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Original Article

Support for Mothers with Intellectual Disabilities During Their Pregnancy and Infant Parenting: Based on a Questionnaire Survey of Counseling and Support Specialists

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Abstract **Objectives**: The purpose of this study was to clarify the situations of support provided by Consultation Support Specialists ("Support Coordinators") to mothers with intellectual disabilities ("MwID") during their pregnancy and early infant parenting. **Methods**: Among the results of a questionnaire survey of Support Coordinators with experience of working with MwID, we examined the responses to the items relating to support to MwID during their pregnancy and early infant parenting, analyzing the data by simple tabulation and qualitative coding (Sato, 2008). **Results**: Our study revealed that the assistance provided by Support Coordinators evolved and expanded as MwID's children grew up. The concrete examples of support identified in the study constituted not only consultation support for MwID but also assistance in maintaining their emotional and physical health and safety. The study also identified other types of support, including parenting support, which evolved along with the children's growth, and support relating to MwID's family environment and daily difficulties. With regard to parenting support in particular, Support Coordinators' direct assistance was confirmed. **Conclusion**: The findings suggested that MwID's children's growth modified the families' needs, prompting the nature of the support to adapt.

Key words: consultation support specialists, mothers with intellectual disabilities, child-rearing, parenting support, structure of support, human rights

I. Introduction

1. Parents with intellectual disabilities

The Convention on the Rights of Persons with Disabilities was adopted in 2006. The convention affirms the right of person with disabilities ("PwD") to marry and found a family (Article 23, (1)(a)). Further, states parties are bound to 'render appropriate assistance to PwD in the performance of their child-rearing responsibilities' (Article 23 (2)).

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Research on support to parents with intellectual disabilities ("PwID") has demonstrated that PwID would be learned parenting knowledge and skills through appropriate training interventions (Feldman et al., 1992; Llewellyn, 2002; McConnell et al., 2008; Wilson et al., 2012 among others). Meanwhile considerable research has been conducted focused on social support[1]. Research on social support has shown that it is effective, in reducing the parenting stress of mothers with intellectual disabilities ("MwID") who currently raise children, to provide social support that is perceived to be satisfactory by the mothers themselves (Feldman et al., 2002). It has also been learned that problems relating to the use of social support increase mental ill health

experienced by parents with intellectual disabilities (Wade et al., 2015). In other words, for PwID, social support is indispensable specially to maintain their mental health. With regard to PwID's support needs, previous studies have predominantly focused on PwID raising infants, and it has been pointed out that research into support providers has been fairly limited (Koolen et al., 2020).

2. Parents with intellectual disabilities in Japan, their parenting and social support

Research by Nobuhara and Nagawa (2021) revealed a strikingly low share of those living in couples (1.65%) and those raising children under the age of 18 (0.75%) among persons with intellectual disabilities who are using welfare services for persons with disabilities. Many of the MwID were married to males without intellectual disability and had started raising children by the time they reached adulthood without resorting to the welfare services. MwID have little informal network, but their use of formal child rearing support services, which involves visiting relevant services in person and making applications, was also found to be limited.

Nunokawa & Kase (2004) examined challenges and problems involved in the provision of social support in different stages of parenting by PwID, revealing that the areas of challenges and problems shift as children grow up, due to the very nature of parenting. From this, it can be surmised that children's growth is closely related to PwID's daily needs and how social support should and could ideally be provided to PwID requiring assistance. Yet, the research only covered the challenges and problems as perceived by the main support providers, leaving the actual situations of support and assistance largely unclarified. It should be pointed out that Nunokawa & Kase's research (2004) has been conducted without taking gender into account. However, expectations about women with disability ("WwD") nonetheless living in their gender role do exist (Itou, 2000). Notwithstanding this expectation, no support system is in place to help MwID in their life events including marriage, childbirth, parenting, and caring partner's parents and thus requires establishment of such measures (Itou, 2000). This is not to agree with the gender stereotypes, but as Itou states, only after establishing support initiatives and enable WwD to get married, give birth and rear child when they wish to, can we go on to discuss the generic issues currently tackled by women without disability (Itou, 2004).

3. Formal support for PwID during their parenting period

In Japan, PwID can benefit from parenting support continually and at home mainly in the form of visits by public health nurses and home nursing care by welfare service providers for PwD.[2] The latter is provided under the Act on the Comprehensive Support for the Daily and Social Life of Persons with Disabilities("The Act"). When PwD wish to receive legally instituted welfare services the welfare services instituted by The Act designed for them, it is required to draw up and submit a Plan for the Utilization of Services ("Plan"). The competent authorities then determine the provision of nursing care grants based on the Plan. While it may be drawn up by grant beneficiaries themselves, most PwD rely on Consultation Support Specialists ("Support Coordinators") who belong to consultation support offices ("Support Offices"). Support Coordinators create the plan by discussing with PwD what support they require in their day-to-day lives and arranging them. Plans drawn up by Support Coordinators include not only legally instituted services the welfare services instituted by The Act but also services that are available from specialists working within systems unspecified by The Act and, if any, support from the community. That is to say, a survey targeting Support Coordinators will help grasp an overall picture of what support and from whom MwID using welfare services receive over the course of their parenting years.

To be sure, such a survey has limits in that it cannot cover MwID who do not use legally insti-

tuted welfare services the welfare services instituted by The Act. Nevertheless, no research has been conducted thus far that clarifies the actual situations of support provided to MwID in Japan in the process of bringing up their children to adulthood, as far as we have been able to ascertain. It is for this reason that it appears necessary and significant to conduct a study that clarifies the situations of support for MwID along with their children's growth. Different people lead different lives, and necessary support will surely change in tandem with the child's growth and changing family environment. However, knowing what support is provided to MwID should enable us to consider appropriate social welfare programs based on the needs in child rearing.

4. Purpose

The purpose of this study is to clarity the situations of support arranged for or provided by Support Coordinators to MwID during their pregnancy and infant parenting.

II. Methodology

1. Survey subjects

The survey targeted Support Coordinators working at 1,000 Support Offices across Japan who had previously assisted or were currently assisting MwID.

The Support Offices covered in the study were selected by random sampling as follows: (1) Data available on the websites of the 53 Prefectures, 20 government ordinance-designated cities, and the Welfare and Medical Service Agency (WAM-NET) were consulted (from July 28 through August 3, 2019); (2) information was collected from the websites, and a list of Support Offices ("List") was drawn up Prefecture-by-Prefecture; (3) the distribution of questionnaire forms among the Prefectures was determined based on the prefectural populations presented in the 2015 National Census results (Statistics Bureau, the Ministry of Internal Affairs and Communications 2016); (4) 1,000 Support Offices (9.15%) were selected by random sampling from among the 10,923 offices on the List.

2. Survey method

The survey was conducted from November 28, 2019 through March 31, 2020 in a self-administered questionnaire format with anonymity option, with the forms sent to the selected 1,000 Support Offices by post.

3. Respondent attributes

The rate of response to the questionnaire was 31.8% (310/976; 22 not received and 2 disqualified). In total, 78 Support Coordinators responded to the question items discussed in this paper. Table 1 summarizes their attributes.

4. Survey content

The questionnaire was designed with reference to Hayashi & Kid (2000) and Nunokawa & Kase (2004). The question items discussed in this paper concerned support for MwID who possessed a medical rehabilitation handbook[3] and used welfare services for PwD, and with whom Support Coordinators were currently working or had previously worked. These question items were presented as multiple-choice questions and open-ended questions (free descriptions). Many of the MwID were raising children at home, but some responses included descriptions of cases in which MwID's child was entrusted to an infant home.

To examine the correlation between support and children's growth, the period during which support is provided to MwID was divided into seven stages according to the progression of pregnancy and the child's age: (a) the first 20 weeks (first half-period) of pregnancy, (b) from the 21st week (second half-period) of pregnancy to childbirth, (c) neonatal (from immediately after childbirth to immediately before the child reaches one month of age), (d) infancy (from one month to immediately before one year of age), (e) preschool childhood (from one year of age to immediately before school enrollment), (f) school-age childhood (from primary school enrollment to graduation), and (g) adolescence

Table 1 Demographic Characteristics of Subjects (*n*=78)

Item	Responses	No. of respondents	Remarks
Age group	20–29	1	No response: 1
	30–39	15	
	40–49	32	
	50–59	17	
	60 and older	12	
Gender	Male	20	Other: 0
	Female	58	
Years of experience assisting persons with disabilities	Below 3 yrs	2	Multiple responses: 3, No response: 2
	3 yrs–below 5 yrs	8	
	5 yrs–below 10 yrs	16	
	10 yrs–below 15 yrs	21	
	15 yrs and above	26	
Years of experience in counseling support	Below 1 yr	3	No response: 1
	1 yrs–below 5 yrs	27	
	5 yrs–below 10 yrs	38	
	10 yrs and above	9	
No. of cases handled	Below 50	28	No response: 3
	51–99	27	
	100–149	12	
	150 and above	8	
Parenting experience	Yes	57	No response: 1
	No	20	

NB: The subject of this study is support coordinators.
Support Coordinators create the plan by discussing with PwD what support they require in their day-to-day lives and arranging them.

(from secondary school enrollment to immediately before 18 years of age).

The multiple-choice questions were composed by itemizing the types of support ("support items") based on previous research. Table 2 lists the support items.

Although this questionnaire survey included other question items, those unrelated to support for MwID during their pregnancy and infant parenting are not discussed in this paper. Among the seven stages of pregnancy and parenting mentioned above, in this paper, our analysis focuses on the stages (a) to (d), that is, from pregnancy to the child's early infancy.

5. Analysis

The responses to the questions concerning the numbers of consultation support users during the different stages and support items provided were first analyzed by simple tabulation.

Qualitative data comprising free descriptions by respondents were analyzed by coding with reference to Sato (2008) in the procedure as follows: 1) verbatim records of the data to be discussed in this paper were created; they comprised (a) the first half-period of pregnancy: 1,290 characters, (b) the second half-period of pregnancy to childbirth: 1,632 characters, (c) neonatal: 1,350 characters, and (d) infancy: 1,971 characters; 2) one researcher developed a code for each excerpt with a meaning from the

verbatim record of each stage; 3) three researchers examined each code thus developed and modified it until all three agreed on it; 4) categories were developed while connections between codes were examined and textual segments were compared; 5) these steps were repeated under the supervision of a researcher well experienced in qualitative research in order to enhance the validity of results.

6. Ethical consideration

The objectives and intentions of this study were explained in a written statement that also indicated that prospective respondents were free to decline participation, and a questionnaire form completed and returned by a respondent was considered as the respondent's consent to participation. Data collected in the study were anonymized so that specific individuals could not be identified and were used exclusively for the study. Due consideration was given to the publication of the research results so as not to enable the identification of individuals. The study was conducted with approval from the Humanities Research Ethics Committee of University of Tsukuba (code 2019-35A).

III. Results

1. The numbers of Support Coordinators assisting MwID during their pregnancy and parenting

The numbers of participants who provided responses regarding each of the seven stages of MwID's pregnancy and parenting were (a) the first half-period of pregnancy: 16, (b) the second half-period of pregnancy to childbirth: 18, (c) neonatal: 20, (d) infancy: 27, (e) preschool childhood: 33, (f) school-age childhood: 36, and (g) adolescence: 23 (with overlaps). Five of the 78 respondents wrote that they began working with MwID after their children reached adulthood. The way these numbers gradually increase as pregnancy advances and children grow up suggests that few Support Coordinators start assisting MwID before or during the first half-period of their pregnancy.

2. Types of consultation support

The respondents were asked to select the support items corresponding to the assistance that they had provided or were providing to MwID. As shown in Table 2, the results indicated that over half the respondents were engaged in the types of support that constitute their primary duty of consultation support (e.g., "consultation" and "arrangement for support"). On the other hand, the results also revealed that some Support Coordinators were engaged in duties that did not fall under their primary responsibility, notably in-person assistance such as accompanying MwID during medical consultations and instructing MwID in childcare procedures (the support items shaded in the table).

3. Free descriptions about consultation support

The survey results mentioned in the preceding section indicate that the Support Coordinators have provided indirect assistance and, as the need arose, direct assistance as well. Free descriptions given by the respondents reveal environments surrounding MwID, the processes through which they have come to receive assistance, the details of support and so forth. The results of our analysis point to four core categories of assistance provided by Support Coordinators to MwID: consultation support, (support for) emotional and physical health and safety, (assistance relating to MwID's) family environment and daily issues, and parenting support. Table 3-1 to 3-3 indicate categories and codes. In this paper henceforth, the core categories, the categories and the codes shown in Table 3-1to 3-3 are marked with three sets of brackets, respectively: { }, < > and [ ]. Excerpts from the respondents' free descriptions are italicized. The following are our detailed commentaries on the core categories.

{Consultation support}

The support items classified under this core

Table 2 Support for MwID during their pregnancy and infant parenting

Stage	Support items	No. of respondents choosing this item	No. of respondents	Percentage
a. First 20 weeks of pregnancy	(1) Accompaniment during medical consultations	3	16	18.8%
	(2) Supported decision making on continuation of pregnancy	3		18.8%
	(3) Arrangement for support	8		50.0%
	(4) Provision of information on childbirth	5		31.3%
	(5) Consultations	11		68.8%
b. Week 21 of pregnancy to childbirth	(1) Accompaniment during medical consultations	5	18	27.8%
	(2) Preparation for maternity expenses	0		0.0%
	(3) Preparation for childbirth	3		16.7%
	(4) Coordination with healthcare institutions	10		55.6%
	(5) Assistance with childbirth formalities	4		22.2%
c. Neonatal	(1) Coordination with healthcare and welfare institutions	12	20	60.0%
	(2) Arrangement for support	11		55.0%
	(3) Formation of a 24-hour support system	4		20.0%
	(4) Instruction in childcare procedures	4		20.0%
d. Infancy	(1) Provision of information on social resources available in the community	14	27	51.9%
	(2) Arrangement for support	18		66.7%
	(3) Instruction in childcare procedures	8		28.6%
	(4) Assistance with nursery admission formalities	10		37.0%

NB: The shaded items involve direct assistance.

category predominantly corresponded to the Support Coordinator's duties. For this reason, under this core category, similar codes were found in different stages (see Table 3-1). The descriptions of these support items mainly concerned the situation in which consultation support began and the contents of consultation support.

Firstly, many descriptions of the situation in which consultation support began were found under the category <consultation support/supported decision making>. For example, a Support Coordinator who had already known the MwID or the child's father before her pregnancy began working with her upon receiving a request for [consultation on pregnancy/report of pregnancy], which is a code. In other cases, Support Coordinators began assisting the MwID in their charge when another organization that had initially looked after her contacted them after her pregnancy was discovered (e.g., [referral from other (healthcare, medical or administrative) organization], [referral from a nursery]).

As for descriptions about the contents of consultation support, the code [consultation on daily life and livelihood] relating to daily difficulties and poverty was found in many stages. To help MwID cope with daily difficulties, including the difficulty of child rearing, the <formation of a cooperation and support system> of professionals took place. Within the category <formation of a cooperation and support system>, there were differences depending on stages. For example, during MwID's pregnancy, the principal focus was [multi-organizational cooperation], which was promoted mainly through the [formation of a support system through support meetings]. On the other hand, the free descriptions indicated that after the childbirth, while the support system thus formed was maintained, [case meetings and consultation] were conducted, which developed into [support through multi-organizational cooperation]. The category <arrangement for support> also evolved through the stages. In concrete terms, immediately before and after

Table 3-1 Structure of support provided by Support Coordinators to MwID

Core categories { }	Categories 〈 〉	Stage (a) Code [ ]	Stage (b) Code [ ]	Stage (c) Code [ ]	Stage (d) Code [ ]	Stage of description	Example descriptions
Consultation support	Consultation support/Supported decision making	Consultations on pregnancy/ report of pregnancy	Consultations on pregnancy			(a) (b)	Advice sought by telephone. Pregnancy reported. Severe vomiting and dizziness; taken to hospital two or three times. Request for advice, followed by consultation at OB/GYN.
		Supportede decision making about childbirth	supported decision making about childbirth		Confirmation of MwID's intention	(a) (b)	After pregnancy was detected, MwID's intention to give birth was confirmed. There was no other choice but to go ahead until childbirth; MwID decided to give birth, after her intention was confirmed.
			Detection of pregnancy in the second half-period			(b)	MwID not aware of pregnancy until second half-period. Handbook for person with ID not yet obtained at this stage. Support Center was working with her sibling (with ID; handbook holder). OB/GYN consultation following request for advice.
		Referral from a public health center	Referral from other (healthcare, medical or administrative) organization		Referral from a nursery	(a) (b) (d)	The city's public health center contacted after her pregnancy was confirmed. Visited MwID after a request for planning support from a healthcare institution and the city's disability welfare section. Received a telephone call from a day nursery asking for support for a mother of a newborn baby and a 1-year-old child.
		Consultations on daily issues	Consultations on family budget and poverty		Consultations on daily life and livelihood	(a) (b) (d)	Consultations on daily problems. Consultations on family budget began at the same time (MwID seeking service of National Council of Social Welfare, her mother-in-law seeking advice on autonomy) Provided emergency consultations (money problem, fatigue from parenting, etc.)
			Planning			(b)	During MwID's pregnancy, a public health nurse worked as key caregiver, providing most support; immediately after childbirth, Support Coordinator drew up a Plan and coordinated with the support office to enable MwID to benefit from public services (housekeeping assistance).
					24-hour response by telephone	(d)	Infant home and Child and Family Center. Visiting days. Arrangement for a mobility assistant. All times. 24-hour reception of telephone calls.
					Provision of information on social resources	(d)	Information shared with the organization providing parenting support; arranged for helpers' support.
	Formation of a cooperation and support system	Multi-organizational cooperation	Consultations and cooperation with multiple organizations	Support through multi-organizational cooperation	Support through multi-organizational cooperation and collaboration	(a) (b) (c) (d)	Support structure was built through meetings. At that time, MwID was shifting to community support from a disabled children's facility after graduating from a special needs school. Communication and coordination with the helper was continued, cooperation maintained with the healthcare institution and public health nurse. Assisted in preparing an environment necessary for a newborn in collaboration with the Child and Family Section and Health Section. Formalities for nursery admission were completed by the child's parents; coordination with the nursey following admission was conducted by the public health nurse and the Ward Office. Support Coordinators shared duties with them, taking up duties such as advice on what to do at the nursery and listening to the parents' complaints about the nursery.
		Formation of a support system through support meetings	Formation of a support system, support meetings for that purpose	Case meetings and consultations	Information sharing mainly through case meetings	(a) (b) (c)	Emergency meeting of caregivers and nighttime assistants was convened [following request for advice from the father living in a group home and the referred mother]; cooperation was promised on condition that a day assistant would be posted at the group home if it would take charge. Case meetings linking the public health center, public health nurses, city hall personnel and midwife were repeated. Meeting of related parties was held at University Hospital after childbirth; contents of support, roles of different organizations, information sharing, etc. were reconfirmed.
				Problems with cooperation		(c)	It was difficult for the parents to raise several children, and cooperation with the child welfare center was indispensable but turned out to be insufficient.
				Handover due to relocation		(c)	After one week of hospitalization [for childbirth], MwID joined her husband at his place to start a new life together; handover of administrative matters necessitated by relocation turned out to be complex.
	Arrangement for support	Coordination for more home nursing care visits	Arrangement for support	Arrangement for support in housekeeping and parenting	Arrangement for support	(a) (c) (d)	Arranged for an increased frequency of the welfare service (visits by home nursing care helpers) that MwID had been using for a long while. A 24-hour system was not put in place because of the husband's presence, but the number of helpers was increased to be ready for emergency response. Arranged for regular visits by a public health nurse, consultations on development, etc.
		Coordination with support for older children	Support for older children/ support coordination			(a) (b)	Provided consultations during MwID's pregnancy with her second child about how to reconcile care for the severely handicapped first born. Coordinated support immediately before and after childbirth for older children with their related organizations; prepared for service use (short-term residential facility).
		Coordination with employer				(a)	MwID quit her work at a facility upon learning of her pregnancy; for physical health management, she started going to the type-B office that she used to go before.

NB 1: Information based on which addresses and individuals could be identified was anonymized during the production of verbatim records. The example descriptions are English translations of the verbatim records.
NB 2: The phrases/terms in [ ] denote corrections or clarifications on descriptions given on the questionnaire sheet or additional elements obtained by the author from the respondents by telephone.
NB 3: The letters designating the stages of description are (a) the first half-period of pregnancy, (b) the second half-period of pregnancy to childbirth, (c) neonatal, and (d) infancy.
NB 4: The cells of codes corresponding to direct assistance by Support Coordinators are shaded.

Table 3-2 Structure of support provided by Support Coordinators to MwID

Core categories { }	Categories 〈 〉	Stage (a) Code [ ]	Stage (b) Code [ ]	Stage (c) Code [ ]	Stage (d) Code [ ]	Stage of description	Example descriptions
Emotional and physical health and safety	Emotional and physical health and safety	Support relating to fits				(a)	Regular medical consultations in preparation for childbirth, and to treat fits; medication started.
		Support for mitigating anxiety			Support for emotional stability	(a) (c)	Increased meeting frequency to mitigate MwID's anxiety. Talked with MwID to give advice-like tips on parenting and introduced the community service office to [reduce] emotional burden on her
					Advice on health issues	(d)	Visited her when she was sick; advised to go see a doctor.
					Coordination with family members for better relationships	(d)	Coordinated for better relationship with her former foster parents.
	Sterilization			Salpingectomy		(c)	MwID reported her salpingectomy because she didn't want a third child.
	Violence/ exploitation by family				Physical aggression by the husband	(d)	After two months [of moving into the husband's parents' house], MwID complained of the husband's violence during a row; MwID was temporarily placed in a shelter.
					Economic exploitation by MwID's birth mother	(d)	MwID's mother (also with ID) supported in the room next door; the mother (grandmother) also handled money and spent it on gambling.
Family environment and daily issues	Family also requiring support	Dealing with and support for the child's father				(a) (a)	The employment support center contacted the child's father and asked his ideas about the future. Assisted MwID's boyfriend in finding employment.
		Difficulty in obtaining support from family members living together				(a)	MwID cannot reply on her family living together for support after childbirth because the family also needs support; she wanted a support system to be put in place for childbirth.
	Environmental changes		Marriage/living together with parents-in-law	Relocation		(b)	MwID got married while pregnant and moved from the welfare facility to the husband's parents' house; home visits began in response to this major environmental change.
	Daily and parenting issues and difficulties		System for monitoring the child in view of the mother's disease			(b)	The need for a constant monitoring system was a major issue if MwID, with epileptic fits, was to raise a newborn herself.
				Difficulty in interpersonal relationships and parenting	Influence of MwID's upbringing	(c) (d)	Listened to MwID on the phone about her relationship with boyfriend, rows with her [husband], problems with her mother and younger brother, parenting stress, and so forth. MwID did not make progress in baby food preparation since she did not understand the need for cooking well, due to her childhood environment void of home cooking.
	Parenthood				Motherhood, maternal awareness	(d)	Helper visits to support MwID and watch over the baby; support terminated due to MwID's lack of awareness.
	Difficulty in using support services		Difficulty in using pregnancy helpers due to poverty	Proposal for service use refused by the mother	Difficulty in using support services	(b) (c) (d)	Proposal for the use of pregnancy helpers in view of the condition of the room refused due to expenses. MwID reported irritation because of the baby's crying at night; short-term stay in a residential facility was recommended, but MwID declined because she was afraid that the facility might take custody of the baby. Despite advice on buying good food items [for preparing baby food], the cancellations of helpers' support became frequent.
	Support from family			Support from family	Support from family and relatives	(c) (d)	Support mainly provided by MwID's family. Support mainly provided by the husband and the parents living together.
	Assistance in employment search				Support for the mother's employment	(d)	Recommended early admission of the baby to a nursey as MwID's parenting skills were not reliable; since the mother's employment is a condition for nursery use, had MwID obtain her handbook for persons with ID and register at the employment support center to receive vocational training.

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NB 2: The phrases/terms in [ ] denote corrections or clarifications on descriptions given on the questionnaire sheet or additional elements obtained by the author from the respondents by telephone.
NB 3: The letters designating the stages of description are (a) the first half-period of pregnancy, (b) the second half-period of pregnancy to childbirth, (c) neonatal, and (d) early infancy.
NB 4: The cells of codes corresponding to direct assistance by Support Coordinators are shaded.

Table 3-3 Structure of support provided by Support Coordinators to MwID

Core categories { }	Categories 〈 〉	Stage (a) Code [ ]	Stage (b) Code [ ]	Stage (c) Code [ ]	Stage (d) Code [ ]	Stage of description	Example descriptions
Parenting support	Accompaniment to OB/ GYN clinic and other medical institutions	Accompaniment to the clinic and related support	Accompaniment to the clinic			(a) (b)	Accompanied MwID for hospital consultations; explained the situation to the physician. MwID mainly accompanied by a helper for medical consultations; Support Coordinator had to accompany the mother when she was expected to receive important information.
	Preparation for childbirth	Assistance with preparation for childbirth	Preparation for, assistance with formalities for, and advice on childbirth			(a) (b)	Maternity education carried out with support from the Children's Affairs Section. Accompanied MwID to the public health center to have a maternity handbook issued there; pregnancy reported to the Children's Welfare Center; contacted MwID's Type-B office to notify her absence for a while.
	Abundant support for mother and child, including visits			Inspection of living conditions		(c)	Living conditions inspected through a monthly visit.
				Public health nurse's visits and similar support	Support mainly provided by public health nurse	(c) (d)	The public health nurse increased visits to ensure the newborn's safety and instruct MwID in parenting. Public health nurse's periodical visit (once/week) continued to check on the baby's condition, including body weight management, and the mother's condition.
				Multi-organizational support through visits	Multi-organizational support through visits	(c)	Regular visits by a public health nurse, [activity center] personnel and Support Coordinator (with one case meeting held every few months).
						(d)	Support was mainly provided by a public health nurse and parenting assistants; Support Coordinator provided backup support together with the welfare facility [that MwID used to go to before], checking her intentions, coordinating with her former foster parents for better relations, or serving as a "shelter" when she had quarrels with her husband.
					Support by helpers	(d)	Support by helpers continued.
				24-hour support system	All-around parenting support	(c) (d)	24-hour support system was put in place, with day support [at the group home] until the baby was old enough to be sent to a day nursery (1 years of age). All-around parenting support by personnel of a living support facility for mothers and children.
	Support for the acquisition of parenting skills			Public health nurse's instruction in parenting skills	Preparation of baby food, explanation about and advice on the weaning period	(c) (d)	Following childbirth, a public health nurse visited every day to instruct MwID in bathing the baby and other procedures, but her level of understanding was low, and the health nurse was asked to give instruction in procedures modified to suit her ability. The city's public health nurse requested instruction in baby food preparation and feeding and parenting support; visited MwID and advised her about how to make and give baby food, different stages of baby food and so on.
					Parenting support by helpers	(d)	Assisted helpers in baby food preparation; waited for MwID's motherhood to develop.
	Assistance relating to nursery use				Assistance relating to nursery admission	(d)	MwID was interested in raising the child at home, but Support Coordinator recommended the use [of nursery] due to the mother's frequent irritation; filled out nursery application documents; MwID was not sure what to write in a statement; worked it out together and prepared a truthful document.
					Issues while on waiting list for nursery admission	(d)	One month after [applying for nursery admission], MwID contacted, saying that she wanted to admit the baby to a nursery soon; inquiries made at Family Support facilities and private nurseries; visited MwID, who was irritated and talked about her stress.
					Support meetings in response to nursery's difficulty in dealing with MwID and child	(d)	Helper visits to support MwID and watch over the baby; support terminated due to MwID's lack of awareness. Meetings convened in view of the nursery's difficulty; support needs were confirmed.
	Admission of the baby to an infant home			Coordination for infant home admission and visits	Coordination for infant home admission and visits	(c)	Infant home as a solution until the baby is in a more stable condition; the mother often visited the baby there with the older child.
	Assurance of the child's development				Support for the child's development and special needs education	(d)	The child's development will be followed once the mother and child start going to a special needs education center together; related organizations were contacted.

NB 1: Information based on which addresses and individuals could be identified was anonymized during the production of verbatim records. The example descriptions are English translations of the verbatim records.
NB 2: The phrases/terms in [ ] denote corrections or clarifications on descriptions given on the questionnaire sheet or additional elements obtained by the author from the respondents by telephone.
NB 3: The letters designating the stages of description are (a) the first half-period of pregnancy, (b) the second half-period of pregnancy to childbirth, (c) neonatal, and (d) early infancy.
NB 4: The cells of codes corresponding to direct assistance by Support Coordinators are shaded.

childbirth, [coordination with support for (MwID's) older children] was carried out, and following the childbirth and during child rearing, support was arranged in such a manner as to anticipate and prepare for emergencies. These findings point to the correlation between the core categories {consultation support} and {parenting support} (the latter is discussed below).

{Emotional and physical health and safety}

As shown in Table 3-2, this core category assembles descriptions of problems relating to MwID's health and safety and responses to these problems. Some Support Coordinators responded to the MwID's problems so as to maintain her emotional and physical health along with the progression of her pregnancy, as exemplified by the codes [support relating to fits], [support for emotional stability] and [coordination with family members for better relationships]. There were also cases in which MwID's emotional problems were caused by <violence/exploitation by (MwID's) family>. Detailed descriptions were also given of cases of emergency assistance involving such abuse.

Except for the case of one MwID who had undergone a surgical <sterilization>, there were no descriptions of invasive medical procedures or family planning.

{Family environment and daily issues}

The descriptions under this core category revealed MwID's family environments and daily issues, as indicated in Table 3-2. These descriptions are commented on in detail below.

There were descriptions of MwID who were able to obtain <support from family> and completed parenting without resorting to external welfare services for PwD. Some descriptions about MwID's family environments suggested the existence of <family members also requiring support> and <environmental changes>. Conversely, for MwID in a family environment with <family members also requiring support>, the Support Coordinators had to arrange for the use of public welfare services for PwD because the MwID in their charge were not able to benefit from sufficient support. With respect to the use of such services, MwID's [Influence of MwID's upbringing] and [Motherhood] were pointed out as issues.

The descriptions of daily issues indicated the way these issues and support provided in response to them changed as MwID's children grew. Concretely, in one case, it was stated that during the MwID's pregnancy, there was much apprehension for a system to be put in place for <monitoring the child in view of the mother's disease> . Following the childbirth, more specific problems, such as "*irritation because the baby cried a lot at night* (example excerpt)," were noted as daily issues. There was also a case in which assistance was provided in arranging for the MwID's employment once the baby was old enough to be entrusted to a day nursey. This was intended to reduce the child-rearing burden on the MwID. Some descriptions pointed to the <difficulty in using (public) support services>, which were provided presumably to deal with daily issues. The <difficulty in using support services> derived from diverse aspects and causes, ranging from expenses to apprehensions about the child's custody and the mother's refusal of helpers' advice.

{Parenting support}

The descriptions under this core category pointed to the general tendency of assistance expanding and evolving as the child grew up, as show in Table 3-3. Direct assistance by Support Coordinators, identified in Table 2, was concentrated in {parenting support} (support items of direct assistance are shaded in the table). The chronological evolution of direct assistance begins with [accompaniment to the clinic] and [preparation for, assistance in formalities for, and advice on childbirth], found among the categories during MwID's pregnancy. Accompaniment to medical institutions available within the framework of public welfare services for PwD is in fact assistance with travelling to and from medical institutions and does not cover accompa-

niment during medical consultations. Because of this limitation, "*the Support Coordinator had to accompany the mother when she was expected to receive important information* [during the consultation]." There were also cases in which Support Coordinators flexibly responded to needs personally expressed by the MwID in their charge, as expressed in this description: "*She called me saying that she had torn up the documents required for hospitalization* [for childbirth] *because she was feeling irritated; so I visited her and filled out the documents for her*." As for <support for the acquisition of parenting skills>, which commenced following childbirth, large numbers of public health nurses and care providers were involved in home nursing care for MwID. In some cases, however, Support Coordinators were also involved in [preparation of baby food, explanation about and advice on the weaning period]. In the infancy stage, under the category <assistance relating to nursery use>, Support Coordinators assisted the MwID in preparing application documents for nursey admission etc.

As with direct assistance, indirect assistance also expanded as the child grew. Support Coordinators were expected to engage in communication and coordination with public health nurses and other personnel involved in home nursing care and the child's nursery and other nursing facilities, as well as in arrangement for support and consultation support.

The MwID's child was entrusted to an infant home in multiple cases. In such cases, Support Coordinators provided [assistance in infant home admission including support for the parents on the occasion] and assistance relating to [visits to the child at the infant home], thereby continuing support for the mother and the child. The reasons for the child's admission to an infant home given in the free descriptions included the following: "*the decision that parenting would be difficult*," "*as a solution until the baby is in a more stable condition*," and "*the baby was temporarily admitted to an infant home because it was difficult for* [the baby's parents] *to raise him due to constant trouble between them*." Other than the cases in which the parents' constant trouble was the main cause of their difficulty in parenting, there were no descriptions of PwID's intentions or assessing the desirability of parent-child separation.

IV. Discussion

This paper has presented the study we conducted to analyze the assistance that Support Coordinators provided to MwID during their pregnancy and infant parenting so as to clarify the actual situations of support for MwID in Japan. Our study that Support Coordinators was not only for {consultation support} but also in the {emotional and physical health and safety} of MwID. Essentially, Support Coordinators work with individuals with disabilities. However, our study revealed that, in assisting MwID, Support Coordinators responded to their and their families' needs by providing **{**parenting support**}** and even helping them deal with their **{**family environment and daily issues**}** in some cases. Particularly in {parenting support}, Support Coordinators were providing direct assistance. Such growing assistance revealed the evolution and expansion of the Support Coordinator's assistance as MwID's children grew up.

As stated in {family environment and daily issues}, assistance was arranged based on the degree of MwID's difficulty in doing household tasks deriving from [Influence of MwID's upbringing] and the degree of [Motherhood], suggesting the social expectations placed upon MwID of their gender. Meanwhile, Support Coordinators did not reach out to MwID if they were able to obtain support from their partner and family members. This is probably why Support Coordinators began working with MwID after their pregnancy became known in many cases (Nobuhara & Nagawa (2021: 112). Meanwhile, in cases where partner and family members were not able to support MwID, some began working with MwID following a referral from a local governmental organization, healthcare institution or child rearing support organization

that the women used upon becoming pregnant. Many formal organizations, including intermediary organizations and welfare service offices for persons with disabilities, cooperated and collaborated in assuring assistance to MwID. In such a situation, the expansion of indirect assistance seems presumably inevitable. On the other hand, our study confirmed direct assistance provided by Support Coordinators which are not their primary tasks, represented by the seven codes in the shaded cells in Table 3-3. Among them, we focus our discussion here on [accompaniment to the clinic], [preparation of baby food, explanation about and advice on the weaning period] and [assistance relating to (the child's) nursery admission]. With regard to [accompaniment to the clinic], the public welfare services for PwD provided under The Act do not fully cover MwID's medical consultations, as mentioned above. However, it is believed that MwID's regular adherence to prenatal checkups largely depends on the availability of accompaniment by support providers (Kid & Hayashi, 2002: 52). That is to say, there is a need to develop a structure that ensures both reasonable consideration on the part of healthcare providers and personal support by MwID advocators during MwID's consultations at the OB/GYN clinic. As for [preparation of baby food, explanation about and advice on the weaning period], our study found some cases in which such support was provided by public health nurses and/or home nursing care providers. In other words, these acts should not necessarily be considered as duties for Support Coordinators. In the cases where Support Coordinators engaged in these types of assistance, they probably did so while being conscious of the assignment of public health nurses and home nursing care providers in the region or by flexibly responding to MwID's needs. PwID require flexible support, and assistance to them must flexibly and closely follow the families' needs at any given time (Tarlton et al., 2006; IASSIDD Special Internet Research Group on Parents and Parenting with Intellectual Disabilities, 2008). However, the free descriptions given by Support Coordinators in our survey suggest that Japan's social welfare system is not constructed in such a way as to allow for flexible responses to the needs of concerned persons and their families. For example, child and family welfare system does not assume parenting by MwID, so Support Coordinators seek cooperation of welfare services for PwD. However, neither do the welfare services for PwD focus much on MwID's needs concerning life events such as marriage, pregnancy, childbirth and parenting nor the lingering gender roles, making it difficult for Support Coordinators to arrange social resources for providing social support for MwID. It is fair to say that these circumstances required Support Coordinators to provide direct support.

Therefore, it is necessary that MwID raising children also be made eligible to receive "visiting care for persons with severe disabilities", a service currently provided only to severely disabled people. The visiting care for persons with severe disabilities is operated flexibly, enabling provision of a variety of assistance for a long period of time by support workers familiar to the MwID in question. To be more concrete, home-based training programs on parenting carried out outside Japan and nimble and well-thought assistance including escort services for children visiting hospital, going to nursery school, and MwID visiting public institutions will be possible (Llewellyn et al., 2002). Furthermore, the research points out the existence of mothers whose intellectual disability manifests during their parenting period (Llewellyn et al., 2010: Nobuhara & Nagawa, 2021). Given this situation, it is also essential to establish a parenting support system available to anyone as long as they are raising children.

V. Conclusion and Limitations

This study has also found that support by Support Coordinators for MwID before and during their pregnancy and neonatal and infant parenting stages expands and evolves as their children grow up, necessitating Support Coordinators to

engage in direct assistance, which are not their primary duties. This situation revealed the need for welfare services that covers circumstances not assumed by both child and family welfare services and welfare services for PwD.

Based on theses, I would like to recommend the following two improvements, namely, 1. Expand the scope of people eligible for receiving visiting care for persons with severe disabilities. 2. Change child and family welfare services to ones that assume the existence of mothers with different difficulties.

The study only focused on MwID already benefitting from welfare services for PwD, and therefore it is limited in that many other MwID were not taken into consideration. This limitation should be addressed in future studies.

Footnote

1 In this study, the term "social support" is defined as "affirmative, active and mutual functions that occur in social relationships [including those with family members and relatives] that surround individuals, such as confidence, affirmation, information sharing, and assistance in the form of material goods, labor and services (Kita, 1997).
2 Some municipalities also dispatch pregnancy and postpartum helpers. Some municipalities also operate their own voluntary parenting support programs.
3 The Medical rehabilitation handbook is issued to those who are judged to have intellectual disabilities by the child guidance center or the Rehabilitation Consultation office for people with intellectual disability (Ministry of Health, Labor & Welfare, 2020).

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