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Original Paper

Support Strategies for Mothers with Intellectual Disabilities by Public Health Nurses

Kinuko SUGIURA[*1] **and Kazuko FUJISAWA**[*2]

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Key words: maternal health support, mothers with intellectual disabilities, public health nurse, disability-inclusive healthcare

Abstract

This study aimed to identify public health nurses' considerations when supporting mothers with intellectual disabilities. Fourteen nurses from three public health centers were interviewed between November 2021 and August 2022 through researcher-facilitated semi-structured focus group interviews, each lasting between 55 and 93 minutes, one for each health center. The analysis of the interview data, in response to the question, "What are your considerations when supporting mothers with intellectual disabilities?" revealed five categories, including "considerations for relationship building and maintenance" and 13 subcategories, such as "creating a comfortable atmosphere for talking." The participants utilized skills developed from their experiences to support parents with intellectual disabilities. To ensure the reproductive health rights of people with disabilities and foster an inclusive society, an educational system tailored to their specific needs must be established to support individuals with intellectual disabilities.

1. Introduction

The United Nations emphasizes diversity, equity, and inclusion as key principles in achieving its Sustainable Development Goals[1]. In support of this, Japan enacted the Law for the Elimination of Discrimination Against Persons with Disabilities in 2016 to promote an inclusive society. As of April 2024, all businesses are required to provide reasonable accommodations for individuals with disabilities.

Sexual and reproductive health rights are crucial to realizing the Sustainable Development Goals[2,3]. These include the right to decide when and how many children to have, the right to a fulfilling sexual life, and access to accurate information and safe, effective contraception[2,3]. Article 23 of the Convention on the Rights of Persons with Disabilities, adopted by the United Nations in 2006 and ratified by Japan in 2014, affirms that "persons with disabilities have the right to marry and form families, and to decide freely and responsibly on the number of their children."[4] Despite these rights, parenting support for individuals with disabilities remains inadequate. In 2022, the United Nations urged Japan to ensure parents with disabilities receive appropriate assistance in fulfilling their responsibilities[5].

Intellectual disability (ID) is defined as a neurological condition that significantly impairs cognitive

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[*1] Department of Midwifery, Seinan Jo Gakuin University
1-3-5 Ibori, Kokurakita-ku, Kitakyushu, 803-0835, Japan
E-Mail: `sugiura@seinan-jo.ac.jp`
[*2] Faculty of Education and Welfare, Biwako-Gakuin University

abilities, including learning, reasoning, and problem-solving[6-8]. It also affects adaptive behaviors necessary for daily living[6-8]. From pregnancy to child-rearing, new mothers must navigate physical and mental changes, manage their health, prepare for childbirth, and acquire parenting skills, among other challenges. Japan provides public support for mothers and families throughout these stages.

Public health nurses (PHNs), employed by local governments, offer support through home visits and parenting classes at health centers. In Japan, the number of child abuse cases handled by Child Guidance Centers continues to increase annually[9]. Of particular concern is the abuse of newborns by their own mothers, which led to the revision of the Child Welfare Law in 2009. The revised law designates "expectant mothers who are recognized as requiring special support after childbirth" as "specified expectant mothers" and established a system to provide continuous support for them from pregnancy to postpartum. It should be noted that many municipalities include expectant and nursing mothers with mental or intellectual disabilities in the aforementioned category.

This study aims to elucidate how PHNs support mothers with ID and to identify key considerations in delivering this support.

2. Methods

2.1 Research design, participants, and data collection

A qualitative descriptive design was employed to explore how PHNs support mothers with IDs. The 14 participating PHNs were affiliated with three health centers (one in City A and two in City B, central Japan): four nurses from the City A center and ten from the two centers in City B. Written requests for participation were sent to municipal healthcare administrators, who consented and helped identify potential participants.

We conducted one semi-structured focus group interview at each health center between November 2021 and August 2022. Participants provided demographic and professional information, including age, years of experience as PHNs, and the number of mothers with IDs they had supported. They were then invited to discuss their experiences supporting these patients. The interview analysis focused on the question, "What were your considerations and efforts in supporting mothers with IDs?" The interview at the health center in City A lasted 55 minutes, while the interviews at the two centers in City B lasted 86 and 93 minutes.

2.2 Data analysis

Data were analyzed using Krippendorff's content-analysis method[10]. The interviews were transcribed, and sections related to supporting mothers with IDs were extracted, labeled according to semantic content, and categorized according to similarity.

3. Results

3.1 Participants' background

Participants included three in their 20s, seven in their 30s, two in their 40s, and two in their 50s. Their years of experience as PHNs ranged from two to 38 years with an average of nine years. The number of mothers with IDs they had supported ranged from one to nine with official ID certification and from "several" to "many" suspected cases (Table 1).

3.2 Categories and subcategories

The analysis identified five categories and 13 subcategories (Table 2) of considerations underlying the support offered to mothers with IDs. The findings are summarized below, illustrated by quotations from participants.

3.2.1 Considerations for relationship building and maintenance

This category included three subcategories: "creating a comfortable atmosphere for talking," "building rapport," and "conveying a supportive attitude." Establishing rapport with mothers with IDs was crucial, and the PHNs took care to create an environment in which their words and actions would not jeopardize this relationship.

In the first stage, if they do not like me, it is over, so I am very cautious. I think, "I want to ask this, but if I say too much,

Table 1 Participants' backgrounds

(*n*=10)

Participants	Affiliations	Age	Years of experience as a public health nurse	Number of mothers with IDs cared for (cases)	
				Mothers with certified IDs (cases)	Mothers with suspected IDs (cases)
A	Health center A	40s	17	1	several
B	Health center A	30s	10	9	many
C	Health center A	20s	1	1	several
D	Health center A	20s	3	4	several
E	Health center B	50s	27	several	many
F	Health center B	30s	19	1	several
G	Health center B	40s	13	3	2
H	Health center B	30s	6	3	several
I	Health center C	50s	38	several	many
J	Health center C	30s	9	2	several
K	Health center C	30s	15	3	several
L	Health center C	30s	11	2	several
M	Health center C	20s	3	1	several
N	Health center C	30s	5	3	several

IDs: intellectual disabilities

Table 2 Considerations applied by participants

Category	Subcategory
Considerations for relationship building and maintenance	Creating a comfortable atmosphere for talking
	Building rapport
	Conveying a supportive attitude
Considerations for mothers' self-esteem	Positive responses
	Conveying mothers' importance
Considerations to compensate for memory challenges	Recall assistance
	Visual aids for memory
Considerations to compensate for comprehension challenges	Using simple language
	Indicating visually
	Showing how it should be done
	Checking details carefully
Considerations to enhance responsiveness	Formulating questions that can be smoothly responded to
	Doing it together

I might be pushing too far today." (Participant D)

The most important thing is not to be disliked and to create a comfortable atmosphere. I am very mindful of this, and it makes me nervous. I try to create a friendly atmosphere and choose my words carefully, even when I feel nervous, and say things like, "That's nice!" or "That's great!" (Participant A)

3.2.2 Considerations for mothers' self-esteem

This category contained two subcategories: "positive responses" and "conveying mothers' importance." The participants emphasized the importance of affirming women with IDs, who often have low self-esteem due to past experiences of devaluation. Participants were also mindful of responding positively and avoiding criticism.

> *I ask questions in a way that affirms her but does not hurt her. When teaching baby care, I tell her, "You do it this way, but there is also this way, which is easier."* (Participant A)
>
> *Many women with IDs have been belittled for not understanding or writing kanji. We must be especially sensitive to the self-esteem of young pregnant women with IDs, who may sometimes act out due to inexperience.* (Participant B)
>
> *I repeatedly told her that she was important, and every time I saw her, I tried to convey this. I would say, "I am here for you," as the conversation often centered around her baby.* (Participant H)
>
> *She was in her last trimester but refused to see an OB/GYN despite my encouragement. I stayed involved, asking where she could visit a doctor, and eventually told her, "You are important to me, and I do not want anything bad to happen." After that, she saw the doctor and safely gave birth in the hospital.* (Participant G)

3.2.3 Considerations to compensate for memory challenges

This category included two subcategories: "recall assistance" and "visual aids for memory." The PHNs implemented strategies such as writing appointment dates and tasks on paper and placing them in visible spots in the mother's home to prevent missed clinic visits or paperwork deadlines. They also made reminder calls before appointments and had support staff send reminder emails on the day of appointments.

> *If you give her a deadline, she will forget, so I post it where she can see it. (Participants A, D, K)*
>
> *I would bring multiple sheets of lined paper and write or draw things for them to avoid forgetfulness.* (Participant D)
>
> *Sometimes I call to make an appointment, but she does not show up. In such cases, I have the staff at the Child Care Support Office send a message to her cell phone, which improves the chances of her attending. Some mothers say, "I forget easily, so having it in writing helps."* (Participant C)

3.2.4 Considerations to compensate for comprehension challenges

This category consisted of four subcategories: "using simple language," "indicating visually," "showing how it should be done," and "checking details carefully." The PHNs compensated for the mothers' lack of comprehension by gently rephrasing healthcare terminology, drawing diagrams, and writing easy-to-read letters. When they visited the mothers' homes, they explained how to prepare a medical questionnaire for their children's medical examinations and then followed up with calls to confirm that the mothers understood the instructions.

> *I am careful not to use difficult words and to speak simply.* (Participant A)
>
> *When I called her at the beginning of the month, I asked, "Do you think you can write a medical questionnaire?" I encouraged her to write as much as she could and told her to call me if she did not understand. When she called, I asked her, "Do you let your child do this? Can you do this?" I asked her specific questions and then explained, "Well, you should write that part down like this."* (Participant C)

3.2.5 Considerations to enhance responsiveness

This category consisted of two subcategories: "formulating questions that can be smoothly responded to" and "doing it together." Participants replaced complex questions with simpler ones to help mothers who had difficulty explaining things. Consequently, the participants obtained the information required to support the mothers.

> *When asking open-ended questions, many people with IDs are confused about how to answer, so I think it helps to narrow the focus and ask something that can be easily answered in a few words.* (Participant D)
>
> *I think we often do it together. Many mothers with IDs cannot cut their babies' nails, so I frequently cut them while showing them how to do it.* (Participant A)

4. Discussion

The fact that PHNs have assisted more mothers with suspected IDs than those with certified IDs highlights the potentially large number of people in Japan who have not yet obtained certification. Although having this official status provides tax and employment benefits, some individuals are discouraged from obtaining it due to potential stigma. Additionally, many potentially eligible persons may be unaware of the application process, lack certification, or do not qualify for government assistance. Since certification must be renewed every two years, at least until adulthood and sometimes beyond, many people abandon the certification process due to its complexity[11].

The results of this study indicate that the participating PHNs provided tailored support to mothers with IDs based on their characteristics. Research on the relationship between working memory and intellectual and developmental disabilities suggests that limitations in working memory may explain some characteristics of individuals with IDs[12]. The strategies used to support memory, comprehension, and responsiveness identified in this study were consistent with those implemented for individuals with intellectual and developmental disabilities in other settings[12,13].

PHNs' considerations were likely informed by their experiential knowledge. There are few opportunities in Japan's public health or nursing education to learn about IDs. Japanese nurses and PHNs typically only learn about people with severe IDs in psychiatric nursing, pediatric nursing, and welfare-related subjects. By contrast, the United Kingdom has a well-established field of "learning disability[†1] nursing," which has been practiced for more than a century. In the United Kingdom, learning disability nurses work in National Health Service (NHS) hospitals and community health centers[14].

Deinstitutionalization and desegregation of persons with disabilities began around 30 years later in Japan than in the United Kingdom. As a result, the system for social inclusion of this population in Japan is still in its early stages. Even healthcare professionals often lack sufficient knowledge about persons with IDs. Until 1996, the Eugenic Protection Law in Japan legalized the sterilization of individuals with IDs, mental disorders, and genetic diseases. In July 2024, the Supreme Court ruled in favor of an individual with a disability who had been forcibly sterilized under this law, asserting that it was unconstitutional and that the government was liable for compensation[15].

Despite the repeal of the Eugenic Protection Law 27 years ago, a comprehensive system to support parents with disabilities remains lacking in Japan. Consequently, medical professionals are insufficiently informed about individuals with IDs. It is imperative to develop an educational system to equip healthcare professionals to support persons with disabilities.

In the United Kingdom, efforts to provide reasonable accommodations for this population have advanced. Mencap[16,17], a support organization for people with IDs, released a report highlighting that such patients did not receive appropriate medical care in NHS hospitals, resulting in a high mortality rate among this population[15,16]. In 2023, NHS hospitals introduced a "health passport" system, which allows patients with IDs and autism to express their unique healthcare needs and preferences[18]. Additionally, the hospitals developed easy-to-read versions of medical information pamphlets, available on their websites, including those on pregnancy, childbirth, and childcare presented in simple, accessible formats[19].

Conversely, in Japan, there is a paucity of studies, apart from those conducted by the authors, demonstrating the extent of support provided by healthcare professionals in healthcare settings. Consequently, this paper holds significant value. Although reasonable accommodation has been obligatory for public institutions since FY2018 and for all business establishments since FY2024, it is evident that public hospitals and healthcare centers have not yet undertaken efforts to provide reasonable accommodations for individuals with IDs with the requisite earnestness. The lack of accessible health-guidance materials presents a substantial challenge. During the interview, all PHNs reported having written letters and created drawings during home visits. This underscores the necessity for developing guidance materials specifically aimed at mothers with IDs.

Japan's declining birth rate accelerated after the COVID-19 crisis, with the number of births estimated to fall below 700,000 in 2024[20] a record low. Furthermore, child abuse is rising rapidly, with cases reported to the police reaching a record high of 122,000 in 2023[21]. Parenting measures have become one of the country's most critical issues, and maternal and child health and welfare policies are being expanded,[22] with local

PHNs playing a crucial role in supporting parenting. Factors contributing to child maltreatment include social isolation, economic difficulties, psychological problems, abusive parental experiences, children who are difficult to raise, and complicated family relationships, all amid weakened human connections due to the rise of the nuclear family and the breakdown of local communities23).

Contrary to the prevailing view of the relationship between parents with IDs and child maltreatment, parental intelligence and identification as having an ID are not strong predictors of parenting ability or child outcomes24,25). Recent research indicates that social stigma toward parents with disabilities, experiences of abuse, parental physical and mental health, socioeconomic factors, life stressors, social support, availability of services, family and child characteristics, and other contextual variables are significant risk factors for maltreatment. Therefore, a "contextual approach" is considered effective26).

However, many people perceive a stronger connection between being a parent with an ID and child maltreatment than the evidence supports. Parenthood is a developmental process that requires individuals to learn and adapt27). This process necessitates support from others, regardless of disability status. Every parent needs support tailored to their individual needs in growing as a parent. For parents with disabilities, this includes devising support according to the characteristics of their disability.

Participants used the skills they developed through personal experience to support parents with IDs. Although their considerations in practice aligned with existing theory, further efforts are needed to disseminate these practices as evidence-based. Therefore, there is an urgent need in Japan to develop an educational system for healthcare professionals and a support system to ensure individuals with IDs receive appropriate assistance and successfully navigate the process of becoming parents.

5. Conclusion

To support the process of parenthood for individuals with IDs, it is essential to understand and accommodate their disability characteristics. Local PHNs, at the forefront of efforts to address the rapidly declining birth rate, have provided appropriate attention based on their experience.

Conflict of interest

The authors declare no conflict of interest.

Ethical considerations

This study was approved by the Research Ethics Committee of Nagoya Women's University (Approval No. 2020-27). Potential participants were provided with a research request form stating the objectives of the study and ethical considerations by the health center administrators. Written informed consent was obtained from participants prior to the focus group interviews, and all information was kept anonymous and confidential and used for research purposes only. Participants had the right to decide whether to participate in the study and could withdraw at any time.

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Note

†1) The term "learning disability" in the United Kingdom has a similar meaning to "intellectual disability."

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