthcare providers caused the pregnant women with severe disabilities to face difficulties of accurately asking

for and understanding information they wanted. More than anything else, healthcare workers' absence or lack of sensitivity to disability and gender was another factor for violating the human rights of pregnant women with disabilities, including gender-based discrimination against the pregnant women and denial of their emotions and sexual autonomy. These women were at times advised to have an unwanted cesarean section on the ground of their disabilities.

(8) Childcare

Women with disabilities were granted the same gender role of care as that of women without disabilities. Of the women with disabilities, female workers with disabilities were by far more burdened with childcare. Due to the burden of childcare, women with disabilities utilized the labor of their activity supporters for raising children rather than for supporting themselves, while giving up assistance and support for themselves.

(9) Sexual harassment and sexual violence

One of the difficulties persons with disabilities, particularly women with severe disabilities usually encountered was sexual harassment and sexual violence. They were exposed defenselessly to a sexually abusive situation in everyday life, in schools, and in the working environment, ranging from sexual discomfort and humiliation by people in friendly or unfriendly relationships to direct sexual molestation and coercive sexual assault. What parents of women with severe disabilities could do in this situation was to physically control their children, and to have unconditional, prevention-centered education and guidance for their children.

(10) Residential facilities

Many of the interview participants pointed out that it was impossible to realize their sexual and reproductive rights including autonomy in residential facilities. Due to a manpower shortage of facility workers, taking care of personal affairs of facility users, that is, persons with severe disabilities, was put off. While their sexual needs were controlled, facility users were often in a risky situation of abuse and sexual violence by facility workers. Nevertheless, the users had difficulties properly reporting or responding to the risks due to the restricted space of residential facilities.

4. Policy Suggestions

1) Enhance the effectiveness of sexuality education considering disability types and characteristics in special education

Special education comprises knowledge, skills, and social adaptation needed in real life of persons with various types of disabilities, including physical, mental, and intellectual disabilities. Special education also includes sexuality education that is the most basic for ensuring sexual and reproductive health and rights. However, according to the persons with disabilities who participated in the interview, sexuality education in special education was conducted without considering the types or degrees of their disabilities. Therefore, it is necessary to enhance the effectiveness of sexuality education and ways of its operation in special education considering their disability types and characteristics. Such sexuality education in special education should be provided equally for students with disabilities not only in special schools but also in general schools.

2) Strengthen disability and gender sensitivity education for healthcare and welfare service workers

Nairobi Principles on Abortion, Prenatal Testing, and Disability jointly announced by the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of Discrimination against Women stress that workers including healthcare workers who provide medical and welfare services for persons with disabilities should provide their services from the intersectional perspective of gender and disability. In other words, education for enhancing their sensitivity to gender and disability alike should be conducted largely on the site. As healthcare and welfare service workers regularly receive training and refresher education, first of all, it is necessary to make education on disabilities and human rights mandatory for all the workers among the existing segmentally-developed subjects of education. In this process, it is also necessary to develop and distribute practical educational materials for them to be sufficiently aware of gender and disability sensitivity and apply this sensitivity to their practice in the field. In addition, it is necessary to regularly perform monitoring and evaluation by establishing a monitoring system to raise the effectiveness of education.

3) Prepare an accessible information and communication channel matching the disability types and characteristics of persons with disabilities

We found that information varied vastly in quantity and quality depending on the disability type. Persons with disabilities needed information and communication when they visited medical institutions in addition to educational institutions, when they carried out their duties in

the workplace, and when they met their acquaintances in daily lives. But they individually had to respond to and manage their sexual and reproductive needs including their sexual autonomy. Therefore, it is necessary to prepare an information and communication channel that provides information necessary for persons with disabilities in diverse areas, including schools, workplaces, residential facilities, and daily lives in a proper manner depending on their disability types and characteristics together with measures and support necessary for their full understanding. Operating a platform-based channel may be proper, but by reflecting opinions of professional developers and voices from the field, it is necessary to operate a sustainable information and communication channel through which persons with disabilities can use and share information.

4) Operate disability-friendly maternity clinics and make up for the system through monitoring

Women with severe disabilities who participated in this study suggested the necessity for operating disability-friendly maternity clinics where they can get counseling and medical information on sexual rights, and necessary healthcare from the first to last menstrual period. If any designated disability-friendly clinic has a structure that causes persons with disabilities to suffer serious difficulties accessing and using the clinic, the structure must be improved for sure. Otherwise, clinics or hospitals designated as disability-friendly maternity clinics should be accessibly operated, and progress of the operation should be monitored and complemented from diverse aspects. Furthermore, going beyond making up for the disability-friendly clinic system, the right to access all medical institutions should be ensured for persons with disabilities

because the right to access medical care service is directly connected to their rights to health and human rights.

5) Ensure the sexual and reproductive health and rights of facility residents and reinforce supervision using the commissioned doctor system at residential facilities

The operation rules for doctors commissioned at residential facilities for persons with disabilities prescribe the roles of the commissioned doctors. The provision defines their roles simply as regularly visiting facility residents to check their health and taking appropriate measures for them if their health conditions have worsened, but does not include specific roles. Therefore, it is necessary to grant more specific roles to the doctors as follows: the commissioned doctor should perform i) the role of examining the environmental conditions inside the facilities and situations of the residents, ii) the role of actively observing and supervising the facilities whether any resident fell victim to violation of sexual rights, including various forms of violence, abuse, and sexual humiliation, or infringement on their right to health related to sexuality, and whether residents are in a situation where they cannot talk about or cannot report inside the facilities, furthermore iii) the role of providing medical treatment, consultation, and information on sexual and reproductive health, including menstrual health management and contraception, and reproductive diseases when they check the current health conditions of facility residents, to ensure the accessibility of the residents, and iv) depending on the case, the role of referring the residents to institutions outside the facilities, such as hospitals, counseling centers and shelters for victims to sexual abuse, and centers for promoting the communication right of persons with disabilities.

Above all, it is necessary to review ways of designating commissioned doctors at residential facilities after they receive education on sensitivity to disability and gender.

6) Develop and introduce goods available for sexual enjoyment considering the disability types and characteristics

In the process of rehabilitation and treatment of persons with disabilities, or in the process of education on sexual counseling, it is necessary to introduce masturbation goods available for sexual enjoyment taking the disability types and degrees into consideration. It is also necessary to develop masturbation goods considering the disability characteristics by identifying the problems of existing goods and demands from users. In addition, when persons with disabilities watch videos as a way of getting sexual pleasure, foreign videos provide Korean captions, but Korean videos do not. As such, persons with hearing impairment said they had difficulties understanding and enjoying the videos. Because the right to sexual enjoyment applies to everyone, not ensuring the right for particular persons with disabilities on the ground of disabilities would be a form of discrimination. This is not necessarily restricted to videos only. If any discriminative content is included in services through the similar media to videos, and in a particular type of disabilities like hearing impairment here taken as an example, it is necessary to review and correct the discriminative content.

Research Areas: Health / Reproductive Rights, Law, Gender-based Violence / Safety, Low Fertility·Aging
Keywords: Disability, Women with Severe Disabilities, Sexual Human Rights, Sexual and Reproductive Rights, Sexual and Reproductive Health

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