

## SURVEY OF SUPPORT FOR PREGNANT AND PUERPERAL WOMEN WITH DEVELOPMENTAL DISABILITIES

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### Abstract

In Japan, no support system for mothers with developmental disabilities is currently in place. This study aimed to clarify the actual situation of support for pregnant and puerperal women with developmental disabilities in obstetrics and gynecology-related facilities. A self-administered questionnaire survey including free-form questions was distributed to 120 obstetrics and gynecology facilities in Prefecture A. The questionnaire responses were analyzed using descriptive statistics. The free descriptions were categorized and analyzed inductively. The valid response rate was 40.8% (n = 49). Twenty-five facilities reported dealing with pregnant and puerperal women with developmental disabilities, more than half of which provided support. None of the facilities had guidelines or pamphlets. Medical professionals felt a [lack of knowledge] and [difficulty in dealing with] support for mothers with developmental disabilities, and demanded the [construction of a support system]. The present findings revealed that all facilities had problems with support systems and regional cooperation. Therefore, the establishment of a support method suitable for pregnant and puerperal women with developmental disabilities is needed.

**Keywords:** Childcare support, developmental disabilities, multidisciplinary collaboration.

### INTRODUCTION

The term developmental disability was coined as a legal term in the United States in the 1960s. In the early 1980s, the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) proposed three types of disorders: infant autism, childhood-onset pervasive developmental disorder, and atypical pervasive developmental disorder. At that time, children developmental disabilities were the focus. In Japan, the term developmental disability began circulating in the 1970s. However, despite the diagnosis of developmental disorders for over 30 years, the legal system in Japan has remained underdeveloped. Although the Developmental Disability Support Law was enacted in Japan in 2004, Japan's response is still currently far behind.

For the purposes of the present study, we focused on adult developmental disorders. It is thought that when the revised version of the DSM-III (DSM-III-R) was published in the late 1980s, the focus was on adults with developmental

disabilities, and thus, the target of developmental disabilities began to include not only children, but also adults. Outside of Japan, a survey is being conducted on people with intellectual and developmental disabilities (IDDs). Health care support for adults with IDDs has been shown to require a navigation system from health-care professionals (Potvin & Fulford, 2019). Older people with IDDs have also shown the need for a personalized care plan and an understanding of the target of the medical staff (Lougheed, 2019). Mothers with IDDs have been shown to experience various problems, including a lack of social support, domestic violence, and concerns about parenting (Xie & Gemmill, 2018), and thus, to require public support from therapists, social workers, public health nurses, and doctors, as well as private support from partners and family members (Heifetz, Brown, Chacra, Tint, Vigod, et al., 2019). In regions other than Japan, research on postpartum mental health and support for women is increasing. For example, postpartum mental health should provide family counseling and health education regarding the needs of patients during hospitalization (Maryati, Astuti & Solehati, 2018). In addition, programs are being developed to prevent postpartum mental health disorders (Pan, Chang, Chen & Gau, 2019). Therefore, even healthy women rearing children are offered more support than those with developmental disabilities.

We believe that the support system for mothers with developmental disabilities from pregnancy to the childcare stage is inadequate, and at present, Japan has still not enacted any new legislation for such mothers, even though they are prone to postpartum depression, suicide, and abuse. Women with developmental disabilities in Japan have difficulty building relationships with their family and performing multiple tasks because of the characteristics of the disorders (Iida, 2018; Iwata, 2015; Nakazawa, Haruki, & Koujida, 2018; Sasaki, Soto, Kudou, & Chouri, 2015). In addition, their families often struggle with specific ways of providing support (Iida, 2018; Iwata, 2015; Nakazawa et al., 2018; Sasaki et al., 2015). Even in these situations, medical staffs have few references to a support system that they can provide to mothers with developmental disabilities who are rearing children.

Given this background, we believe that it is necessary to establish a

support system for women with developmental disabilities from pregnancy to the childcare period at an early stage. However, we thought that without understanding the actual situation of medical practice in Japan, it would not be possible to build a support system for women with developmental disabilities and those who provide support. Therefore, the purpose of this study was to investigate the actual situation of support for pregnant and puerperal women with developmental disabilities in actual obstetrics and gynecology-related facilities.

## **METHOD**

### **Survey method**

This study was designed as a self-administered questionnaire survey. Questionnaires were distributed by mail to 120 obstetrics and gynecology facilities (i.e., hospitals with obstetrics and gynecology departments, obstetrics and gynecology clinics, and midwifery hospitals) throughout Prefecture A in Japan for a fact-finding survey. We asked the managers, ward chiefs, and directors of the maternity homes to complete and return the questionnaires. The collection period was from January to March 2021.

The questionnaire was composed of items on the following nine topics: medical status; number of obstetric beds; developmental disability tendency and presence/absence of support for people with developmental disabilities; corresponding type of developmental disability; corresponding health-care professional; how to respond in the hospital; support for discharge; medical professionals working with multiple occupations; and cooperation destination. Some questions allowed multiple answers whereas others asked for only one. Answers regarding ideas for support for pregnant and puerperal women with developmental disabilities were given using free descriptions.

### **Analysis methods**

#### *Questionnaire analysis method*

The questionnaire was analyzed using descriptive statistics in Microsoft Excel 365 (Redmond, WA, USA). The responses were tabulated for each item in the questionnaire and expressed as percentages. Numerical values were then

compared for each item and analyzed.

*Free description analysis method*

The responses given as free descriptions regarding ideas for support were inductively categorized and coded while taking care to retain their meaning. They were then classified into codes with similar meanings and sorted into subcategories. The subcategories were then divided into groups based on similarity. These groups were given new names and reclassified as categories and new categories.

**Ethical considerations**

The questionnaire was conducted anonymously and did not contain any personal information, which made it difficult to identify any participating facility. The collected questionnaires will be stored strictly for 10 years and then discarded. This study was approved by the ethics committee of our institution (No. 1611; approval date: January 8, 2021).

**RESULTS**

**Summary of survey results**

We distributed questionnaires to 120 facilities. The recovery and valid response rates were 45.0% (n = 54) and 40.8% (n = 49), respectively. Among all facilities, one omission and four closures were excluded from the analysis.

Regarding medical conditions (multiple answers allowed), many hospitals had gynecology (81.6%) and obstetrics (59.2%) outpatients. In addition, obstetric admission was not possible in 50.1% (n = 26) of the institutions, although 51.0% had dealt with developmental disabilities or pregnant and puerperal women with developmental disabilities (Table 1).

**Table 1. Overview of Obstetrics and Gynecology-related Facilities N = 49**

Medical status	Gynecological outpatient	81.6%
	Obstetrics outpatient	59.2%
	Obstetric hospitalization (including delivery handling)	46.9%
	Breast care outpatient (including a midwifery home specializing in breast care)	42.9%

	Gynecological hospitalization and postnatal care (no hospital facility)	30.6%
	Midwifery outpatient	24.5%
	Postpartum care (with hospital facilities)	22.4%
Obstetric hospitalization facility	1–20 beds	18 cases
	21–40 beds	5 cases
	Facilities that had never dealt with developmental disabilities or pregnant and puerperal women with developmental disabilities	49.0%
	Facilities that had dealt with developmental disabilities or pregnant and puerperal women with developmental disabilities	51.0%

### **Current status of facilities that had dealt with developmental disabilities or pregnant and puerperal women with developmental disabilities**

Twenty-five institutions treated pregnant and puerperal women with developmental or developmental disabilities. The most frequent developmental disorder encountered was attention deficit hyperactivity disorder (ADHD), which accounted for about half. Autism spectrum disorders (ASD) and learning disabilities (LD) were similar. Most of the medical specialists were general doctors or nurses. In addition, a psychiatrist was involved when the consent of the person was obtained. Many facilities did not provide support, including guidelines or pamphlets. However, mechanisms to share information from pregnancy to the postpartum childcare period were in place for pregnant women who needed support in cooperation with a public health nurse. There was also a medium for working with a psychiatrist to visualize the time schedule.

Regarding discharge support, outpatient breast department appointments and health examinations were available at 2 weeks after discharge. Guidance to family members other than the husband (e.g., parents, step-parents, siblings) was more common than guidance to the husband. The next most common form of discharge support was to introduce the women to psychosomatic medicine (psychiatry). Midwives and chief nurses dealt with the collaboration between medical personnel and other occupations (e.g., health-care workers, social workers). Regarding support partners, municipal health centers were the most common, followed by psychosomatic medicine (psychiatry) (Table 2).

**Table 2. Actual Conditions of Each Facility for Pregnant and Puerperal Women with Developmental Disabilities *N* = 25**

Types of developmental disabilities (Multiple answers allowed)	ADHD	40.0%
	ASD	20.0%
	LD	16.0%
	Developmental disability tendency	80.0%
How to respond in the hospital (Multiple answers allowed)	Conference	36.0%
	Create a format for sharing information with other departments	16.0%
	Study group	4.0%
	Not supported	72.0%
	Guidelines and pamphlets	0.0%
Support for discharge (Multiple answers allowed)	Make an appointment for a breast care outpatient clinic or a medical examination 2 weeks after discharge	60.0%
	Guidance for family members other than the husband (e.g., parents, step-parents, siblings)	52.0%
	Introducing psychosomatic medicine (Psychiatry)	40.0%
	Guidance for husband	36.0%
	Prioritize sleep (including the mother and child not sharing the room at night)	32.0%
	Psychosomatic medicine (psychiatry) consultation during hospitalization	28.0%
	Make a phone call after discharge	16.0%
	Not individualized	24.0%
	Other	12.0%
	Occupations that collaborate with other occupations (e.g., public health nurses, social workers) (Multiple answers allowed)	Midwives
Nurse chiefs		32.0%
Doctors		8.0%
Cooperation destination (Multiple answers allowed)	City health center	84.0%
	Psychosomatic medicine (psychiatry)	44.0%
	Social worker	24.0%
	Prefectural health center	16.0%
	Clinical psychologist	12.0%
	Not a partner/counselor	12.0%

ADHD: attention deficit hyperactivity disorder; ASD: autism spectrum disorder; LD: learning disorder.

## Opinions

As shown in Table 3, thoughts on support for pregnant and puerperal women with developmental disabilities were categorized into four categories. Below, categories are indicated by [ ] and subcategories by < >.

**Table 3. Thoughts on Support for Pregnant and Puerperal Women with Developmental Disabilities**

Category	Subcategory
	<Need to create an environment for guidance and support by incorporating family members such as husbands>
[Construction of a support system]	<Need to prepare a childcare environment through community support including community building and financial support> <Each facility wishes to share patient information with hospitals, health centers, maternity homes specializing in breast care, psychosomatic medicine, etc.> <Specialized facilities for developmental disorders and a support system for specialists are required>
[Lack of knowledge]	<I do not know how to deal with them because of insufficient knowledge among the medical staff> <I want notes and indicators of support methods based on manuals and guidelines>
[Difficulty dealing with]	<There are large individual differences, it takes time and labor to respond individually, and they feel the limit> <The patient's intention is prioritized, so it is difficult to collaborate with other departments>
[Actual efforts]	<Predicting and responding to the deterioration of the child-rearing environment in the future> <Focusing on support to prevent social loneliness and abuse>

## DISCUSSION

### Research facility background

Japan's total fertility rate in 2019 was 1.36, while that in the surveyed prefecture was 1.39 (Ministry of Health, Labour and Welfare, 2020, 2021). Japan's total fertility rate continues to fall. Comparing the surveyed prefecture with others across Japan, there is almost no difference. In the present study, 120 obstetrics and gynecology-related facilities and midwifery associations in the prefecture were surveyed. However, four had closed because of a decrease in the

number of births and aging doctors. Gynecological outpatients accounted for the largest percentage. Under these circumstances, obstetrics and gynecology-related facilities provide medical care for pregnant and puerperal women. Based on these results, we believe that these women require personalized and generous medical care because of the isolation of child-rearing due to the nuclear family, child-rearing outside the area where they grew up, less involvement of their husbands in child-rearing, and a decrease in the number of children per family. We also believe that cooperation with other departments and occupations is essential for obstetrics and gynecology-related facilities to be able to provide safe and comfortable support.

### **Actual condition of research facility**

The most common developmental disorder in the study facilities was ADHD, followed by ASD and LD. A study of health-care professionals dealing with ASD after adolescence found that understanding the characteristics of ASD alone was not sufficient, and that it was difficult to respond because of the complexity of symptoms due to secondary disabilities and the effects of life history (Iida, et al., 2020). Medical professionals should be able to consider guidance and support methods that capture their characteristics. Furthermore, the results of this study showed that the tendency to experience developmental disabilities was very high. Developmental disability tendencies are only the subjective sensation of the health-care professional dealing with the patient. However, it has been reported that women with ADHD may be more likely to develop postpartum depression after the birth of their first child (Dorani, Bijlenga, Beekman, Someren & Sandra, 2021). Therefore, more attention needs to be paid to mothers with developmental disabilities.

The most common response for in-hospital responses was the holding of conferences. On the other hand, 72.0% of the facilities did not provide support. None of the facilities had guidelines or pamphlets. The category of [Lack of knowledge] included the subcategory <I want notes and indicators of support methods based on manuals and guidelines>. In addition, the category of [Difficulty dealing with] included the subcategory <The patient's intention is



prioritized, so it is difficult to collaborate with other departments>. Based on this situation, it is necessary to educate medical professionals, provide unified support methods, and index cooperation methods.

Specifically, a particular midwife was involved with people with developmental disabilities. Midwives were the profession that most often collaborated with other professions (e.g., health-care workers, social workers). In general, it is the midwife who provides childcare guidance and discharge support to pregnant and puerperal women. Most facilities were connected to the local health center. Some facilities did not have a partner or provide consultations. Therefore, an index is needed to clarify the division of roles of each medical staff.

These findings indicate that facilities strove to continue to support people with developmental disabilities even after discharge. Many facilities therefore tried to create a support environment involving the families of husbands and mothers and children. Postpartum mothers require emotional support from people close to them, such as their partners (Maryati, Astuti & Solehati, 2018). Therefore, the involvement of medical professionals from pregnancy should include helping partners (Mamuroh, Sukmawati & Nurhakim, 2019). Developmental disabilities are difficult to understand visually, and it is difficult to understand their characteristics, even within families (Usui & Ishimura, 2017). Whether the family has a receptive attitude depends on whether people with developmental disabilities are positive (Usui & Ishimura, 2017). Therefore, health-care professionals need to be cautious when requesting cooperation from families. Medical professionals were demanding [Construction of a support system], such as through consolidating the corresponding facilities in the prefecture. Parental ADHD can adversely affect early parent–child interactions (Kittel-Schneider, Quednow, & Leutritz, 2021). Therefore, a support system needs to be established from the pregnancy period, as does a system that enables sufficient involvement from the early puerperium period.

### **Study limitations and future tasks**

This study was conducted in only one prefecture. Support for pregnant and puerperal women with developmental disabilities may vary from region to region,

but we believe it is desirable to receive uniform support nationwide. Therefore, in the future, we plan to keep track of the situation nationwide.

## CONCLUSIONS

This study revealed that more than half of the facilities provided their own support. However, the results also suggested that all the facilities had problems with a support system and regional cooperation.

## REFERENCES

- Crossman, M.K., Parish, S.L., Hauser-Cram, P., Garcia, D.A., & Warfield, M.E. (2018a). The influence of early intervention, informal support and the family environment on trajectories of competence for fathers raising children with developmental disabilities. *Res Dev Disabil*, 81, 122–133. <https://doi.org/10.1016/j.ridd.2018.04.025>.
- Crossman, M.K., Warfield, M.E., Kotelchuck, M., Hauser-Cram, P., & Parish, S.L. (2018b). Associations between early intervention home visits, family relationships and competence for mothers of children with developmental disabilities. *Matern Child Health J*, 22(4), 599–607. <https://doi.org/10.1007/s10995-018-2429-x>.
- Dorani, F., Bijlenga, D., Beekman, A.T.F., Someren, E.J.W., & Sandra, K.J.J. (2021). Prevalence of hormone-related mood disorder symptoms in women with ADHD. *J Psychiatr Res*, 133, 10–15. <https://doi.org/10.1016/j.jpsychires.2020.12.005>.
- Heifetz, M., Brown, H.K., Chacra, M.A., Tint, A., Vigod, S., Bluestein, D., & Lunskey, Y. (2019). Mental health challenges and resilience among mothers with intellectual and developmental disabilities. *Disabil Health J*, 12(4), 602–607. <https://doi.org/10.1016/j.dhjo.2019.06.006>.
- Iida, N. (2018). A consideration into four cases of child care supports for mothers with highly-functioning autistic spectrum disorder. *Social Welfare Science Research*, 7, 149–157. (in Japanese).
- Iida, T., Shingu, N., & Hori, Y. (2020). Behavioral characteristics in adolescents and adults with autism spectrum disorder through observation-based evaluation of psychiatric occupational therapy. *Japanese Occupational Therapy Research*, 39(6), 725–732. (in Japanese) [https://doi.org/10.32178/jotr.39.6\\_725](https://doi.org/10.32178/jotr.39.6_725).
- Iwata, C. (2015). The difficulties and needs of mothers with high-functioning autism spectrum disorders (ASD) in raising children: Qualitative analysis of mothers with HF-ASD. *Social Welfare*, 53(3), 44–57.

[https://doi.org/10.24469/jssw.56.3\\_44](https://doi.org/10.24469/jssw.56.3_44).

- Kittel-Schneider, K., Quednow, B.B., Leutritz, A.L., McNeill, R.V., & Reif, A. (2021). Parental ADHD in pregnancy and the postpartum period – A systematic review. *Neurosci Biobehav Rev*, 124, 63–77. <https://doi.org/10.1016/j.neubiorev.2021.01.002>.
- Kokol, P., Vošner, H.B., Završnik, J., Vermeulen, J., Shohieb, S., & Peinemann, F. (2020). Serious game-based intervention for children with developmental disabilities. *Curr Pediatr Rev*, 16, 26–32. <https://doi.org/10.2174/1573396315666190808115238>.
- Lougheed, D.C. (2019). Approach to providing care for aging adults with intellectual and developmental disabilities. *Canadian Family Physician*, 65(Suppl 1), S14–S18.
- Mamuroh, L., & Nurhakim, F. (2019). Relationship between husband support And pregnancy control In pregnant women Sukawening Puskesmas Garut. *Journal of Maternity Care and Reproductive Health*, 2(1), 51-56. <https://doi.org/10.36780/jmcrh.v2i1>.
- Maryati, I., Astuti, N. F., & Solehati, T. (2018). The Perception of Women with Postpartum Depression Towards Family Supports. *Journal of Maternity Care and Reproductive Health*, 1(1), 1-9. <https://doi.org/10.36780/jmcrh.v1i1.11>.
- Medina-Mirapeix, F., Lillo-Navarro, C., Montilla-Herrador, J., Gacto-Sánchez, M., Franco-Sierra, M.Á., & Escolar-Reina, P. (2017). Predictors of parents' adherence to home exercise programs for children with developmental disabilities, regarding both exercise frequency and duration: A survey design. *Eur J Phys Rehabil Med*, 53(4), 545–555. <https://doi.org/10.23736/s1973-9087.17.04464-1>.
- Ministry of Health, Labour and Welfare (2004). Developmental disability support measures. [Cited 15 Mar 2021.] Available from URL: [https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/hukushi\\_kaigo/shougaihashukushi/hattatsu/index.html](https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/hukushi_kaigo/shougaihashukushi/hattatsu/index.html).
- Ministry of Health, Labour and Welfare (2020). Reiwa 2nd year white paper on measures against the declining birthrate. [Cited 21 Mar 2021.] Available from URL: <https://www8.cao.go.jp/shoushi/shoushika/whitepaper/measures/w-2020/r02pdfhonpen/pdf/s1-7.pdf>.
- Ministry of Health, Labour and Welfare (2021). Table 5: Total fertility rate by mother's age (5-year-old class) and birth order (breakdown). [Cited 21 Mar 2021.] Available from URL: [https://www.mhlw.go.jp/toukei/saikin/hw/jinkou/kakutei19/dl/09\\_h5.pdf](https://www.mhlw.go.jp/toukei/saikin/hw/jinkou/kakutei19/dl/09_h5.pdf).

- Ministry of Health, Labour and Welfare (2020). What is a local child-rearing support base project (overview). [Cited 21 Mar 2021.] Available from URL: <https://www.mhlw.go.jp/content/000666540.pdf>.
- Nakazawa, K., Haruki, A., & Koujida, R. (2018). [Aiming to improve perinatal mental health literacy] Examination of continuous childcare support from pregnancy for women with autism spectrum disorders. *The Japan Perinatal Mental Health Society*, 4(1), 67–72. (in Japanese).
- Olusanya, B.O., Davis, C.A., Wertlieb, D., Boo, N-Y., Nair, M.K.C., Halpern, R., Kuper, H., Breinbauer, C., Vries, P.J., Gladstone, M., Halfon, N., Kancherla, V., Mulaudzi, M.C., Kakooza-Mwesige, A., Ogbo, F.A., Olusanya, J.O., Williams, A.N., Wright, S.M., Manguerra, H., Smith, A., Echko, M., Ikeda, C., Liu, A., Millea, A., Ballesteros, K., Nichols, E., Erskine, H.E., Santomauro, D., Rankin, Z., Smith, M., Whiteford, H.A., Olsen, H.A., & Kassebaum, N.J. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the Global Burden of Disease Study 2016. *Lancet Glob Health*, 6, e1100–e1121. [https://doi.org/10.1016/S2214-109X\(18\)30309-7](https://doi.org/10.1016/S2214-109X(18)30309-7).
- Pan, W-L., Chang, C-W., Chen, S-M., & Gau, M-L. (2019). Assessing the effectiveness of mindfulness based programs on mental health during pregnancy and early motherhood - A randomized control trial. *BMC Pregnancy Childbirth*, 19, 346. <https://doi.org/10.1186/s12884-019-2503-4>.
- Potvin, L.A., & Fulford, C. (2019). What adults with intellectual and developmental disabilities say they need to access annual health examinations: System navigation support and person-centred care. *Can Fam Physician*, 65(Suppl 1), S47–S52.
- Sasaki, M., Soto, C., Kudou, H., & Chouri, A. (2015). Consideration on pregnancy, childbirth, and childcare support for women with Asperger's syndrome: Approach to cases characterized by commitment and comprehension. *Proceedings of the Japanese Nursing Association: Health Promotion*, 45, 101–104.
- Usui, J., & Ishimura, I. (2017). Necessary assistance in informing those with developmental disabilities? —Through interviews with those concerned—. *Tokyo Seitoku University Clinical Psychology Research*, 17, 153–159. (in Japanese).
- Xie, E., & Gemmill, M. (2018). Exploring the prenatal experience of women with intellectual and developmental disabilities. *Canadian Family Physician*, 64, S70–S75.