

# Public Health Nurses' Support for Children with Autism Spectrum Disorder (ASD) and their Parents, Tailored to the Level of Parental Acceptance and Local Characteristics

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## Abstract

**Purpose:** To explore forms of support by public health nurses to parents of children with autism spectrum disorder (ASD), tailored to the level of parental acceptance of the disorder and local characteristics

**Methods and design:** Descriptive qualitative study was undertaken.

**Sample:** Nine public health nurses who were providing support to parents of children with ASD participated.

**Measurements:** Data were collected through semi-structured interviews. Analysis of the data identified two themes: (1) current situations of children with ASD, their parents and family, and (2) forms of public health nurses' support for those parents.

**Results:** Situations of the children, their parents and family included: (1) parental recognition of signs of ASD in their children, and (2) current levels of parenting support. Forms of public health nurses' support included: (1) building support systems to assist parental acceptance, (2) support before the parents recognize their children's ASD, (3) support while the children are using support centers, (4) assistance to enable ongoing support.

**Conclusion:** Providing support tailored to local characteristics and parents' values leads to building support systems that help parental acceptance. Educating parents to recognize signs of ASD, mentoring junior nurses, and intervention based on an understanding of the whole family are also important.

**Keywords:** Public health nurses; Children with ASD; Support for parental acceptance; Local characteristics; Early support; Continuing support; Multi-occupation collaboration

## Introduction

The parliamentary "Act on Support for Persons with Development Disabilities" has been in place for over 10 years in Japan and there have been increasing efforts to raise public awareness of autism spectrum disorder (ASD). Article 5 of this Act states that municipalities must pay sufficient attention to early detection of ASD at health check-ups which are prescribed in the Maternal and Child Health Act [1].

Children with ASD often pose difficulties in parenting and establishing relationships. It has been pointed out that these difficulties can lead to child abuse when the child's characteristics are not correctly understood and there is a lack of support systems that share the care for the child available to the parents [2]. In addition, children with ASD sometimes have difficulty in adapting to the classroom once they are of school-age [3].

These facts have led to the recognition of the importance of rehabilitation at an early preschool stage [4]. Also, the 5-year-olds' health check-up has been found to be beneficial as a preschool screening because of the need for early intervention [5,6]. Public health nurses come into contact with children from an early age; therefore they are expected to play a role in the detection of ASD at infant health check-ups or health check-ups for children starting school. They are in a good position to introduce specialist developmental support to those children in need at an early stage [7].

In response to the call for early detection and provision of continuous support, there have been studies on parental acceptance of their children's ASD as well as studies on public health nurses' support

for children with pervasive developmental disorder (PDD) and their parents [8-10].

Previous studies in Japan and overseas reported that mothers of children with ASD were experiencing greater stress compared to mothers of typically developing children and intellectually disabled children [11-13]. They are typically under more stress due to difficulties in parenting arising from their children's characteristics [14].

The Committee for Policies on Support for Persons with Developmental Disabilities reported that detection of ASD at infant health checkups and the checkup for children starting school and referral to early rehabilitation are public health nurses' roles. In reality, despite a variety of available support services having accumulated over time, the know-how tends to remain specific to local areas or individual support providers [1]. Common problems that can arise include public health nurses who do not understand the fundamentals of ASD, do not notice children's developmental problems, or are facing difficulties in providing support to parents who have noticed their children's developmental delay but feel negative about receiving support [2,3]. We

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conducted a pilot study in 2015-16. The study showed that public health nurses in remote areas without rehabilitation facilities were trying to improve childcare workers' rehabilitation skills through training and dispatch of coordinators. In addition, support services provided by public health nurses for early rehabilitation for children with ASD are significantly influenced by the level of parental acceptance and local characteristics. Provision of support customized to local characteristics is also important in terms of establishing community support systems.

The aim of this study was to explore forms of public health nurses' support and how they are tailored to the level of parental acceptance and local characteristics.

## Methods

### Sample

Demographics of participants in this study are shown in Table 1. Participants were nine public health nurses who were providing support to children with ASD. We conducted a nation-wide survey using a written questionnaire. Among the respondents who consented to be interviewed, 9 public health nurses who were providing support for children with ASD in rural areas were selected for interviews.

### Study period

March – August 2015.

### Procedure

Data were collected in semi-structured interviews. Semi-structured interviews are a method where several questions are set to assure collection of desired data, but interviewees are allowed to talk freely. Interviewees are directed to questions as necessary during the interview. In this study we chose semi-structured interviews because we aimed to clarify forms of support including not only home visits and health check-ups, but also the ones tailored to individual situations such as the level of parents' acceptance of support and family circumstances, and may have had the unintended consequence of helping the children and their parents.

Interviews were conducted in private rooms in public health centers and recorded with consent. Survey items were: i) support systems to enable early support provision; ii) support tailored to the level of parental acceptance of their children's ASD; iii) support for parents who have not accepted their children's ASD.

### Design and method of analysis

Design was a qualitative descriptive study [15]. Interviews were

Case	Age	Years of experience as a public health nurse	Years of experience supporting children with ASD
1	30s	≥ 11	≥ 11
2	40s	≥ 11	≥ 11
3	40s	≥ 11	≥ 11
4	50s	≥ 11	≥ 11
5	30s	≥ 11	≥ 11
6	50s	≥ 11	6 – 10
7	40s	≥ 11	≥ 11
8	30s	3 – 5	3 – 5
9	20s	3 – 5	<3

**Note:** ASD = autism spectrum disorder. Maximum value available in the choices was ≥ 11 years for years of experience as a public health nurse and years of experience supporting children with ASD.

**Table 1:** Participants' demographics.

transcribed verbatim and itemized so that one sentence contained one meaning. These accounts were analyzed, classified, and integrated according to similarity. Data were classified into i) situations of the children, parents, and families; ii) forms of public health nurses' support for parents of children with ASD.

Concepts and categories were verified, reviewed, and revised during analysis in order to enhance the reliability of data. Analysis was conducted under the supervision of a community health nursing researcher who had experience as a practitioner previously working for a municipal government.

We assured scientific rigor and veracity based on the definition by Guba and Lincoln in order to enhance the credibility of the data.

Transcribed data were checked whether they reflected actual interviews to ensure clarity. This was done by a public health nurse and a community nursing researcher/educator who had experience in infant health checkups and providing support to children with ASD as a practitioner. To ensure credibility, interviews were conducted at locations of interviewees' choice where they felt comfortable in order to encourage interviewees to speak freely. To ensure transferability, verbatim transcripts were created for individual research questions, which were subdivided so that each piece of data contained one meaning. The contents of interviews were extracted and classified in a fact-based and consistent manner. Verifiability was ensured by recording the analysis method used in the first case and using the same method for the following cases.

Categories were subdivided into subcategories. Typical narratives were displayed in quotation marks and altered when necessary to protect privacy in a way that they would still hold the same meaning.

### Definition of terms

In this study, we defined parental acceptance as the acceptance of "their child" who has a disorder, not the acceptance of the "disorder" of their child [16]. We presumed that utilization of support organizations was evidence of acceptance of the disorder. Forms of support were classified according to before and after children and parents started using support organizations. Nakata described "the process in which parents gradually recognize their children's disorders is like climbing spiral stairs. They sometimes get tired of climbing endless stairs and feel like denying the disorder. Diagnosis is likely being reconfirmed at each of those times [17]".

We postulate that the process of parental acceptance of their children's disorder is as defined by Nakata. In this study we define parental acceptance as three phases as follows: support for parental acceptance before parents recognize their children's disorder, support for parental acceptance while using support centers, and assistance to enable ongoing support. We defined forms of support customized to these three phases as support tailored to the level of parental acceptance and used this definition in analysis.

### Ethical considerations

Participating public health nurses were informed of the purposes of the study verbally as well as in writing. They were also informed that participation was voluntary. Data were to be used for research purposes only and it was ensured that regions and individuals were unable to be identified during analysis. Approval (No. 1016) was obtained from the Ethics Committee of XXXXXX University prior to obtaining consent from public health nurses.

Results

A total of 2099 pieces of data were extracted from verbatim transcription of interviews with 9 public health nurses who were providing support to children with ASD. Analysis resulted in grouping the data into two concepts, i) the situation of the children, parents and families and ii) forms of public health nurses' support to parents of children with ASD. Data were classified under categories which were subdivided into subcategories. Categories were classified into codes.

Participants

Nine public health nurses who participated in interviews ranged in age from their twenties to fifties (Table 1). Six of those nurses each had 11 or more years of experience in supporting children with ASD, while the other 3 nurses each had less than 11 years of experience.

The situation of children and families

The codes, categories, and subcategories relating to “the situation of the children, parents and families” are summarized in Table 2.

Codes included “parental recognition of signs of ASD” and “the current level of parenting support”. Under “parental recognition of signs of ASD”, there were two conflicting situations, which were “parents are experiencing distress about their children’s development” and “lack of parental recognition of the children’s developmental delay”. Items found under the code of “the current level of parenting support” included “challenges relating to needs and budgets for health checkups and placement of pediatricians” in “issues around support systems for children with ASD.” This shows that there were situations where communities were facing challenges meeting the needs specific to local characteristics, and also the placement of pediatricians.

Forms of public health nurses’ support for parents of children with ASD

Data regarding public health nurses’ support extracted from narratives of interviews were classified into 3 stages; support before parents noticed signs of ASD, support while using support centers, and assistance to enable ongoing support. Data are shown in Table 3. We also created a separate code, “building support systems to facilitate parental acceptance”, as analysis showed that public health nurses were building support systems to facilitate parental acceptance throughout the 3 stages.

Building support systems to facilitate parental acceptance

Categories that emerged under the code “building support systems to facilitate parental acceptance” were “creating support systems”, “taking opportunities of contact with physicians to refer to intervention”, “educating parents”, “training childcare workers”, and “mentoring junior nurses”.

As seen in the subcategory “sharing support facilities with neighboring municipalities” under “creating support systems”, support centers were shared among neighboring areas when they are unavailable in each municipality.

In Japan, all 47 prefectures have Support Centers for Persons with Developmental Disorders. Support Centers for Persons with Developmental Disorders are specialized organizations aimed at providing comprehensive support to children (and adults) with ASD. These centers are run by prefectural or major cities’ governments, or social welfare corporations and non-profit organizations designated by the governor.

Despite the presence of rehabilitation centers within the prefecture, sometimes children with ASD are unable to use the facility when they are not within a practical distance. We found that public health nurses were “training childcare workers” in such cases.

The participants expressed their situations in this regard as follows:

“Our local coordinator visits the local childcare center and trains their childcare workers on how to deal with children with ASD (Case A)”.

“Our coordinator has been running quaterly advice sessions for childcare workers. Those childcare workers have increased their knowledge on how to deal with children with ASD (Case B)”.

“Our area only has one public childcare center and no private kindergartens or childcare centers, so all local children attend this public childcare center. All children go through the filter of this childcare center. So we have concluded that what we should do is to enhance the abilities of their childcare workers to deal with children with ASD (Case C)”.

“I do rounds of childcare centers with childcare workers and our coordinator. Our coordinator is a retired elementary school teacher who used to work in special needs classes. I also visit childcare centers with a village council worker who has a qualification as an early childhood teacher (Case D)”.

Childcare centers are available in most remote areas. In remote areas children start attending childcare centers when they are 3 or 4 years old as a substitute for kindergarten even when the mother is not working. In some areas all children go through the filter of childcare

Codes	Categories	Examples of subcategories
Parental recognition of signs of ASD	Current situation of parental recognition	Parents are experiencing distress about child's development
		Lack of parental recognition of the child's developmental delay
Current situation of parenting support	Current situation of support for children with ASD and their families	Current situation of support for children with ASD and their families
		Current initiatives for ongoing support during schooling
		Current support systems for children with ASD suited to local circumstances
		Current dissatisfaction about schools that are not equipped for children with ASD
	Issues around support systems for children with ASD	Family background and developmental history of the child
		Issues around the roles of rehabilitation specialists who advise how to support children with ASD
	Status of children while schooling	Issues relating to needs and budgets for health check-ups and the placement of pediatricians
		Status of children who refuse support before entering school and meet difficulties after entering school

**Note:** ASD = autism spectrum disorder

**Table 2:** Situations of Children and Parents.

Codes	Categories	Subcategories
Building support systems to facilitate parental acceptance	Building support systems	1. Sharing support centers with neighboring municipalities
		2. Referral to support services based on an understanding of the characteristics of medical institutions and rehabilitation centers
		3. Liaising with surrounding municipalities and allied professionals to provide support
	Taking opportunities of contact with physicians to refer children to intervention	4. Placing value on liaising with doctors
		5. Using health checkups as an opportunity for diagnosis because of a lack of pediatricians in the municipality
		6. Understanding family circumstances and parental recognition and initiate intervention through home visits in cooperation with doctors
	Educating parents	7. Educating parents to recognize signs of their children's ASD.
	Training childcare workers	8. Developing childcare workers who can support children with ASD
	Mentoring junior nurses	9. Passing experience-based practical knowledge onto junior nurses
Support to encourage parental acceptance before they recognize signs of ASD	Cooperation with organizations and professionals specializing in pre-school children	10. Making observations of children at different times and places and providing support in cooperation with childcare centers and kindergartens
		11. Providing support customized to the children's characteristics, considering prospective multidisciplinary support
		12. Providing ongoing support liaising with other allied professionals
	Development of good relationships with parents	13. Informing parents that the public health nurses are always available for consultation
		14. Providing long-term support to the parents so that it leads to their utilization of support facilities.
		15. Continuous involvement of public health nurses in cooperation with other professionals to assist parents to recognize signs of ASD
	Assistance for parents to recognize signs of ASD in their children	16. Helping parents to notice signs of ASD based on the knowledge of the children's behavior at kindergarten
		17. Analyzing parents' background to gauge what they recognize about their children's condition
		18. Providing support while judging whether there are discrepancies between actual developmental problems and parent's perceptions of those problems
		19. Waiting until parents notice signs of their children's ASD
		20. Talking to parents at every opportunity
		21. Assisting parents to gain accurate knowledge about ASD so that they do not feel guilty about putting their children in rehabilitation
	Informing parents of support organizations	22. Informing parents of the benefits of receiving support services and lowering the mental hurdle for receiving support services
		23. Knowing the expertise of each support provider and explaining the need for them to the parents
		24. Understanding the parents' values and introducing support services at the right time
Support for parental acceptance while using support centers	Provision of support that meets the parents' needs	25. Coordinating support services taking parent's own issues into account
	Being compassionate about parents' feelings	26. Provision of support while assessing parental understanding and acceptance of explanations of the children's development
		27. Staying considerate about negative parental feelings towards receiving support
Assistance to enable ongoing provision of support	Assisting parents so that ongoing support can be provided	28. Giving parents practical advice about their children's development as they reach milestones
		29. Sharing and celebrating with parents their children's progress resulting from intervention
		30. Providing support taking the power balance within families into account
	Providing comprehensive support	31. Assessing the presence or absence of abuse while providing support
		32. Providing support based on the level of parent's childrearing burdens, taking into account their circumstances
		33. Providing support showing respect for the parents' childrearing styles and only conveying the children's current condition to create a common understanding within families
		34. Providing support corresponding to the parents' values with an understanding of local characteristics

**Note:** ASD = autism spectrum disorder

**Table 3:** Forms of Public Health Nurses' Support for Parents of Children with ASD.

centers at some stage. Municipal public health nurses were found to be working to improve childcare workers' support capacities so that they could learn how to deal with children with ASD and provide rehabilitation at childcare centers. This appeared as the subcategory of "developing childcare workers who can support children with ASD". It was also found that experienced nurses were "passing experience-based practical knowledge onto junior nurses".

### Support for parental acceptance before they recognize signs of ASD

A code of "support to encourage parental acceptance before they recognize signs of ASD" was created to cover categories of

"cooperation with organizations and professionals specializing in pre-school children", "development of good relationships with parents", "assistance for parents to recognize signs of ASD in their children" and "informing parents of support organizations".

We found that public health nurses were "making observations at different times and places and providing support in cooperation with childcare centers and kindergartens". An example of this is:

"In our municipality, we ask childcare centers to find time to deal with cases individually as much as possible (Case G)".

This means nurses make observations not only at scheduled infant health checkups but also at daily sessions at childcare centers



and kindergartens. Public health nurses, childcare workers, and kindergarten teachers worked together to observe children at different times and places while judging whether the parents had noticed their children's ASD. As seen in the subcategory "providing support customized to the children's characteristics, considering prospective multidisciplinary support", nurses got childcare centers involved in providing support. "We public health nurses explain that childcare centers are places to rehearse cooperation so that homeroom teachers, support staff, and parents can get together and cooperate when children start school (case 4)."

In "informing parents of support organizations", it was found that nurses were informing parents of the benefits of receiving support services to lower the mental hurdle for receiving support services. Examples came from interviews:

"This year we advertised, for the first time, parenting consultation rounds as part of infant health checkups (Case B)".

"It usually leads to intervention when we tell the parents whether or not to receive intervention makes a huge difference throughout the lifetime of the child (Case C)".

This is necessary because there is a common misunderstanding that support centers are for severely disabled people and psychiatric patients. In some areas rehabilitation centers are actually located in the same building as the center for severely disabled children. There are also cases where therapy services are provided in psychiatric clinics. In these cases, there are adverse effects from visiting such facilities that may overcome the benefit of receiving therapies. Even without such special circumstances, prejudice against children and parents who attend rehabilitation centers tend to discourage them from receiving rehabilitation services. This prejudice arises because attending such support centers is unusual in itself. It is important to make the parents aware of the benefits of attending rehabilitation centers to override their hesitation. Nurses informed parents of what kind of therapies and education their children would be receiving and also the expected outcome of those therapies and education.

### **Support for parental acceptance while using support centers**

"Provision of support that meets the parents' needs" and "being compassionate about parents' feelings" was extracted under "support for parental acceptance while using support centers". Mothers who are caring for children with ASD sometimes have additional burdens, for example, having an ill husband or parent. It is important that mothers are freed of such major challenges. Public health nurses need to coordinate support services keeping the mothers' circumstances in mind. There are also cases where the parents have ASD themselves. Nurses organized support services to meet the needs of such parents.

Under "provision of support that meets parents' needs", "staying considerate about negative parental feelings towards receiving support" was extracted. One participant expressed their experience as follows:

"When I met the parents in the area we just chatted about general things about their child rather than developmental problems just to keep in touch. Then when I saw them at health checkups we discussed our concerns and also informed their childcare center. That way we finally got them to receive support (Case H)".

This meant listening to the parents during home visits or over the phone without disapproving of their negative feelings about attending support centers.

### **Assistance to enable ongoing provision of support**

Under the code of "assistance to enable ongoing provision of support", categories "assisting parents so that ongoing support can be provided" and "provision of comprehensive support" were extracted. A subcategory "sharing and celebrating with parents their children's progress resulting from intervention" was extracted under category "assisting parents so that ongoing support can be provided". Public health nurses shared and celebrated the children's progress with the parents who were using support centers. Under "provision of comprehensive support", "providing support taking the power balance within families into account" was extracted. In Japan, some families still have a patriarchal view of family structures. In such families, childrearing is considered the mother's role and household decisions require the father's permission. When public health nurses identified that was the case, they met the father and explained the need for intervention. In some areas they also provided support in accordance with the parents' values and local characteristics. An example is: "There was a parent who asked one of us public health nurses to visit their home because they did not want to go to the health checkups. It's like we are raising children by the whole community here (Case I)".

Some parents do not think the 18-months and 3-year-old health checkups are necessary despite them being legislated in Japan. In some areas parents only took their first and second children to those checkups and not after that because they felt they could judge anomalies from their experience. Also, in areas where people value a laid-back approach to childrearing, it is difficult to make them understand the need for specialized care. In such cases nurses tailored their approach according to the parents' values and, for example, recommended attending support centers where parents had networking opportunities.

## **Discussion**

### **Provision of support based on local characteristics**

The category "building support systems" included "sharing support centers with neighboring municipalities", "referral to support services based on an understanding of the characteristics of medical institutions and rehabilitation centers", "liaising with surrounding municipalities and allied professionals to provide support". Particularly in rural areas in Japan, support centers for children with ASD are shared by multiple municipalities. In "training childcare workers", public health nurses played a role in "developing childcare workers who can support children with ASD".

Public health nurses' roles also include connecting parents and allied professionals by sharing information on their children's development and available support services [4].

Nurses were also found to be customizing their support according to local characteristics when working with children with ASD, their parents, and relevant organizations.

In "providing comprehensive support", it was seen that public health nurses adjusted their support to cater to parents' values and local characteristics. Santoso et al. stated this about a situation in Indonesia, similar to Japan [18].

In Indonesian culture, as elsewhere around the world, mothers' roles are not limited to caring for their children with ASD who require constant monitoring, but mothers also take care of other children. In a qualitative study Safe et al. identified that mothers had difficulty performing multiple roles as well as having limited time to meet their own needs. Subsequently, mothers may experience an unhealthy life balance.

The situation is no different for many families in Japan. Mothers who care for children with ASD perform multiple roles and have difficulty fulfilling their own needs. It is necessary that public health nurses understand the mother's situation in the family and local characteristics when providing support to them.

Wiedenbach regarded the purpose of nursing as to fulfill a need for help, and stated the most important skill in nursing was to identify individual needs for help. The present study indicated that public health nurses were providing support based on identification of a need for help. This was seen in "providing support taking the power balance in the family into account" and "providing support based on the level of parent's childrearing burden, taking into account their circumstances".

### Support by development of human resources

Participants indicated that they were facilitating parental acceptance by educating the parents and mentoring junior public health nurses. Educating parents involved helping them to recognize signs of ASD.

When it comes to the feelings of the parents when their children are diagnosed with a disorder, Tsutsumori stated that "the therapist needs to detect the parents' confused emotions and accept them as a reality. It is not sufficient, however, to see the confusion. There must also be empathy. Something beyond technical skills may be required [19]. It is not possible to provide support to parents who do not understand their children's characteristics and difficulties. Therefore, participants helped parents to understand the situation and educated them so that they were able to accept support. Helping parents to accept their children's disorder is only possible when there is empathy between parents and public health nurses. When parents feel assured that they have been listened to, it should lead to parents' appreciation of public health nurses' support. It is desirable that public health nurses support and educate the parents so that the parents and nurses can develop empathy.

There was a case in which the parent grew as a parent after going through various emotions in the course of accepting their child's ASD. The parent read books on ASD and tried hard to gain knowledge about their child's condition while vacillating between denial and acceptance. This parent also took various actions to inform other parents at the childcare center of her child's ASD and seek their understanding [20]. This case revealed what kind of support the public health nurse was providing to the parent to enable them to take such actions. The nurse waited while the parent worked through feelings of disbelief until the parent felt prepared to receive support. The nurse then provided support with an understanding of how the parent felt about receiving support.

Acceptance of a disability involves recurring cycles of denial and acceptance Estes et al. Hence it is important to provide support to the parents after they have accepted the diagnosis and started receiving support.

In mentoring junior public health nurses, it is important for experienced nurses to help those more junior to be able to educate parents so that they are all working towards a common goal.

### Support for the whole family

Subcategories that emerged under the category of "providing comprehensive support" showed that that public health nurses considered, in providing support services, the power balance within families as well as the level of the parent's childrearing burden based on their family circumstances. They also respected the parents'

childrearing styles and just conveyed the facts about their children's condition so that they could develop a common understanding within families.

As shown in Tone, in most cases it is mothers that accompany children with ASD when attending rehabilitation centers and participate in consultation programs [14]. Mothers of children with ASD, however, are under huge parenting stresses as Estes et al. reported the mothers of children with ASD were experiencing higher parenting stresses than the mothers of children with developmental delays without ASD and the mothers of typically developing children [21]. Therefore it is important to have an understanding of the mothers' parenting stresses and their position within the family in providing support. Ishii et al. quoted this view from a public health nurse [22].

From my perspective and experience as a PHN, I firmly believe that having the family and child's support are absolutely necessary for providing effective quality client-centered care. Though it is often a challenge to grasp the true reality of each family's life style and difficulties, I try doing this where possible, as it is central to the overall success of any intervention. Also, supporting the family by helping them to identify, fully understand and take advantage of their strengths is an ongoing challenge.

Public health nurses need to support not only children with ASD but also the whole family based on an understanding of their lifestyle, which is crucial to help parents to accept their children's disorder.

Public health nurses were found to be encouraging families to build a common understanding as seen in the subcategory "providing support showing respect for the parents' childrearing styles and only conveying the children's current condition to create a common understanding within families" under the category of "provision of comprehensive support". It was reported that the mothers of children with PDD found the period "until establishing a common understanding with their husbands" most stressful, although this was a study on mothers of children with PDD [23].

It is important for therapists to consider this underlying stress when suggesting modifications and thought-out approaches on childrearing at home [14]. "Providing support based on the level of parent's childrearing burdens, taking into account their circumstances" also suggested the way public health nurses could help parents to receive ongoing support. In case 7, for example, the family was about to move houses when they were given a recommendation to attend a support center and they decided not to follow the recommendation at that time. The parent, however, later called the public health nurse and started using the support center. This demonstrates that what leads to provision of ongoing support is knowing parents' overall burden and adjusting support accordingly.

Parents often live with anxiety after an early diagnosis until their children are set up to receive therapies, typically vacillating between denial and acceptance of the diagnosis during this period [17]. A parent's narrative showed that the way the public health nurse helped parental acceptance before the parents recognised their child's disorder was "waiting until the parents noticed signs of their child's ASD". As in this example, it is important to identify whether the parents and families are in denial or acceptance at that time and lay out the support accordingly.

Notifying the parents of their children's disorder is the starting point of the process of gradual acceptance. At the same time, it has a significant meaning as a motivation for receiving therapy services

[24]. ASD is most frequently detected at health check-ups, and often by public health nurses. Public health nurses not knowing how to inform the parents, and how to provide advice is a major challenge for the future [25].

Public health nurses first encounter the family structure at health checkups. Then they need to quickly identify the parents' needs and help them sympathetically [26]. In doing so, nurses liaise with childcare workers and kindergarten teachers to assist parents to recognize their children's disorder as shown in "making observations of children at different times and places and providing support in cooperation with childcare centers and kindergartens".

These findings demonstrate that the role of public health nurses is to provide support for parental acceptance tailored to the cycles of denial and acceptance, which continue even after they start receiving intervention services.

## Conclusion

This study revealed that forms of public health nurses' support for parents of children with ASD, based on local characteristics and the level of parental acceptance, included provision of support tailored to local characteristics and support to assist parental acceptance of their child's ASD. It also suggested that public health nurses assisted parental acceptance by educating parents to help them recognize signs of ASD in their children, mentoring junior nurses, and providing comprehensive support based on family circumstances.

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