

Promoting Early Identification of Autism in Public Health Centres in Japan

Submitted by

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ABBREVIATIONS

ADEC	Autism Detection in Early Childhood
ADEC-J	Autism Detection in Early Childhood-Japanese
ADI-R	Autism Diagnostic Interview-Revised
ADOS-2	Autism Diagnostic Observation Schedule-Second Edition
ADOS-G	Autism Diagnostic Observation Schedule-Generic
ASD	Autism Spectrum Disorder
BISCUIT	Baby and Infant Screen for Children with Autism Traits
CARS-TV	Childhood Autism Rating Scale-Tokyo Version
CBQ-R	Child Behavior Questionnaire-Revised
CHAT	Checklist for Autism in Toddlers
DISCO	Diagnostic Interview for Social and Communication Disorders
DSM-5	Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition, Text Revision
Enjoji Scale	Enjoji Analytical Developmental Scale for Infant and Children
FU	Follow-up Service Using
IBC-R	Infant Behavior Checklist-Revised
JSCCP	Japanese Society of Certified Clinical Psychologists
Kyoto Scale	New Kyoto Scale of Psychological Development
M-CHAT-JV	Modified Checklist for Autism in Toddlers-Japanese Version
NFU	Non follow-up Service Using
NPV	Negative Predictive Value
PARS	Parental-interview ASD Rating Scale

PDDAS	Pervasive Developmental Disorders Assessment System
PPV	Positive Predictive Value
SACS-J	Social Attention and Communication Surveillance-Japan
S-M Scale-3	Social Maturity Scale-Third Edition
SRS-P	Social Responsiveness Scale-Preschool
SRS-2	Social Responsiveness Scale-Second Edition
STAT	Screening Tool for Autism in Two-Year-Olds
TABS	The Tokyo Autistic Behavior Scale

ABSTRACT

The overall objective in undertaking the research presented in this thesis was to promote early identification of autism in Public Health Centres in Japan that is appropriate and feasible within the existing practices at these Centres. In Japan, the statutory 18-month health check-up at Public Health Centres offers a universal opportunity for autism screening, but the average age of an Autism Spectrum Disorder (ASD) diagnosis among Japanese children remains at approximately four years of age. Finding from the literature review of the autism early identification pathway in Japan, and the survey study targeting Public Health Centre professionals suggested that the after-check-up follow-up services at these Centres play a significant role in (a) achieving better autism screening outcomes, (b) providing intervention and other support for children who screened positive at the 18-month general check-up and their parents prior to diagnosis, and (c) promoting parental acceptance of their child's disability, which is an important motivator for parents to seek a formal diagnosis. The survey study also revealed both the necessity and the absence of Level 2 autism screening within the follow-up service. Based on the findings from a review of autism screening instruments in Japan and the survey study, a Level 2 autism screener, the Autism Detection in Early Childhood (ADEC; Young, 2007), was selected as a tool for use at Public Health Centres, and the Japanese adaptation of the ADEC (ADEC-J) was developed. A further study was conducted to examine the effectiveness of the ADEC-J with 60 young Japanese children. The ADEC-J was validated with the Japanese Autism Diagnostic Observation Schedule, Second Edition (Lord et al., 2015), and showed promise as a reliable and accessible Level 2 autism screening instrument for use within the follow-up service at Public Health Centres in Japan.

STATEMENT OF AUTHORSHIP

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

The author made the largest contribution to the research design and data collection, completed all analyses, and led in the drafting of the thesis. Professor Cheryl Dissanayake and Dr. Darren Hedley, the principle and co-supervisor of this thesis respectively, have assisted with the research design, interpretation of findings, and drafting process. Professor Emerita Emiko Kezuka, Gunma Prefectural Women's University, and Professor Midori Okuno, Gunma University of Health and Welfare, have contributed to the recruitment, data collection, and cultural adaptations of the studies.

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Hiroko Kawashima

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Chapter 1

General Introduction

Autism Spectrum Disorder (ASD; hereafter autism) is a life-long neurodevelopmental condition characterised by impairments in social communication and interactions as well as the presence of repetitive and restricted interests, behaviours, or activities including anomalies in sensory responsiveness (American Psychiatric Association, 2013). The prevalence of autism has shown a marked increase in the last two decades (Sasayama et al., 2020). Although the increase requires cautious interpretation (Blumberg et al., 2016; Elsabbagh et al., 2012; Rødgaard et al., 2019), recent comprehensive studies estimated that autism affects one in 54 children (1.8% of the population) in the United States (Maenner et al., 2020) and one in 32 to 36 (2.9% to 3.1%) in Japan (Nishimura et al., 2019; Sasayama et al., 2020).

The onset of autism is typically in early childhood, with symptoms becoming observable during the first two years of life (Barbaro & Dissanayake, 2009). A diagnosis of ASD may be provided from around 12 months of age, but can be reliably made by the age of two (Barbaro & Dissanayake, 2016; Barton et al., 2012; Guthrie et al., 2013; Zwaigenbaum et al., 2015). With increasing evidence that interventions at an early stage of development improve the prognosis of children diagnosed with ASD (Dawson et al., 2010; Howlin et al., 2009; Kasari et al., 2010), improving the detection of autism in infancy and toddlerhood has become a global challenge (World Health Organization, 2013).

Diagnosis of ASD is reliant on an individual's developmental history and behavioural observations as valid biological markers are yet to be determined (Abrahams & Geschwind, 2008; Klin & Jones, 2015; State & Šestan, 2012; Zwaigenbaum et al.,

2015), and unlikely to be achieved for all forms of autism. Extensive research has identified early behavioural markers of autism (see Barbaro & Dissanayake, 2009 for a review), leading to the development of many screening instruments (Marlow et al., 2019; Zwaigenbaum et al., 2015); however, to date, no single screening tool is universally recommended (Charman & Gotham, 2013; Zwaigenbaum et al., 2015).

Behavioural markers of autism in early childhood include, in the social communication and interaction domain, reduced eye contact and atypicality in eye gaze, reduced responsiveness to name, initiation and response to joint attention, imitation, and social gestures (Barbaro & Dissanayake, 2013; Ozonoff et al., 2010; Zwaigenbaum et al., 2005). Restricted and repetitive interests and behaviours may also exist, although are often less apparent compared to older children (Barbaro & Dissanayake, 2009), such as spinning, lining and visual or other sensory exploration of objects, and hyper- or hyposensitivity to particular sensory stimuli (Young et al., 2003; Zwaigenbaum et al., 2005).

Autism in Low-resource Settings

With autism recognised globally, there has been an expansion of clinical attention and research interest in recent years from high-resource countries to lower resource countries and settings, as well as to non-English speaking and/or non-European cultures (Barbaro & Halder, 2016; de Vries, 2016; Durkin et al., 2015; Hahler & Elsabbagh, 2015). However, there does remain an imbalance of knowledge and translation of research findings across regions. A particular challenge has been the development of culturally appropriate tools including screening tools (Barbaro & Halder, 2016) and the cultural adaptation of existing tools which have largely been developed in English-speaking countries (Marlow et al., 2019; Soto et al., 2015).

Soto et al. (2015) noted that the recent increase in adaptations of screening

instruments for autism developed in a different language or culture may have resulted from the extensive resources and effort required to create a new tool specific to the local language and culture. However, their review of cultural adaptations of autism screening tools identified a wide range of variation in adaptation processes and overall lack of conformity with guidelines, suggesting the need of rigorous cultural adaptation and validation of tools and detailed report of the research process (Soto et al., 2015).

Japan is generally considered a high-resource country. In regards to autism research, Japan has produced comprehensive epidemiological studies since early 80's while the detailed estimates of autism prevalence remain unknown for 90% of the world population (Durkin et al., 2015; Elsabbagh et al., 2012). Nonetheless, domestic inequality exists in early autism detection, diagnosis and intervention opportunities between higher- and lower-resource settings within Japan (Takahashi et al., 2015). Overall, smaller municipalities with a population of less than 30,000, which account for approximately 50% of all municipal governments in Japan, have much fewer resources than larger municipalities. For instance, less than 40% of these smaller municipalities were found to have medical organizations capable of early diagnosis of developmental disorders, including ASD, and only around 60% have early intervention facilities within their community. Moreover, public health nurses in smaller municipalities who are engaged in universal infant health check-ups may lack experience in identifying developmental delays and determining the presence of autism in young children (Takahashi et al., 2015).

The availability of autism screening practices also differ among Public Health Centres, where the abovementioned health check-ups are undertaken, particularly in terms of the use of a validated screening instrument (Japanese Society of Certified Clinical Psychologists [JSCCP], 2014; Yamazaki et al., 2016). For instance, the Japanese adaptation of the Modified Checklist for Autism Traits (M-CHAT-JV; Kamio & Inada,

2006; M-CHAT: Robins et al., 2001) is reportedly the only standardised autism screening tool used for the statutory 18-month health check-up across different prefectures (JSCCP, 2014; Yamazaki et al., 2016). In 2015, though, the nationwide usage rate of the M-CHAT-JV at Public Health Centres remained a low 12.1% (Ministry of Health, Labour and Welfare, 2016). It was suggested that some of major obstacles to the use of assessment instruments at medical, public health, and social welfare institutions in Japan were the paucity of both human and financial resources as well as adequate knowledge among staff (Matsumoto et al., 2013). Additionally, the yes/no parental report format utilised in the M-CHAT is of concern due to the cultural characteristic among Japanese individuals who tend to avoid giving clear or direct answers to questions (Kamio et al., 2014).

The Current Research

The overarching aim in the research presented in this thesis was to determine a culturally appropriate way to improve early identification of autism in Public Health Centres in Japan that is feasible for lower-resource municipal governments. To achieve this, a literature review and a survey study were conducted to understand current practice regarding autism screening and diagnosis within the Public Health Centres and to identify challenges surrounding the use of an early autism screening instrument. The Autism Detection in Early Childhood (ADEC; Young, 2007) was then chosen as a potential instrument for use in this context, which was translated and adapted before undertaking a validation study of its use in a low resource setting in Japan.

The specific study objectives were:

1. To investigate autism screening practices at Public Health Centres in Japan, with a particular focus on the use of secondary autism screening instruments as well as prioritised objectives and challenges of follow-up services offered to children at higher risk of developmental difficulties within the centres

(Study 1).

2. To develop a Japanese adaptation of the ADEC (ADEC-J) following the guidelines for translation and adaptation of instruments (World Health Organization, n.d.) (Study 2).
3. To validate the ADEC-J with an international “gold-standard” diagnostic instrument, the Japanese adaptation of the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2; Lord et al., 2012; for Japanese, Lord et al., 2015) (Study 3).

Thesis Structure

Following this general introduction (Chapter 1), Chapter 2 comprises a literature review with a focus on early identification and follow-up pathways of children at high likelihood of developing autism in Japan, as well a review of early autism screening and diagnostic instruments that have been utilised within the Japanese population. Chapter 3, 4, and 5 present Study 1, 2, and 3, respectively, with Chapter 4 introducing the ADEC. Chapter 6 provides a general discussion of the findings from these three studies and will also provide recommendations for future research and clinical practice at Public Health Centres in Japan.

The term “ASD” is used in the thesis when referring to a diagnosis following the latest diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association, 2013), where ASD has become an umbrella term that encompasses once-separated diagnoses (Vivanti et al., 2013; Volkmar & McPartland, 2014). The term autism is used more generally when not referring to a diagnosis but rather to those with a diagnosis of ASD.

Chapter 2

Review of the Early Identification of Autism and Autism Screening Instruments in Japan

Early Identification and Subsequent Pathways

In Japan, the Maternal and Child Health Act stipulates that every municipal government conducts complimentary health check-ups for young children aged 18- to 24-months and 36- to 48-months (hereafter 18- and 36-month check-ups, respectively). Although the screening of autism and other developmental conditions is not an explicit aim of these check-ups, the Act on Support for Persons with Developmental Disabilities established in Japan in 2004 requires active efforts to screen for developmental disorders at statutory infant health check-ups (Kono & Ito, 2011). Hence, consistent with the Act, the 18-month check-up provides the first universal opportunity to identify early signs of autism (and other conditions) in young Japanese children. Notably, the second opportunity for statutory general population screening does not present until much later, at 36 months, beyond what would be considered the most opportune time to detect autism. Check-ups at other age periods, such as nine to ten, 12, or 24 months, are offered in some communities but are not prevalent (Japanese Society of Certified Clinical Psychologists [JSCCP], 2014). Given the early onset of autism symptoms (Barbaro & Dissanayake, 2009; Zwaigenbaum et al., 2019), it is crucial to utilise the 18-month general health and wellbeing check-up and related follow-up framework to ensure the early identification of children at high likelihood of developing autism in Japan. The purpose in undertaking this review was to (a) provide an overview of the Japanese statutory infant health check-up system and the ensuing referrals in relation to autism screening and diagnosis in particular; and (b) to review instruments that are currently

available in Japan for this purpose.

In this review and the following chapters, the term “screening” is used to refer to any type of effort aiming to identify children displaying early signs of certain developmental anomaly, whether using a standardised instrument or other methods. When specifically referring to the attempt to identify early signs of autism, “autism screening” or similar terms will be used. Statutory health check-ups are required to screen for various developmental risks including that of autism, but may not utilise condition-specific screening tools or items in screening practice. Such non-specified risk assessments for developmental disabilities are referred to as “general developmental screening”. Similarly, the term “support” is used as an umbrella term for a wide range of help provided to children and/or their families unless otherwise specified. In contrast, the term “intervention” is used to refer to conscious efforts to address the developmental concerns identified through screening in order to promote the child’s development. The term “support” is inclusive of some form of intervention service. Importantly, the term “follow-up service” used in the thesis refers to a range of “support” provided by Public Health Centres to those children identified with developmental risk at a check-up and their parents.

Statutory Infant Health Check-ups and Autism Screening

The free statutory health check-ups are characterised by high attendance rates, mass screening format, and involvement of public health nurses. The attendance rates at the 18- and 36- month check-ups are consistently over 90% nationwide (Ministry of Health, Labour and Welfare, 2018), rendering the system universal. The great majority take the form of mass screening at Public Health Centres instead of individual screening at contracted medical facilities (Yamazaki et al., 2016). This means that during intake, where screening for developmental disabilities including autism is often incorporated,

multiple parent-child pairs are simultaneously interviewed while the children are observed in a same room. Because the check-up includes a mandatory a set of procedures required by the Maternal and Child Health Act, there is only a limited time frame that can be spent on screening for specific developmental conditions, including autism. The screening also must be achievable in a setting where the child being tested is surrounded by multiple other parent-child pairs.

Intake is usually undertaken by registered public health nurses; psychologists may or may not be present at check-ups and, when they are, it is typically for specialised consultation and not for general intake (JSCCP, 2014; Sasamori et al., 2010). Notably, the public health nurses are typically generalists with their duties ranging from maternal and child health, elderly health, and welfare for people with intellectual or other disabilities (Okamoto et al., 2008; Saeki et al., 2007). They thus have different levels of training and experience that may affect their ability to recognise signs of autism or other developmental disabilities, particularly when these are subtle. Consequently, the outcome of screening greatly depends on individual expertise (Ministry of Health, Labour and Welfare, 2014) with potential variability in successfully identifying those children who need follow-up for developmental concerns. In order to improve the reliable and consistent identification of the early signs of autism at statutory health check-ups, the use of standardised early autism screening instruments is much desired (Yamazaki et al., 2016), particularly to compensate for the skill gap among nurses.

The Ministry of Health, Labour and Welfare currently have two recommendations for autism screening instruments to use at the statutory health check-up: the Japanese version of the Modified Checklist for Autism in Toddlers (M-CHAT-JV; Kamio & Inada, 2006) for the 18-month check-up, and the Parental-interview ASD Rating Scale (PARS; Tsujii et al., 2006) for use at the 36-month check-up. In 2015, the nationwide usage rates

of the M-CHAT-JV and PARS at these check-ups were 12.2% (212 out of 1741 municipal governments) and 3.7% (65 out of 1741), respectively (Ministry of Health, Labour and Welfare, 2016). No other instruments were mentioned in this government report. Data from other Japanese surveys supports the low usage of standardised autism screening tools at Public Health Centres (JSCCP, 2014; Matsumoto et al., 2013), mostly due to the lack of human and financial resources, and adequate knowledge among staff (Matsumoto et al., 2013).

Detection, Diagnosis, and Intervention

Outside of Japan, recent advances in early autism detection has increased rates of early referral and diagnosis (Baird, 2001). Diagnosis is deemed important as it is often the essential first step to access needed support, including early intervention services (Ibañez et al., 2019; Kaufman, 2020). Clark et al. (2017) reported that children who were diagnosed at 24-months had significantly more access to early intervention compared to those diagnosed later (between age three and five) and thus showed better cognitive and language abilities as well as lower levels of restricted and repetitive behaviours at school age. Diagnosis and subsequent access to intervention at around 24-months of age also predicted better cognitive outcomes among young adults with autism (Anderson et al., 2014). These findings emphasise the importance of early identification and diagnosis of ASD to increase the chances of earlier access to intervention.

To date, no nationwide research has been published on the average age at which children are diagnosed with ASD in Japan. Studies with smaller samples have reported that the average age when the families were notified of the child's autism was around four years old (Futagi & Yamamoto, 2002; Iwasa et al., 2014; Maeda et al., 2009; Matsunaga & Hiroma, 2010), which is similar to that in the United States (Centers for Disease Control and Prevention, 2014), and Australia (Bent et al., 2015). A more recent

Japanese study utilising large clinical data has reported the average age of diagnosis to be 7.2 years ($SD = 4.2$) and the mode age to be three years (Kurasawa et al., 2018). Given the extensive literature supporting reliable diagnosis by 24 months of age (e.g., Barbaro & Dissanayake, 2017; Zwaigenbaum et al., 2015) and the benefits of earlier intervention (Dawson et al., 2010; Howlin et al., 2009), this is undoubtedly late, missing a valuable period for early intervention.

The average age of an ASD diagnosis in Japan may be partially attributed to the disparity in the infrastructure for child healthcare among Japanese municipal governments (Ashizawa, 2003). According to a survey targeting smaller municipalities with a population of less than 30,000, which account for more than half of local governments in Japan, less than 40% have medical organisations that are capable of early diagnosis of developmental disorders (Takahashi et al., 2015). Therefore, referral to external medical institutions may not be viable, or there may be a long waiting list due to the limited capacity within such institutions. Additionally, a Japanese study identified parental lack of knowledge regarding appropriate medical institutions and the younger age of the child as two of key factors associated with the time lag between first parental concern about their child's development and the first visit to a paediatric psychiatric service capable of early diagnosis of ASD (Fujiwara et al., 2011).

Many Japanese parents first become concerned of their child's development when the child is between one to two years (Futagi & Yamamoto, 2002; Matsunaga & Hiroma, 2010), and are often first notified of their child's potential developmental concerns at the 18-month check-up (Kono & Ito, 2011; Maeda et al., 2009). In contrast, the average age of first specialised consultation is three years ($SD = 19.23$ months; Matsunaga & Hiroma, 2010) and a diagnosis of ASD is generally given at between three to four years, as noted

previously (e.g., Maeda et al., 2009; Matsunaga & Hiroma, 2010). Together the data suggest that parents may be reluctant to see a doctor when their child is very young (Fujiwara et al., 2011; Sasamori et al., 2010), even if they already have concerns or are recommended for a referral by their local public health nurse.

Importantly, in Japan, delays in diagnosis do not necessarily result in delays in the onset of intervention (i.e., relatively intensive intervention at an institution outside Public Health Centres). Natsubori (2002) noted that enactment of the universal 18-month check-up in 1977 made it possible for children to commence intervention prior to a medical diagnosis, including those with a likelihood of autism. Her study compared children who were born before and after the enactment and found significant differences in the average ages of first consultation at a public institution and onset of intervention between the two groups. In the case of children who received the 18-month check-up, both events preceded the diagnosis contrary to the other group. A similar trend was reported in a parental survey in which the most common age of onset of intervention was reported to be between age two and three years, whereas the most common age of diagnosis was between ages three and four (Maeda et al., 2009). This appears to be due to the Japanese child healthcare structure enabling children with developmental concerns to directly access to intervention services outside Public Health Centres without a formal diagnosis (Morimoto, 2016; Takano & Murakami, 2017), which is in contrast to many Western systems where diagnosis is an essential first step to accessing early intervention services (Ibañez et al., 2019).

However, as with the availability of medical institutions capable of diagnosing ASD early, the availability of early intervention facilities depends on the local child healthcare infrastructure (Sasamori et al., 2010). According to the aforementioned survey, only around 60% of smaller municipal government in Japan have early intervention

facilities in their community (Takahashi et al., 2015). Moreover, parental resistance to the use of intervention services has also been reported (Mizuta. et al., 2005), probably due to the difficulty in accepting their child's disability (Ichise, 2016). The central setting that provides early intervention, though not intensive, and other support is therefore deemed to be the after-check-up follow-up services offered by Public Health Centres.

Follow-up Process

When a child screens positive for a developmental concern, including autism, at the 18-month check-up, the Public Health Centre typically offers a range of follow-up services for the purpose of monitoring and providing various supports to the children and their caregivers (Kono & Ito, 2011)¹. The types of follow-up service include individual specialist consultations, parent-child group intervention, home and preschool visits, as well as referral to an external medical or intervention institution (JSCCP, 2014; Kono & Ito, 2011).

As described in the previous section, referral to a medical or intervention institution can be challenging due to both the paucity of resources and parental resistance. To overcome these difficulties and ensure a reliable identification of developmental concerns, some municipal governments have incorporated the check-ups and the follow-up process into a larger, more comprehensive early support system, including for autism. Figure 2-1 illustrates the system in the cities of Toyota (Kawamura et al., 2008) and Yokohama (Honda et al., 2009). Here, the 18-month check-up serves as the primary screening opportunity and the 36-month is treated as a “fail-safe”. Further, the follow-up process serves as opportunities for further assessment, as well as early

¹ As defined earlier, when the terms “follow-up” and “follow-up service” are used in this and following chapters, these refer to the provision of support to children and their families and not to the monitoring of children for the purpose of screening quality control.

intervention and other supports. As a result, the entire system enables children found to be at high likelihood of autism at a check-up to be seamlessly connected to follow-up, diagnosis, and specialised intervention, without missing the valuable timeframe for early intervention. Such a comprehensive approach is, however, only possible because of (a) the presence of a core facility that can provide diagnosis, intervention, and supervision and (b) a collaborative network between the core facility and other local child healthcare/childcare facilities, inclusive of the Public Health Centres (Honda et al., 2009; Kawamura et al., 2008).

Many Japanese municipal governments, particularly smaller ones, are much less resourced than the services available following the detection at statutory health check-ups in Toyota and Yokohama, as presented in Figure 2-2. In this general model, both access to early diagnosis and early intervention is limited as presented by the dotted lined arrows. Consequently, the follow-up service at Public Health Centres is expected to carry two important functions. The first role is to further assess the referred children, including more detailed screening for autism risk, and provide necessary support. As illustrated in Figure 2-2, preschool-aged children and their parents may spend several years receiving support via the Public Health Centre until they reach school age, with the parent-child group intervention being the first and only early intervention opportunity available to them. However, the details of the intervention programmes vary from centre to centre, and frequency of the programme is generally as low as once per month (Kono & Ito, 2011). It is important to note that this provision does not serve as an ideal autism intervention, which needs to be intensive and individualised to cater to the heterogeneity of autism symptom presentation. However, in low resourced municipalities where the group intervention at Public Health Centres may be the only immediately available intervention, the value of having an opportunity to intervene to promote the child's

development should not be overlooked. Further, to effectively utilise what is available within each municipality, including the low-intensity group intervention programme, assessing and prioritising of referred children who are in higher need of behavioural intervention, and designing a programme to address their specific developmental challenges are necessary.

A second role of the follow-up service is to aid parental understanding and acceptance of their child's developmental concern or disability. Despite the ability to, when available, access early intervention facilities prior to a formal diagnosis (Morimoto, 2016; Takano & Murakami, 2017), a diagnosis of ASD remains important as it facilitates receipt of relevant social welfare services, including "reasonable accommodations" at school and workplace in accordance with the Japanese Act for Eliminating Discrimination against Persons with Disabilities (Tanaka, 2016). In order to promote diagnosis of ASD in the country, overcoming parental resistance to visit a medical institution is necessary. In this view, studies on post-diagnostic parental acceptance have shown that acceptance by Japanese parents was promoted by improved understanding of their child's autism symptoms (Futagi & Yamamoto, 2002), and reception of intervention before diagnosis (Natsubori, 2002). These reports indicate that providing appropriate psychological support and education on autism to caregivers as well as intervention to their children may aid parental readiness to access and receive an ASD diagnosis for their child. However, little research has examined how the follow-up services at Public Health Centres contribute to cultivating parental acceptance of their child's disability and encouraging them to visit a medical institution.

Figure 2-1

Comprehensive Autism Support System in Toyota (left; adapted from Kawamura et al., 2008) and Yokohama, Japan (right; adapted from Honda et.al., 2009).

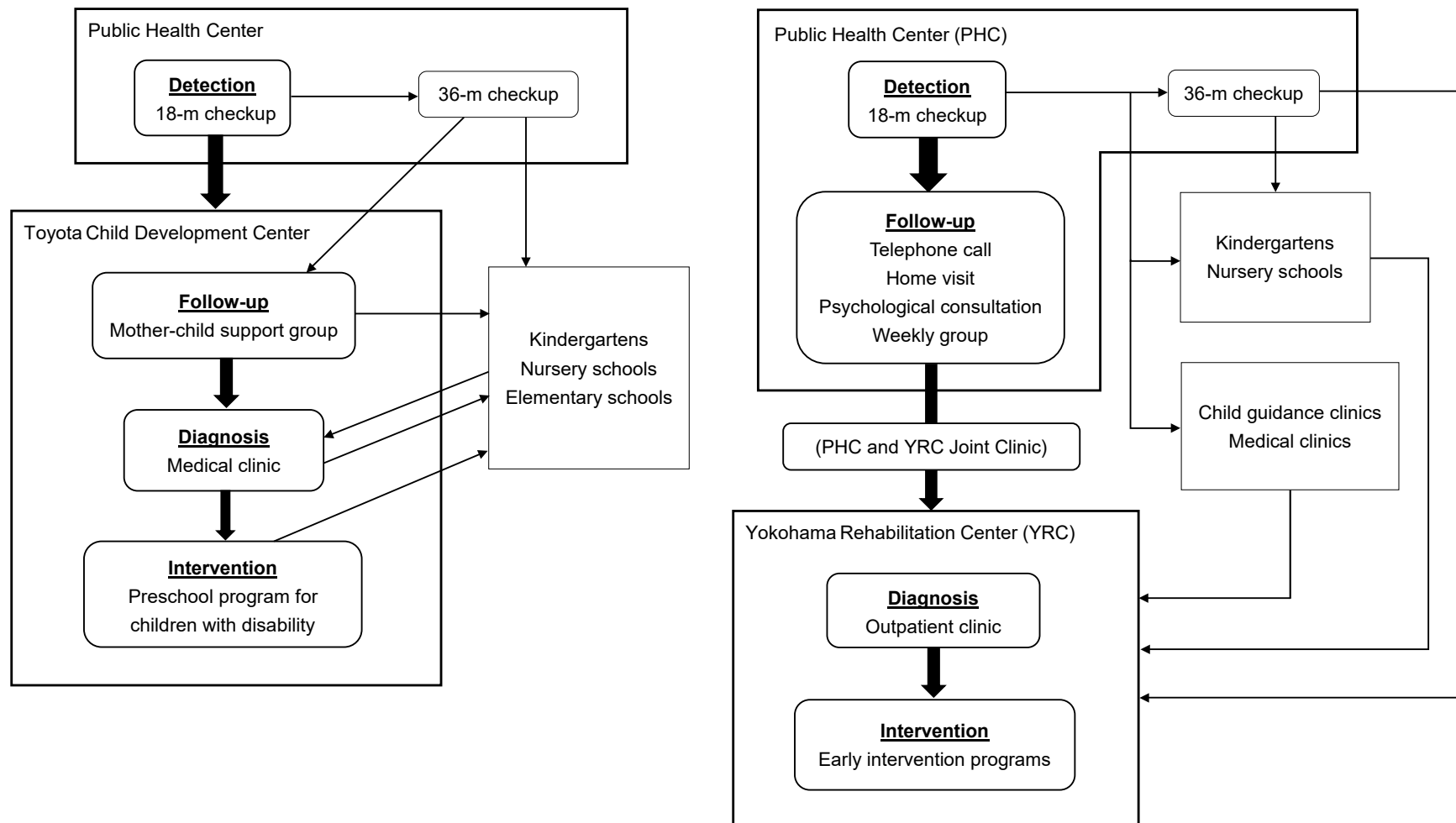
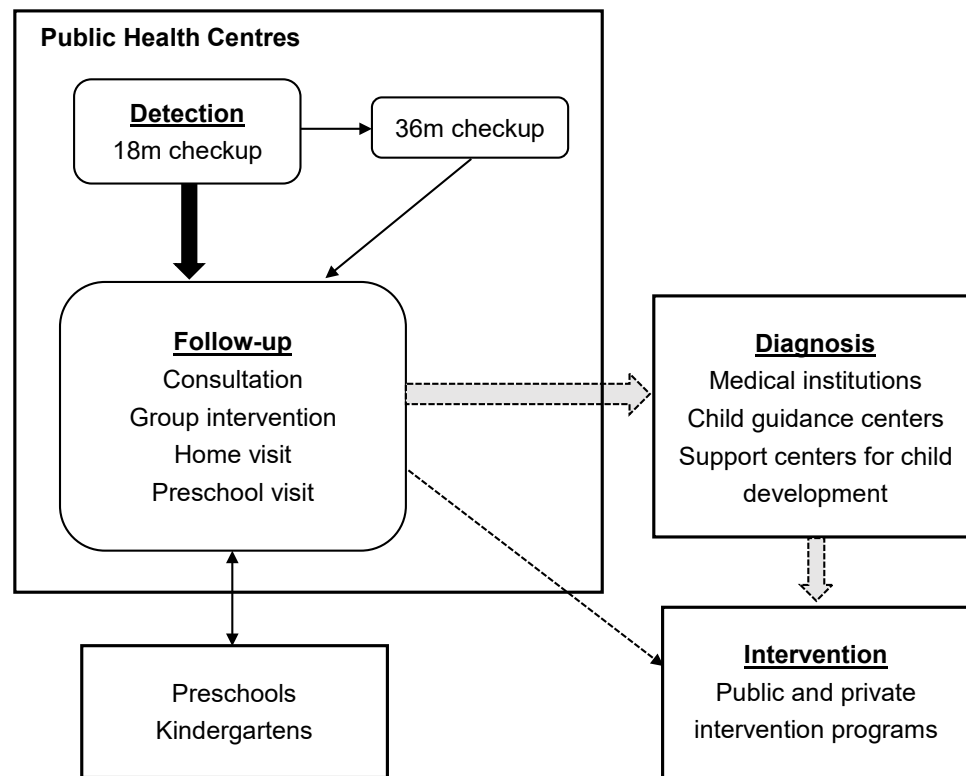


Figure 2-2*A Generic Model of Early Detection and Support for Autism in Japan*

Interestingly, the average age of an ASD diagnosis was 40 months in Toyota (Kawamura et al., 2008), and the average age of referral to the medical clinic was 35 months in Yokohama (Honda et al., 2009), consistent with reports from Japanese studies in different regions (e.g., Maeda et al., 2009; Matsunaga & Hiroma, 2010). It is noteworthy that despite the better resourced and comprehensive support systems in Toyota and Yokohama, a similar age of diagnosis and referral is apparent compared to less comprehensive and resourced systems elsewhere in the country. According to Iwasa et al. (2014), the delay in informing parents of their child's diagnosis within the Yokohama framework is often intentional by the medical practitioner due to concern that the parents' psychological wellbeing may be adversely affected if their child's condition

is made known to them. Instead, the follow-up stage of the system offers support for children and their parents, including less-intensive intervention immediately after detection at a check-up (Honda et al., 2009), and some children are sent to the specialised, more-intensive intervention programme prior to informing parents of the diagnosis (Iwasa et al., 2014). These findings further highlight the magnitude of hesitancy about early diagnosis among Japanese parents. Identification of the key barriers and enablers of an early diagnosis in relation to the follow-up services will constitute an important research topic.

Secondary Autism Screening at Follow-up

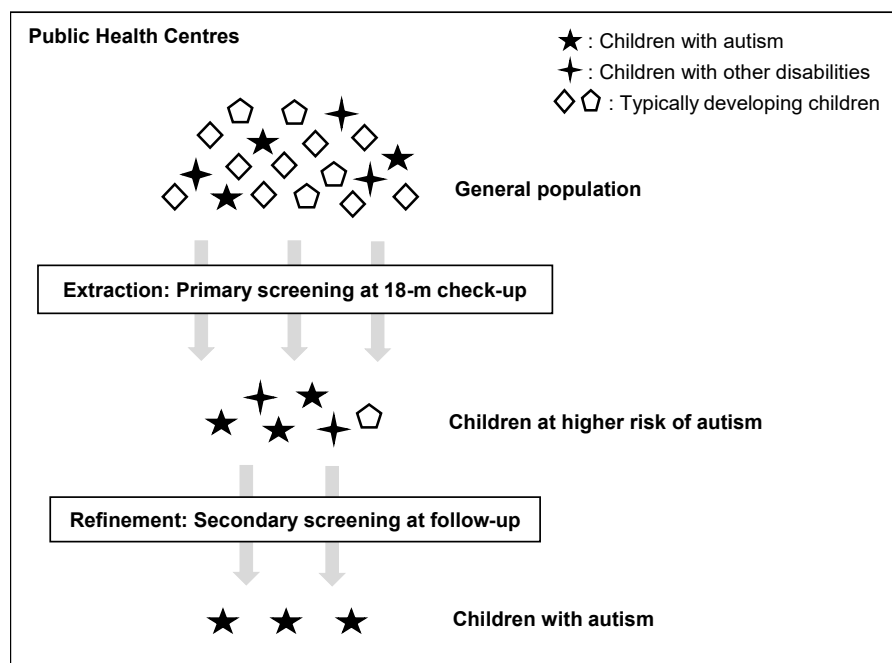
The early support framework centred around the follow-up services at Public Health Centres and provided without diagnosis (see Figure 2-2) is sometimes called “support before diagnosis” and is now encouraged by the Japanese Ministry of Health, Labour and Welfare (Yamazaki et al., 2016). To enhance the early identification of autism and support before diagnosis at Public Health Centres, Yamazaki et al. (2016) highlight the importance of further assessment of children during follow-up. This idea overlaps with the ‘Extraction and Refinement Strategy’ within the Yokohama framework where primary (Level 1) screening at the 18-month check-up aims to identify every child with any developmental concerns (Extraction) and secondary screening (Level 2) undertaken within the follow-up service aims at specifying the likely diagnosis (in this case ASD) among the referred or ‘high-risk’ children (Refinement) (Figure 2-3; Honda et al., 2009). However, their survey confirmed that while general developmental assessments such as the New Kyoto Scale of Psychological Development (Koyama et al., 2010) were used at some of the centres, screening tools specific to developmental disorders, including autism, were rarely used (Yamazaki et al., 2016). To date, few studies have investigated the instrument use within follow-up services at Public Health Centres. One small-scale

survey study confirmed the low-usage of screening instruments at Public Health Centres (Matsumoto et al., 2013). Hence, the introduction of autism -specific screeners for secondary assessment during the follow-up process has been recommended. (Yamazaki et al., 2016).

The following section encompasses a review of the existing early autism screening instruments used in Japan in an effort to inform current practices at Public Health Centres, and to identify future needs and research directions.

Figure 2-3

Extraction and Refinement Strategy in Yokohama (based on Honda et. al., 2009)



Screening Instruments

Early screening instruments may be categorised into three groups (Barton et al., 2012; Charman & Gotham, 2013). Level 1 screeners are designed to identify individuals at risk of a specific condition within the general population (i.e., for primary screening in

Figure 2-3). These are typically used in primary care settings, hence should be brief and easy to implement and interpret. Level 2 screening tools provide a further, more refined evaluation to those identified by Level 1 tools (i.e., for secondary screening in Figure 2-3). The goal is to identify specific diagnoses from an “at-risk” cohort, and to fast-track children to appropriate diagnostic or intervention services. Administration and interpretation of Level 2 screeners generally require more time and expertise and are typically administered in a setting where specialised teams or organisations are unavailable, and a formal diagnosis is difficult to obtain. Finally, standardised diagnostic instruments are employed to help form a diagnosis, although ultimately judgment relies on the clinical experience and expertise of the administrator (Charman & Gotham, 2013). According to this categorisation, a Level 1 screener is the most appropriate for use at the statutory health check-ups, since it screens the general population, whereas a Level 2 screener is suitable at the stage of follow-up.

In reviewing screening instruments, the important psychometric properties to consider are sensitivity, specificity, and positive and negative predictive values (PPVs and NPVs, respectively). The sensitivity of a tool indicates how accurately it can identify children with the condition (in this case autism; also called true positive ratio), and the specificity indicates how accurately the tool can exclude children without autism (also called true negative ratio). Ideally, a screening tool will have a sensitivity and specificity that exceeds .70 (Dumont-Mathieu & Fein, 2005). It is important to note, however, that high levels of sensitivity are more important in Level 1 tools, and specificity in Level 2 measures, with some trade-off possible depending on the level of screening being undertaken. The PPV represents the probability of the child actually having autism when the result is positive, while the NPV is the probability that the child does not have autism when the result is negative.

Level 1 Screening Instruments

Table 2-1 summaries the Level 1 autism screening tools used in Japan. There are three tools suitable for use in children aged 18 to 24 months, which is the population that receives the 18-month check-up. The Checklist for Autism in Toddlers (CHAT; Baron-Cohen et al., 1992) consists of nine parental interview items (Section A) and five behaviour observation items (Section B) designed for use with children aged 18 months. The Japanese adaptation of the CHAT was reported to have a high sensitivity (.89) and PPV (.86) in its preliminary study (Koyama et al., 2005), although the participants in this study were high-risk children instead of a low-risk community sample; moreover the mean age of children was 28.7 months, much higher than the intended population for the original CHAT. Koyama et al. (2010) extracted four items out of the five behaviour observation items that performed best in discriminating children with autism from those without, and reported moderate to good sensitivity, specificity, PPV and NPV (.85, .73, .77, .81, respectively). The psychometric properties of the Japanese CHAT as used in the general population currently remain unknown. With regard to the original CHAT, a recent review on autism screening instruments (Zwaigenbaum et al., 2015) critiqued it based on its poor sensitivity (.18 after a 6-year follow-up of the cohort monitored at 18 months of age; Baird et al., 2000).

Originally based on Section A of the CHAT, the Modified-CHAT (M-CHAT) has 23 parent report items, and due to poor psychometrics (see Yuen et al., 2018) now includes a follow-up telephone interview (Robins et al., 2001). The target age for use is 24 months, with the follow-up interview included to improve specificity while maintaining sensitivity. Its Japanese adaptation, M-CHAT-JV, was introduced as a screener for potential use at the 18-month check-up, with a lower cut-off score (two instead of three) to adjust for the lower target age (Kamio & Inada, 2006). Although a

preliminary study reported excellent sensitivity and specificity (.92 and .95, respectively), all parents of the autistic children failed to notice the absence of some of typically observed behaviours (i.e., responds to name, makes eye contact, responds to smile, and wonder if s/he is deaf), suggesting a cultural effect (Kamio & Inada, 2006). To address this issue, illustrations were added for these four items that ask about negative symptoms (the absence of typical behaviours) (Inada et al., 2011). A validation study conducted after this change yielded moderate sensitivity (.75) and good specificity (.89), despite the follow-up telephone interview not being included (Inada et al., 2011).

A more recent study on the M-CHAT and the follow-up telephone interview resulted in much lower sensitivity (.48) than reported above, implying the tool was less sensitive to autism without intellectual disability (Kamio et al., 2014). Outside of Japan, similar results have been reported in a general population study using the Sinhala M-CHAT in Sri Lanka, which returned sensitivity of .25 (Perera et al., 2009). Furthermore, studies using the original M-CHAT in the US have reported a PPV ranging from .06 to .36 without the follow-up telephone interview (Chlebowski et al., 2013; Kleinman et al., 2008). Kamio et al. (2014) suggest that sensitivity may be improved by having some of the M-CHAT items observed by the public health nurse. This suggestion was based on the observation that the yes/no format may hinder accurate reflection of caregivers' observations, noting the cultural characteristic whereby Japanese people tend to avoid giving clear or direct answers to questions.

Table 2-1*Level 1 Autism Screening Instruments in Japan*

Tool	Details	Reference	Participants	Sensitivity and Specificity	PPV and NPV	Note	Original
CHAT-J	Parental interview (Section A) and interactive observation (Section B) 14 items (9 in Section A and 5 in Section B) Yes-no rating for both sections Designed for use in children aged 18 months Not officially available for public use	Koyama et al. (2005)	High-risk population aged under 3 years ASD group: $n = 47$, $M_{\text{age}} = 28.4$ months, $SD = 3.7$, range = 21-35 Non-ASD group: $n = 23$, $M_{\text{age}} = 29.0$ months, $SD = 3.9$, range = 18-35m	Sensitivity = .89; Specificity not presented	PPV = .86; NPV not presented	Parents of children aged over 2 years retrospectively answered to Section A.	Baron-cohen, Allen, & Gillberg (1992)
		Koyama et al. (2010)	High-risk population aged 2 years ASD group: $n = 52$, $M_{\text{age}} = 30.1$ months, $SD = 3.4$, range = 24-35 Non-ASD group: $n = 48$, $M_{\text{age}} = 31.0$ months, $SD = 3.0$, range = 25-35	Based on four items from Section A with most discriminative power: Sensitivity = .85; Specificity = .73 IQ-matched subgroup Sensitivity = .74; Specificity = .78	Based on four items from Section A with most discriminative power: PPV = .77; NPV = .81 IQ-matched subgroup PPV = .71; NPV = .80	The study examined effectiveness of the CHAT-J in detecting ASD among 2 year olds. Only Section A was used. There was a significant difference in mean IQ between two ASD and non-ASD groups.	
M-CHAT-JV	Parental report and follow-up telephone interview 23 items in full version and 9 items in short version (Inada et al., 2011) Yes-no rating Designed for children aged 18 months Available online for public use (free of charge)	Kamio & Inada (2006)	General population aged 18 to 24 months (attending 18-month check-up), $N = 659$	With cutoff of 3 out of 23 items: Provisional sensitivity = .92; Provisional specificity = .95 With cutoff of 2 out of 10 key items: Provisional sensitivity = .83; Provisional specificity = .97	With cutoff of 3 out of 23 items: Provisional PPV = .30; Provisional NPV not presented With cutoff of 2 out of 10 key items: Provisional PPV = .37; Provisional NPV not presented	A lower cutoff score was employed since the M-CHAT-JV aims for 18 months rather than 24 months.	Robins, Fein, & Barton (2001)
		Inada et al. (2011)	Discriminant validity sample: General population aged 18 to 24 months (attending 18-month check-up), $N = 1,187$	Provisional sensitivity = .75; Provisional specificity = .89 Short version Sensitivity = .65; Specificity = .89	Provisional PPV = .11; Provisional NPV = 1.00 Short version Provisional PPV = .09; Provisional NPV = .99	Illustrations were added for negative symptoms. Follow-up telephone interviews were not conducted. Psychometric properties of a short version were reported.	

Tool	Details	Reference	Participants	Sensitivity and Specificity	PPV and NPV	Note	Original
M-CHAT-JV (cont.)		Kamio et al. (2014)	General population aged 18 to 24 months (attending 18-month check-up), $N = 1,187$	Without the follow-up telephone interview: Provisional sensitivity = .73; Provisional specificity = .84 With the follow-up telephone interview: Provisional sensitivity = .48; Provisional specificity = .99	Without the follow-up telephone interview: Provisional PPV = .12; Provisional NPV not presented With the follow-up telephone interview: Provisional PPV = .46; Provisional NPV not presented	The low sensitivity of two-stage screening may be due to the high ratio of screen positive cases that did not respond to the telephone interview (124 of 319 cases).	
Gazefinder®	Eye tracking system 5 types of video clips (About 2 minutes to complete) The algorithm automatically outputs the result Designed for use at 18 month checkup Available from vendor	Tsuchiya et al. (2015)	Predictive validity study Mixed population ASD group: $n = 37$, range = 20 to 26 months Community sample: $n = 426$, range = 18 to 24 months	Provisional sensitivity = .78; Provisional specificity = .88 (Presence or absence of ASD diagnoses among community sample is unknown)	Provisional PPV = .36; Provisional NPV = .98		Not applicable
PARS (Preschool part)	Parental interview 34 item in full version (about 30 minutes to complete) and 12 items in short version (Adachi et al., 2012) Three-point scale rating Asks behaviors during pre-school years Published and available for public use	Tsujii et al. (2006)	Study 2 Clinical population ASD group: $n = 55$, $M_{\text{age}} = 5\text{years } 9\text{ months}$, $SD = 10\text{ months}$ Non-ASD group: $n = 31$ (7 clinical and 24 typically developing), $M_{\text{age}} = 5\text{ years } 3\text{ months}$, $SD = 10\text{ months}$	Sensitivity = .89; Specificity = .94	PPV = .96; NPV = .83	Designed as a Level 2 screening tool, but recommend for use at 36-month check-up by the Ministry of Health Labour and Welfare.	Not applicable
		Adachi et al. (2008)	Same as in Tsujii et al. (2006)	Short version Sensitivity = .89; Specificity = .97	Short version PPV = .98; NPV = .83	Study on a short version.	

Tool	Details	Reference	Participants	Sensitivity and Specificity	PPV and NPV	Note	Original
PARS (cont.)		Ito et al. (2012)	Mixed population aged 3 to 38 years (Overall) Preschool sample ASD group: $n = 39$, $M_{\text{age}} = 5.1$ years, $SD = 1.0$, range = 3-6 Non-clinical group: $N = 132$, $M_{\text{age}} = 4.8$ years, $SD = 1.0$, range = 3-6	Age-group specific data are unavailable	Age-group specific data are unavailable		
		Nakajima et al. (2012)	General population aged 36 to 48 months (attending 36-month check-up), $N = 1,202$	Unavailable due to the absence of follow-up information	Unavailable due to the absence of follow-up information	The short version (Adachi et al. 2008) was used in the following manner: 1) A nurse interviews the parent (about 10 minutes), 2) a psychologist interviews the same parent, reviewing the initial scores and 3) the psychologist revises the scores as needed to obtain final scores.	
		Nakajima et al. (2013)	General population aged 36 to 48 months (attending 36-month check-up), $N = 1,402$	Unavailable due to the absence of follow-up information	Unavailable due to the absence of follow-up information	The short version (Adachi et al. 2008) was used in the following manner: 1) A nurse interviews the parent (about 10 minutes), 2) a psychologist interviews the same parent, reviewing the initial scores and 3) the psychologist revises the scores as needed to obtain final scores.	
SRS-P	Parental/teacher report 65 items (15 to 20 minutes to complete) 3-point scale rating Designed for children aged 3 years Can be used as both Level 1 and 2 screeners Published and available for public use	Stickley et al. (2016)	Mixed population aged 2 to 4.5 years ASD group: $n = 40$, $M_{\text{age}} = 40.73$ months, $SD = 6.38$, range = 26-51 Non-ASD clinical group: $n = 34$, $M_{\text{age}} = 40.35$ months, $SD = 5.02$, range = 34-50 Community group: $n = 357$, $M_{\text{age}} = 38.63$ months, $SD = 3.35$, range = 25-50 months	ASD vs. community Mother ratings: Provisional sensitivity = .83; Provisional specificity = .82 Teacher ratings: Provisional sensitivity = .83; Provisional specificity = .80 ASD vs. non-ASD clinical Mother ratings: Sensitivity = .83; Specificity = .44 Teacher ratings: Sensitivity = .82; Specificity = .68	Not presented	Mother and teacher ratings were analyzed separately with different cutoffs. Raters might be aware of diagnoses in ASD and non-ASD clinical group. Convergent validity: Mother ratings of ASD children strongly correlated with the Japanese ADI-R total scores (Tsuchiya et al., 2013) ($n = 30$, $r = .73$, $p < .01$), and moderately with Social and Communications scores of the Japanese ADOS (Kuroda et al., 2013) ($n = 30$, $r = .43$, $p < .02$).	Pine et al. (2006)

Turning to technology based tools, an eye tracking device called Gazefinder® (JVC Kenwood Corporation, Yokohama, Japan) was designed to operationalise more subjective indices characteristic of autism, namely gaze patterns, for early identification, with use at the 18-month check-up in mind (Tsuchiya et al., 2015). A set of short video clips are played to the child for approximately two minutes while s/he is seated on the mother's lap; the eye tracker device simultaneously measures the length of fixated gazes on preselected regions of interest in the clips (Ebisawa & Fukumoto, 2013; Tsuchiya et al., 2015). In a study aimed at developing a diagnostic algorithm, only 4% of the participants were excluded from analysis due to an insufficient data acquisition rate (50% was set as a threshold). The algorithm provided good sensitivity (.78) and specificity (.88) when comparing autistic children with those from a general population sample; however, the children in this community sample were not followed up, and their diagnostic status remains unknown (Tsuchiya et al., 2015). The low feasibility of wide adoption of such a tool needs to be considered as well, as implementing the Gazefinder® across Public Health Centres, particularly in low resource settings, would be questionable.

A further two instruments are available for use at the 36-month check-up. The Parent-interview ASD Rating Scale (PARS; formerly PDD-Autism Society Japan Rating Scale) was developed by a group of Japanese researchers to inform a diagnosis of ASD from infancy to adulthood (Tsujii et al., 2006). Of the 57 interview items, 34 are used to assess preschool-aged children (i.e., aged three to six years). Despite the developers' intention, the PARS is recommended as a screener for the 36-month check-up by the government (Ministry of Health, Labour and Welfare, 2016), which is why it is categorised as a Level 1 tool here.

Tsujii et al. (2006) and Adachi et al. (2008) tested the PARS preschool items and a short version (12 of 34 items), respectively. They reported excellent sensitivity

(both .98), specificity (.94 and .97), and PPV (.96 and .98), respectively, although parental bias might have affected the scores since they were already aware of their child's diagnosis, and many of them answered retrospectively ($M_{\text{age}} = 5$ years 6 months, $SD = 10$ months). Based on this promising result, a population study was conducted using the short version at 36-month check-ups (Nakajima et al., 2012). Parents were first interviewed by a public health nurse and then by a psychologist who reviewed and revised the initial score to finalise the assessment. Unfortunately, there is no follow-up report on the discriminative properties of the PARS short version in this cohort. Ito et al. (2012) compared PARS scores with scores of a “gold standard” diagnostic interview tool, the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994; Tsuchiya et al., 2013 for the Japanese adaptation). The subscales and total score of the PARS showed only weak to moderate correlations with the Japanese ADI-R, with no separate analyses undertaken on younger participants (age range of the whole sample: 3—38 years).

The preschool version of the Social Responsiveness Scale (SRS; Pine et al., 2006) was originally designed to assess treatment response of 3-year-olds with autism. The Japanese adaptation was created and examined for validity as both a Level 1 screener (by comparing autistic and community samples) and a Level 2 screener (by comparing autistic and non-autistic clinical samples) (SRS-P; Stickley et al., 2017). The former set of data yielded a sensitivity of .83 and a specificity of .82, although, again, the community sample was not followed up and their diagnostic status remains unknown. When used as Level 2 tool, satisfactory sensitivities (.81-.82), but low to moderate specificities (.43-.68) were found, depending on whether the rater was a mother or a teacher. A limitation of the study, as identified by its authors, is that the raters of the clinical sample were not blind to the child's diagnosis.

Issues with Level 1 Screening Instruments

In introducing an early screening tool, it is pragmatically beneficial to minimise additional costs to existing maternal and child health procedures (Charman et al., 2002). Given that the combined use of a parental report and a direct observation allows better screening (Charman & Gotham, 2013; Gotham et al., 2011), the structure of the CHAT may more feasible and informative. However, population studies on the CHAT-J are required before considering its use at the 18-month check-up. The advantages of the M-CHAT-JV is its format, briefness, and accessibility. Nurses can ask parents to fill out the questionnaire either before or during the check-up without creating significant impact on existing operations. The M-CHAT-JV questionnaire, supplementary illustrations, and the follow-up telephone interview manual are freely available online, possibly being one of the reasons why it is the most prevalently used tool, although still not very common, within Public Health Centres in Japan.

The use of the M-CHAT-JV at the statutory health check-ups (JSCCP, 2014; Ministry of Health, Labour and Welfare, 2016; Yamazaki et al., 2016) remains unclear, including whether the follow-up telephone interview is administered as intended. Yamazaki et al. (2016) mentioned the partial use of the M-CHAT items at some Public Health Centres, and it is unknown whether they employed the validated short version (Kamio, Haraguchi, et al., 2015). Moreover, the M-CHAT-JV has low sensitivity, which raises concerns that children with autism will be missed (Barton et al., 2012). It has also been reported that ratings on the M-CHAT-JV by mothers were significantly different from direct observations of the same children by specialists, suggesting parental report may not be sufficiently reliable (Ishii et al., 2013; Tamai et al., 2014). This is a challenge identified in other research comparing assessments by parents and specialists (Stone et al., 1994; Takei et al., 2010). Further, no modifications have been made to the

administration format of the M-CHAT-JV (as of 2020), despite repeated discussion about this by the developers of the Japanese adaptation (Kamio & Inada, 2006; Kamio et al., 2014). Thus, the Gazefinder may be able to provide more objective assessments; however, instalment and maintenance costs may not be affordable for a Public Health Centre. Further, to confirm its efficacy, a follow-up study on the community sample tested by Tsuchiya et al. (2015) is needed.

Developed in Japan, the PARS provides a culturally suitable tool, with detailed interview lines supplied in the manual which are helpful for appropriate administration. The full version may, however, be lengthy (30 minutes to complete) to adapt to the 18-month check-ups, and the short version lacks psychometric data for use as a Level 1 screener as the community samples used in studies have not been followed up (Nakajima et al., 2012, 2013), which is also the case with the SRS-P (Stickley et al., 2017). More research is thus needed to determine the usefulness of these instruments as Level 1 screeners.

Instrument Design Suitable for the Statutory Health Check-up

The instruments in use in Japan currently do not have sufficient evidence to support their use at the statutory health check-ups as Level 1 screeners. This is not surprising as it has already been reported elsewhere that no individual screening tools have been recognised for universal use (Charman & Gotham, 2013; Zwaigenbaum et al., 2015). Even within the scope of this review, more research is required for each of the tools discussed here.

In an effort to avoid the shortcomings apparent in using the aforementioned tools within the statutory health check-ups, it may be prudent to develop a different model of screening. Since nurses are the primary staff undertaking screening at the statutory check-ups, improving their level of expertise is equally as important as the performance

of the screening tool itself. Further, the challenge surrounding parental report tools discussed above highlights the importance of professional involvement in the screening process, including administration of the tool, and reviewing and interpreting screening results. The two-step administration of the PARS at the 36-month check-up was part of an ongoing effort to develop a training system for public health nurses on early autism screening (Nakajima et al., 2013). Unfortunately, however, this instrument is not designed for use in children as young as 18 months, and the tools suitable for this population (i.e., CHAT-J, M-CHAT-JV, and Gazefinder®) have no built-in training for child healthcare professionals who administer and interpret the results from the tools. In order to take full advantage of the 18-month check-up and multiple screening opportunities of the Japanese check-up system, as well as to address the risk of relying only on parental report, the idea of developmental surveillance by public health nurses is worthy of consideration.

The Social Attention and Communication Surveillance (SACS) approach was developed in Victoria, Australia, to monitor early signs of autism in children throughout infancy and toddlerhood by repeatedly monitoring children's behaviours at 12, 18 and 24 months (Barbaro & Dissanayake, 2010). A large-scale community-based study ($N = 20,770$) reported good to high estimated sensitivity (.69 to .84), excellent estimated specificity (.998 to .999) and high PPV (.81) (Barbaro & Dissanayake, 2010). Notably, this approach incorporated training of maternal and child health nurses on interactive behavioural observation items, and screening was conducted as part of children's routine health checks within the universal maternal and child health service (Barbaro et al., 2011). The roles of the Victorian maternal and child health service and nurses parallel the roles in the Japanese Public Health Centres and nurse-based check-ups, with the exception that the maternal and child health check-ups are undertaken individually at a

20 to 30 minute appointment, rather than at mass screenings, as is the case in Japan (Nashiro, 2015). This difference is thought to affect the degree of tension and performance of children at the time of assessment, with the Japanese setting considered to be more challenging for young children (Okuno et al., 2015).

With this challenge in mind, the SACS framework was adopted and modified for the Japanese setting, and the feasibility and effectiveness of the Japanese adaptation were assessed within a community cohort ($N = 166$) (Okuno et al., 2014; Okuno & Kezuka, 2016). Characteristic of this Japanese adaptation of the SACS (SACS-J) was (a) the inclusion of items that assess general development, in accordance with the Maternal and Child Health Act, (b) item selection mindful of developmental stages (i.e., different set of tasks at different ages), (c) task and toy selection that is more engaging to young children, and (d) a reduced total number of items to cope with the time limitation during the check-up (Okuno & Kezuka, 2016). In the study, public health nurses in a small town were trained on interactive behavioural observation items, and conducted check-ups at 15, 20 (as the 18-month), 27, and 38 (as the 36-month) months. The 15- and 27-month check-ups are unique to this local government, although having extra assessment opportunities before and after the statutory check-ups is not uncommon nationwide (JSCCP, 2014). The two-year monitoring of the cohort identified four types of developmental trajectories based in the social and communication items, confirming the utility of adopting a surveillance approach (Okuno & Kezuka, 2016). The group considered at the highest likelihood of autism consisted of 12 of 166 children (7.2%) who consecutively failed the SACS-J at 15 and 20 months, with three children having received a medical diagnosis of ASD by the time of the report (Okuno & Kezuka, 2016). The SAC-J approach is significant as it was specifically designed to fit within the Japanese statutory health check-up system. In the absence of one definitive screening

instrument, repeated interactive assessments by public health nurses at both statutory check-ups (18- and 36-months), and other check-ups if available, appears to be an ideal approach to monitor children for autism. However, it is important to note that the SACS-J is still under evaluation. Further, Level 1 screening is not the focus of this thesis which, instead, addresses the scarcity of Level 2 screeners in Japan.

Level 2 Screening Instruments

In order for a tool to be useful within the follow-up service after the 18-month check-up, it needs to be appropriate for children aged 18 to 24 months. Table 2-2 provides a comprehensive list of Level 2 screeners for autism in Japan that fulfill this criterion. Given the recent findings that early detection of autism becomes more reliable and stable after a child reaches 14 months of age (Pierce et al., 2019; Sánchez-García et al., 2019), 18 months is considered reasonably early in the Japanese maternal and child health context. The PARS and SRS-P in Table 2-1 are also available as Level 2 screeners; however, both tools are designed for children aged three years or older (Stickley et al., 2017; Tsujii et al., 2006), and are thus not considered further here.

The Childhood Autism Rating Scale-Tokyo Version (CARS-TV; Kurita et al., 1989) is a Japanese adaptation of a 15-item behaviour observation tool, the CARS (Schopler et al., 1980). A study on the CARS-TV reported good sensitivity (.86) and specificity (.83), high PPV (.97), but low NPV (.50) in distinguishing children with autism from those with intellectual disabilities (Tachimori et al., 2003). The low NPV was due to the difference in the number of children in each group (ASD: $n = 430$, intellectual disabilities: $n = 75$), acknowledged by the authors, with further study needed with more participants in the non-ASD group. Moreover, the broad age range of participants (range = 2.1—29.3 years) was limiting, especially as the CARS is meant to be used with children. As the study analysed assessment data collected over a 10-year

period, the ages provided did not reflect age at the time of CARS-TV administration but at the time when the data were re-examined for the study.

There are three Level 2 parental questionnaires. The Tokyo Autistic Behavior Scale (TABS; Kurita & Miyake, 1990) comprises 39 items selected for use in children (no age range specified). In a validation study of the TABS (Tachimori et al., 2000), sensitivity (.68) and specificity (.59) were unsatisfactory when used with children with autism ($n = 111$) or intellectual disability ($n = 70$) aged under four years; however, the psychometric properties on the 10-item short version were more promising (sensitivity = .78, specificity = .71). More recently, researchers examined whether the combined use of the TABS and a Japanese developmental measure, the Tokyo Child Development Schedule (Kurita et al., 1985), could differentiate autistic children without intellectual disability from those with Attention-Deficit/Hyperactivity Disorder or other developmental disorders (Suzuki et al., 2011). Although it yielded good sensitivity (.75), specificity (.84), PPV (.72) and NPV (.86), the number of children in the IQ-matched sample was relatively small ($n = 72$), and only one item (“becoming extremely upset when the pre-set order of doing things is changed”) was chosen from the TABS as having most discriminating power when combined with two items (“pretending that the child was grown up and playing the role of mother or father” and “talking to a friend about the child’s experience”) from the Tokyo Child Development Schedule.

Table 2-2*Level 2 Autism Screening Instruments in Japan*

Tool	Details	Reference	Participants	Sensitivity and Specificity	PPV and NPV	Note	Original
CARS-TV	Behaviour observation 15 items 7-point scale rating Can be used for anyone in their childhood Published and available for public use (a different translation from CARS-TV)	Kurita, Miyake, & Katsuno (1989) Tachimori, Osada, & Kurita (2003)	Clinical population aged under 16 years $N = 167$, $M_{\text{age}} = 5.1$ years, $SD = 2.6$ (130 children were aged 5 years or younger) Clinical population ASD group: $N = 430$, $M_{\text{age}} = 6.7$ years, $SD = 3.9$, range = 2.1-24.5 Intellectual disability group: $N = 75$, $M_{\text{age}} = 6.7$ years, $SD = 4.2$, range = 3.1-29.3 It is clear whether the ages were at the time of CARS administration or when the data were analyzed for this particular study.	Not presented Sensitivity = .86; Specificity = .83	Not presented PPV = .97; NPV = .50		Schopler, Reichler, DeVellis, & Daly (1980)
TABS	Parental report 39 items in full version; 10 items in short version (Tachimori et al., 2000) 3-point scale rating Age range for use not specified Not officially available for public use	Kurita & Miyake (1990) Tachimori et al. (2000) Suzuki, Tachimori, Saito, Koyama, & Kurita (2011)	Validity study Clinicl population, $N = 102$, $M_{\text{age}} = 4.5$ years, $SD = 1.7$ Clinical population aged under 4 years $N = 181$ (111 ASD and 70 intellectual disability), $M_{\text{age}} = 34.4$ months, $SD = 8.7$ IQ matched sample ASD group: $n = 24$, $M_{\text{age}} = 52.79$ months, $SD = 14.59$ ADHD group: $n = 24$, $M_{\text{age}} = 63.17$ months, $SD = 26.23$ Other developmental disorders group: $n = 24$, $M_{\text{age}} = 55.83$ months, $SD = 19.49$	Not presented Sensitivity = .68; Specificity = .59 Short version Sensitivity = .78; Specificity = .71 Sensitivity = .75; Specificity = .84	Not presented PPV = .72; NPV = .53 Short version PPV = .81; NPV = .68 PPV = .72; NPV = .86	A 2-point scale rating was employed for research purpose. The study examined whether the combined use of TABS and a developmental measure, Tokyo Child Development Schedule (TCDS; Kurita, Uchiyama, & Takesada, 1985) can differentiate ASD without intellectual disability from ADHD or other developmental disorders. The psychometric properties presented in the study were based on 3 items (one from TABS and two from TCDS) with most discriminative power.	Not applicable

Tool	Details	Reference	Participants	Sensitivity and Specificity	PPV and NPV	Note	Original
IBC-R	Parental report 24 items in full version; 12 items in short version 2-point scale rating Asks behaviours from birth to 2 years old Age range for use not specified Not officially available for public use	Kanai, Osada, Koyama, & Kurita (2004)	High-risk population $N = 131$ (71 ASD and 60 non-ASD), $M_{\text{age}} = 4.1$ years, $SD = 2.2$, range = 0.8-13.7	Full version Sensitivity = .76; Specificity = .67 Short version Sensitivity = .80; Specificity = .70	Full version PPV = .73; NPV = .70 Short version PPV = .76; NPV = .75	There was a significant difference in age and in IQ between ASD and non-ASD clinical groups, with both higher in the latter. However, no age or IQ matched subgroups were mentioned in the study.	IBC: Osada et al. (2000)
CBQ-R	Parental report 32 items 4-point scale rating Ask behaviours after infancy Age range for use not specified Not officially available for public use	Izutsu et al. (2001)	High-risk population ASD group: $n = 269$, $M_{\text{age}} = 6.9$ years, $SD = 10$, range = 2-25.7 Non-ASD group: $n = 31$ (7 clinical and 24 typically developing), $M_{\text{age}} = 5$ years 3 months, $SD = 10$, range = 2.7-26.9 It is clear whether the ages were at the time of CARS administration or when the data were analyzed for this particular study.	Sensitivity = .71; Specificity = .72	PPV = .90; NPV = .42	The study examined whether CBQ-R can aid differential diagnosis between ASD and non-ASD intellectual disability. A 2-point scale was employed for research purpose.	CBQ: Osada et al. (2000)
BISCUIT	Behavior observation and parental interview in Part 1 (ASD screening), parental interview in Part 2 (comorbid symptoms assessment) and Part 3 (challenging behaviors assessment) 62 item in Part 1; 57 items in Part 2; 15 items in Part 3 3-point scale rating Designed for use in children aged 17 to 37 months to assess ASD traits and comorbid difficulties Not available for public use	Kamio et al. (2015)	High-risk population aged 17 to 37 months $N = 76$ (73 ASD, 3 non-ASD) $M_{\text{age}} = 30.2$ months, $SD = 5.1$	Not presented	Not presented	Convergent validity of Part 1 with the M-CHAT was high ($r = 0.74$).	Matson et al. (2009a), Matson et al. (2009b)

The second domestic questionnaire, the Infant Behavior Checklist-Revised (IBC-R; Kanai et al., 2004) is a modified version of the IBC (Osada, Nakano, et al., 2000), and consists of 24 items that ask about the child's behaviours during the first two years of life. Kanai et al. (2004) compared the results of the IBC-R with autism and non-autism clinical groups, reporting good sensitivity (.76) and moderate specificity (.67). Participants were parents of children aged 0.8 to 13.7 years, suggesting their reports were largely retrospective. Furthermore, there was a significant difference in age and in IQ between the two groups.

The Child Behavior Questionnaire-Revised (CBQ-R; Izutsu et al., 2001) is another parental report measure modified from its predecessor (Osada, Kato, et al., 2000). While it does not specify the appropriate age for use, the tool consists of 32 items representing autism-specific behaviours that manifest after infancy. Fair sensitivity (.71) and specificity (.72) were reported when tested with 345 parents of autistic children or with intellectual disability, or typically developing children (Izutsu et al., 2001). However, the broad age range of participants (range = 2—26.9 years) was again a limiting factor as the tool was designed for use in children. Given that the study utilised assessment data collected over 10-year period, and similar to the CARS-TV study reviewed above, it is likely that children's age reflect their age when data were re-examined.

The Baby and Infant Screen for Children with aUtIsm Traits (BISCUIT; Matson, Wilkins, Sevin, et al., 2009; Matson, Wilkins, Sharp, et al., 2009) was adapted into Japanese for the purpose of comprehensively understanding difficulties in young autistic children so that clinicians can identify and cater to their specific needs (Kamio, Honda, et al., 2015). It comprises three sections rated through parent interview and behaviour observation: Part 1 (62 items) is designed to assess autism symptoms and inform the

diagnosis, Part 2 (65 items) to assess commonly observed comorbid conditions, and Part 3 (17 items) to assess other frequently occurring challenging behaviours. Seventy-six children aged 17 to 37 months referred due to developmental concerns were assessed with the Japanese BISCUIT (Kamio, Honda, et al., 2015). No data were provided on discriminant validity due to the small size of the non-ASD clinical sample (3 of 76 children). A correlation between the total score of Part 1 and the number of failed items on the M-CHAT ($r = .74$) was high, though it should be noted that the M-CHAT is a Level 1 screener.

Issues with Level 2 Screening Instruments

The existing Level 2 tools currently utilised in Japan fall short of fulfilling the requirements for a robust tool to differentiate children with autism from those with other developmental challenges that can be used within the Japanese follow-up service. None of the tools in Table 2-2 either has an explicit age range for use or has been examined specifically with younger age groups. This is problematic because some of the symptoms characteristic of autism are more subtle and not as evident during the very early years of life, becoming more apparent and frequent after age three or four (Barbaro & Dissanayake, 2009). For example, repetitive and stereotyped behaviours, interests, and activities (e.g., hand flapping, lining up of objects) and sensory and atypical motor mannerisms (e.g., mouthing, sensitivity to sound) are not commonly found in infancy and toddlerhood, commonly developing after three years of age (Gray & Tonge, 2001; Young & Brewer, 2002). Hence, the design of a screener, be it Level 1 or 2, should be sensitive to the target age group. Importantly, validation should be conducted within the specified population.

The TABS and CBQ-R items are clearly in need of review prior to being applied to children below three years of age, as 18 out of 39 questions of the TABS and 19 out of

32 of the CBQ-R refer to restricted and repetitive behaviours, sensory and motor mannerisms, or other behaviours that are not in the social interaction and communication domain, which is the dominant area of difficulty during infancy and toddlerhood (Barbaro & Dissanayake, 2009). In contrast, the IBC-R consists of autistic symptoms frequently observed in the first two years of life. The study which examined this tool, however, was largely retrospective (Kanai et al., 2004), failing to demonstrate its utility as a prospective Level 2 screening tool. The CARS-TV also lacks evidence to support its efficacy in children aged under age 3 (Tachimori et al., 2003), even though the behaviour observation format of the CARS-TV may allow for more flexible assessment depending on the child's age. The BISCUIT is the most age-appropriate of all the tools examined, but the data on the Japanese adaptation are very preliminary (Kamio, Honda, et al., 2015).

Another issue identified in reviewing the Level 2 tools pertains to feasibility and practicality. While the Japanese version of the CARS is the only tool currently available for public use (Schopler et al., 2008), it does not contain tasks to elicit target behaviours (i.e., not an interactive tool) nor does it have objective rating criteria; it also requires a deep understanding of typical and atypical development, including signs of autism (Schopler et al., 2008). These issues will pose a challenge for use within the follow-ups undertaken at the Public Health Centres where securing qualified and appropriately trained personnel is an issue (Matsumoto et al., 2013).

The comprehensive structure of the BISCUIT (i.e., having both observation and parent interview items and assessing not only autism traits but also comorbid symptoms and related challenging behaviours) may be more helpful in assessing children and providing support to their parents, both of which are crucial within the follow-up service. One concern is the long administration time due to its comprehensive nature; however,

the administrator may be able to choose one or two parts most relevant to the child, so that the session can be completed within the assigned time.

Another issue is that the screening instruments identified in this review were based on the previous versions of the DSM and are thus not aligned with current diagnostic criteria for ASD. As no reliable biological markers are available, diagnosis of ASD is reliant on developmental history and behavioural presentation (Abrahams & Geschwind, 2008; Klin & Jones, 2015; Zwaigenbaum et al., 2015). The latest edition of DSM (DSM-5; American Psychiatric Association, 2013), made a significant shift from its predecessor (American Psychiatric Association, 2000) in the conceptualisation of autism based on current evidence regarding autism. For instance, the distinct diagnostic entities (i.e., autistic disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified) were combined under the umbrella term of ASD with different specifiers and levels of severity. The traditional triad of symptoms were collapsed into a dyad of social and communication deficits and restricted and repetitive patterns of behaviours, interests, or activities, with the addition of atypical sensory responses. None of the Level 2 instruments used in Japan have been re-examined in the light of these changes. This is also a limitation seen in the Level 1 instruments.

To summarise, there is an acute need for a reliable and validated Level 2 screening tool that is explicitly designed for use with children aged between 18 and 24 months, and which is feasible for use within Public Health Centres in Japan. Among those that have been studied, the Japanese BISCUIT appears to have the most potential, although further research is required on its psychometric properties. Further, any existing or new instruments must conform to the latest diagnostic criteria that reflect up-to-date understanding of autism.

Diagnostic Instruments

Diagnostic instruments generally involve lengthy and intensive administration, scoring, and training (Charman & Gotham, 2013). As a result, their use within the Japanese public health context is untenable (Tsujii et al., 2006). A Level 2 tool may thus be more appropriate for use at the follow-up session discussed earlier. However, in the summary of recommendations to the maternal and child health service, Yamazaki et al. (2016) referred to the Japanese adaptation (Lord et al., 2015) of the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2; Lord et al., 2012) as a potential tool used for secondary assessment during the Japanese follow-up service. In order to discuss whether a diagnostic tool is a suitable and feasible option, existing diagnostic instruments are also briefly reviewed below (see Table 2-3).

The Pervasive Developmental Disorders Assessment System (PDDAS; Kurita et al., 2008) is a semi-structured parent interview tool developed in Japan. Testing with 141 children who visited a public consulting institution for developmental concerns, the tool successfully identified all ($n = 77$) children with autism. However, the authors did not provide sensitivity and specificity estimates, and the age range of participants was broad (2—11 years), with no separate analysis for infants and toddlers. Tsuchiya et al. (2013) translated the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994), an internationally recognised interview tool, into Japanese. Their study reported high specificity (.92) and NPV (.92), but low sensitivity (.53) and PPV (.55) in identifying children with autistic disorder² aged below four years. No significant differences were found between children (aged below five years) with a diagnosis of autistic disorder and the other ASD subtypes on the scores of any subdomain of the Japanese ADI-R (Tsuchiya

² A subtype of ASD defined in the previous edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000).

et al., 2013). The administration of this tool to parents typically takes over one hour in duration.

The third tool is the Japanese adaptation of the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al., 2002). Uno (2016) examined performance of the Japanese DISCO with 56 persons with or without ASD ($M_{age} = 10.2$ years, range unknown), but no psychometric properties were reported. Administration of this tool to parents also takes over one hour in duration.

The Autism Diagnostic Observation Schedule-Generic (Lord et al., 2000) is a semi-structured interactive behaviour observation tool; the newer edition is the ADOS-2. The ADOS-G was translated into Japanese and has been examined for its psychometric properties in differentiating individuals with autism and those without (Kuroda et al., 2015; Kuroda & Inada, 2012). Of the four modules, the relevant modules in the context of the early years are Module 1 (Pre-verbal or single-word level) and 2 (Phrase speech level). The study reported for high sensitivity (.96 and .95) and good specificity (.87 and .79) for Module 1 and 2, respectively, although the number of participants were small ($n = 36$, $n = 48$, respectively). Administration time of these modules with young children typically takes around 45 minutes.

The module selection guideline was modified in the ADOS-2, with the Toddler Module added for use in children younger than 31 months whose language level is two-word sentences or below (Lord et al., 2012). Despite the publication of the Japanese ADOS-2 in 2015, the psychometric properties of the Toddler Module in the Japanese population have not been presented. The developers of the Japanese ADOS-G also noted that replacement of some test items was necessary to ensure the kit was more culturally appropriate, despite this being prohibited by the developers of the original ADOS (Kuroda & Inada, 2012).

Table 2-3*ASD Diagnostic Instruments in Japan*

Tool	Details	Reference	Participants	Sensitivity and Specificity	PPV and NPV	Note	Original
PDDAS	Semi-structured parent interview About 90 minutes to complete Age range for use not specified Not officially available for public use	Kurita, Koyama, & Inoue (2008)	High-risk population ASD group: $n = 77$, $M_{\text{age}} = 4.6$ years, $SD = 2.2$, range = 2.0-11.0 Non-ASD clinical group: $n = 64$ (including 10 without any DSM-IV Axis I or II disorder), $M_{\text{age}} = 5.2$ years, $SD = 2.0$, range = 2.3-10.7	Not presented	Not presented	In IQ/DQ matched individuals aged under 4, ASD group scored significantly higher than non-ASD clinical group in 8 items out of 12 major items, and 12 out of 36 regular items. PDDAS identified all 77 individuals in ASD group as having ASD.	Not applicable
ADI-R	Semi-structured parent interview About 90 minutes to complete Appropriate for children with mental ages of 2 years or over Published and available for public use	Tsuchiya et al. (2013)	Validity study AD: $n = 138$, $M_{\text{age}} = 11.7$ years, $SD = 4.3$, range = 2-19 PDDNOS: $n = 89$, $M_{\text{age}} = 8.5$ years, $SD = 5.1$, range = 2-19 Non-PDD: $n = 90$ (including 78 without psychiatric diagnosis), $M_{\text{age}} = 6.4$, $SD = 3.7$, range = 2-17 The mean age of AD group was significantly higher than the other two.	Age matched group data (below 4 years, $n = 73$) in identifying AD Sensitivity = .53; Specificity = .92 Data for AD and PDDNOS are unavailable.	Age matched group data (below 4 years, $n = 73$) in identifying AD PPV = .55; NPV = .92 Data for AD and PDDNOS are unavailable.	For individuals aged under 5, there was no significant difference between AD and PDDNOS groups in any subdomains of the ADI-R.	Lord et al. (1994)
ADOS-G Module 1	Semi-structured interactive observation About 60 minutes to administer Module 1 is appropriate for children who are preverbal or use single words Module 2 is appropriate for children who use phrases ADOS-2 is published and available for public use	Kuroda & Inaba (2012)	Not applicable	Not applicable	Not applicable	Initial report of the development of the Japanese version.	Lord et al. (2000)
		Kuroda et al. (2015)	Module 1 ASD group: $n = 18$, $M_{\text{age}} = 27.1$ months, $SD = 4.3$ Non-ASD group: $n = 18$ (10 clinical, 8 TD), $M_{\text{age}} = 26.6$ months, $SD = 6.5$, range Module 2 ASD group: $n = 24$, $M_{\text{age}} = 59.8$ months, $SD = 10.4$ Non-ASD group: $n = 24$ (21 clinical, 3 TD), age data not presented	Module 1 Sensitivity = 0.955; Specificity = 0.870 Module 2 Sensitivity = 0.95; Specificity = 0.79	Not presented		
DISCO-11	Semi-structured parent interview Not available for public use	Uno (2016)	ASD group: $n = 36$, $M_{\text{age}} = 10.4$ years, $SD = 2.0$ Non ASD group: $n = 20$ (13 TD, 7 clinical), $M_{\text{age}} = 10$ years, $SD = 6.0$	Not presented	Not presented	Criterion related validity: The agreement rate of the Japanese DISCO diagnoses and DSM-IV-TR diagnoses were 96.4%.	Wing et al. (2002)

There is a lack of validation studies of ASD diagnostic instruments that are used in Japan. Overall, psychometric data are preliminary and do not provide evidence that actively support their use, especially within the follow-up service. In terms of feasibility and practicality, the PDDAS and DISCO are not publicly available. While published for clinical use, the Japanese ADI-R does not yet provide the algorithms for toddlers (i.e., aged 12 to 47 months; Kim & Lord, 2012) and is thus only appropriate for children with mental ages above two years, and the Toddler Module of the ADOS-2 has not been researched in Japan.

Summary and Future Directions

In the Japanese maternal and child health context, the statutory 18-month health check-up provides an important universal opportunity for early autism screening alongside general developmental screening. After a child is found to be at high likelihood of developing autism, it is suggested that Japanese parents need some time and support to accept their child's condition, leading to delays in visiting a medical institution for diagnosis following referral. The follow-up service has a key role in filling the time gap between detection and diagnosis, by providing some form of early intervention and support to the child and their parents. In order to maximise the screening performance at the check-up and to improve the quality of assessment, intervention, and consultation within the follow-up service, the use of validated screening instruments is strongly recommended.

For the statutory check-up at 18 months, a Level 1 screener for the general population is considered appropriate. The review of studies on existing Level 1 instruments has identified pragmatic issues and insufficient evidence for universal screening at 18 months. More research is needed to establish the psychometric properties of existing instruments during the statutory check-up. To ensure reliable screening, the

need for training of public health nurses, who are the primary staff undertaking the mass check-ups, is indicated. A developmental surveillance approach that includes repeated interactive behavioural observations by nurses appears an important avenue worth exploring.

Level 2 screeners are designed for use with children with developmental concerns as identified through Level 1 screening, and most suitable for use within the follow-up service. The same issues noted with the Level 1 tools were also apparent with the Level 2 instruments, with none identified as promising for use within the follow-up service. A number of diagnostic instruments used in Japan were also reviewed, with most being lengthy and requiring intensive training for administration, scoring and interpretation, deeming them unfeasible for use within Public Health Centres. A new Level 2 instrument is needed for use within the Japanese context that better fits into the follow-up service setting.

Lastly, one overarching issue across all levels of instruments is the lack of conformity with the current DSM-5 diagnostic criteria. The significant changes in the behavioural definition of ASD in the DSM-5 which were an outcome following advances in knowledge of the condition should ideally be reflected within instruments used for identifying autism.

The statutory health check-up and follow-up framework is undoubtedly an ideal setting for the early identification of autism in the Japanese maternal and child health context. The absence of universally recommended tools should be regarded as a significant limitation. In an ideal screening system within Public Health Centres, Level 1 autism screening should ensure high sensitivity such that all children presenting with early signs of autism are referred for further examination. At Level 2 screening, using an instrument with high specificity is ideal to reliably identify those children who are most

likely to be developing autism, eventually leading to a confirmed diagnosis. Furthermore, given the heterogeneity of autism presentation and its timing, Level 1 screening should be offered multiple times over the course of early development, and Level 2 screening should readily follow Level 1. Future research needs to be mindful of these requirements and examine instruments that are feasible and accessible for use with the Public Health Centres in Japan, thereby enabling earlier access to intervention and supports prior to a confirmed diagnosis of ASD.

Chapter 3

Autism Screening Practices Within Community Public Health Centres in Japan

As outlined in Chapter 2, the statutory 18-month health check-up at local Public Health Centres in Japan provides an opportunity to monitor every child for early signs of autism and other developmental conditions. Children who screen positive for any developmental conditions or delay are referred to follow-up services within the Public Health Centre that typically includes specialist consultation and parent-child group interventions, as well as referral to external intervention facilities (Japanese Society of Certified Clinical Psychologists [JSCCP], 2014; Kono & Ito, 2011). Characteristic of this system is the provision of support without requiring or prioritising a formal diagnosis. This contrasts with the practice in most Western nations where the common first step following identification of concern is referral for a formal assessment and diagnosis, which is typically required for the child to access intervention services (Ibañez et al., 2019).

Children who are offered follow-up services usually comprise a mixture of both severe and borderline cases of developmental disabilities, as well as those without developmental concerns, but whose parents have challenges with their parenting (Gokami, 2007). The Public Health Centre is responsible for assessing each child's and parent's needs in delivering follow-up services and, in doing so, prioritises those with higher needs which is essential to make the most of limited resources. For instance, the parent-child group intervention is usually the only form of follow-up service that provides active behavioural intervention within Public Health Centres even though the intensity of the programmes is generally low. Hence, it is ideal for the centres to allocate children with higher needs to the parent-child group intervention, target each

participant's need in the programme, and then refer children with the highest needs to an external, more intensive intervention programme. In doing so, it is important to work with parents to emphasize the importance of this approach for their child's optimal development. The necessity of such decision-making points to the necessity of secondary screening within Public Health Centres in an effort to further determine each child's presenting characteristics that can inform his/her needs.

Secondary screening and assessments (i.e., more detailed assessment of children identified with developmental risks) in Japan were typically outsourced to local Child Consultation Centres or medical institutions in the past, prior to developmental disabilities being as widely recognised as they are today. The concept of secondary screening, particularly for autism, is therefore relatively new to many Public Health Centres. The need for targeted autism screening at the statutory health check-up was first advocated in 2004, with governmental research beginning to report secondary autism screening as part of follow-up services in mid-2010 (Yamazaki et al., 2015, 2016). Moreover, the use of standardized autism screener, as is recommended as standard procedure in Western countries (Johnson et al., 2007; Le Couteur, 2003; Nachshen et al., 2008), is not widespread in Japan.

Of the autism screening instruments used or recommended in Japan, reviewed in Chapter 2, the Japanese Modified Checklist for Autism in Toddlers (M-CHAT-JV; Kamio & Inada, 2006) is used at the 18-month check-up by around 12 percent of Public Health Centres across Japan (Ministry of Health, Labour and Welfare, 2016). Although it has been suggested that the use of a Level 1 screener at the check-up would compensate for the varying skills and experience among public health nurses (Yamazaki et al. 2016), details of the implementation and the impact of the M-CHAT-JV use remains unexamined (JSCCP, 2014; Yamazaki et al., 2016).

Precious research on the follow-up service within Public Health Centres have primarily focused on the range of services and staffing (Gokami, 2007; JSCCP, 2014; Sasamori et al., 2010) and case studies (see Kono & Ito, 2010). Further, although the uncommon use of assessment instruments including autism screeners have been reported (Matsumoto et al., 2013; Yamazaki et al., 2016), the details of instrument use (e.g., what instruments are used, barriers to use) throughout Japanese Public Health Centres is currently unknown.

Given the widely acknowledged importance of early intervention for children with autism (e.g., Anderson et al., 2014; Clark et al., 2017; Dawson et al., 2012; Vivanti et al., 2016), the role of Public Health Centres in Japan to detect and reliably identify autism as well as to provide intervention and support, mindful of each child's characteristics and needs, is becoming increasingly salient. The aim in the current study, therefore, was to investigate the status of the mandated 18-month check-up and the follow-up services offered at Public Health Centres across Japan with particular reference to secondary screening for autism and the use of standardized measures in practice. In addressing the research questions outlined below, the intention was to inform recommendations for improved practises with regard to screening, assessment and intervention within the universally accessible services at Public Health Centres in Japan.

Research Questions

- (1) What are the current autism screening practices at the 18-month check-up within Public Health Centres in Japan?
- (2) What are the foci and challenges within follow-up services for children and parents identified at 18-month check-ups?
- (3) What are the screening and assessment practises and tools undertaken within the follow-up services within Public Health Centres?

Methods

This study was approved by the Research Ethics Committee of the Nihon Institute of Medical Science, Japan (#2019009) with reciprocal approval from the Human Ethics Committee of La Trobe University.

Participants

Participants were 239 individuals (98.3% female) representing 239 Public Health Centres (i.e., one representative from each centre) in Japan. Participants reported varying years of experience in the maternal and child health field (Table 3-1) with 49% having 10 or more years of experience. The significantly lower ratio of male nurses reflects the overall gender trend among public health nurses, in which male nurses only account for around 1% of the population (Sasaki & Kamibeppu, 2012).

Recruitment

The survey was mailed to 767 (40% of 1916) Public Health Centres in Japan, with 239 surveys returned (31%). The selection of 767 centres was entirely random to exclude any selection bias. The survey (see Appendix A) was enclosed with a cover letter, and information about the project including informed consent, and a pre-paid envelope for return. The letter specified that the respondent needed to be the public health nurse in charge of the maternal and child health division or someone equivalent. It also requested the nurse to pass on the questionnaire to the appropriate personnel in cases where a different division had jurisdiction over the follow-up service. Return of the questionnaire was regarded as informed consent to participate in the study. The survey was anonymous and did not contain any personally identifiable information.

Materials

The survey was developed specifically for the study by the candidate in consultation with subject matter experts described below, and based on an extensive

review of studies on the statutory infant health check-up and the follow-up procedures at Public Health Centres in Japan. Two Japanese psychologists were consulted, one with a public health nurse license, to develop question and answer options that reflect practices and common perceived challenges within follow-up services. The completed survey was then reviewed by an independent public health nurse to ensure the questions and wordings were appropriate for the Japanese maternal and child health service context. Table 3-2 outlines the content of the survey, which has been translated from Japanese (see Appendix A-2 for the original Japanese survey).³

Table 3-1

Respondent Information (N = 239)

		18-m check-up		Follow-up	
		<i>n</i>	%	<i>n</i>	%
Gender	Male	3	1.3	3	1.3
	Female	234	98.3	234	98.3
	Missing	2	0.8	2	0.8
Years of experience	20+	50	21.0	41	17.2
	15-20	34	14.3	31	13.0
	10-15	33	13.9	32	13.4
	5-10	51	21.4	54	22.7
	1-5	57	23.9	65	27.3
	Less than 1	8	3.4	10	4.2
	Missing	6	2.5	6	2.5

³ All translations from Japanese to English provided in the present report were conducted by the candidate, who is a trained translator. Original Japanese data can be obtained from the candidate.

Table 3-2*Survey Summary*

Section	Themes	Type	Examples
A	General information of respondents	Close-ended	Gender: 1) Male 2) Female
B	General information of responding municipalities	Close-ended	What is the population of your local government in the fiscal year of 2018? 1) More than 500K 2) 200K to less than 500K 3) 50K to less than 200K 4) 10K to less than 50K 5) Less than 10K
C	Autism screening and use of the M-CHAT at the 18-month check-up	Combination of close-ended and multiple choice	<u>If you choose M-CHAT in C-2, select how you administer M-CHAT.</u> 1. Number of items 1) Use all 23 items 2) Use 10 key items 3) Use selected items (how many: _____) 4) Other (_____)
D1 to 8	Prioritised objectives and challenges of follow-up service	Combination of close-ended, multiple choice, and ranking	Choose top three priorities of parent-child group intervention and rank them from 1 to 3.
D9 to 10	Use of assessment tools within follow-up services	Combination of open-ended and multiple choice	Please choose all assessment tools used in services selected in C-2, and answer in which service(s) and by which profession(s) each tool is used.

Results

Municipality Information

As observed in Table 3-3, local governments with a smaller population size (of 50,000 or less) account for 64% of the responding sites while those with over 200,000 only account for 8.4%. This reflects national population statistics where corresponding proportions are 62.6% and 9.3% respectively (Ministry of Health, Labour and Welfare, 2014). Similarly, 70.2% of the sites had less than 500 births while 14.2% had more than 1,000 births in 2018, with corresponding national proportions being 74.4% and 13.6% respectively in 2013 (Ministry of Internal Affairs and Communications, 2015). These data indicate the representativeness of the data obtained from the current sample.

Table 3-3

Municipality Information (N = 239)

		<i>n</i>	%
Population	500K+	6	2.5
	200-500K	14	5.9
	50-200K	65	27.3
	10-50K	99	41.6
	Less than 10K	54	22.7
	Missing	1	0.4
Number of births	5K+	4	1.7
	1-5K	30	13.2
	500-1K	31	13.6
	100-500	82	36.0
	Less than 100	82	36.0

Question 1: What Are the Current Autism Screening Practices at the 18-month Check-up Within Public Health Centres in Japan?

Of the 239 Public Health Centres, 97.5% ($n = 233$) reported that the 18-month check-up is held in the form of mass screening, with one reporting that part of the check-up was conducted individually at private clinics; however, autism screening, along with some other check-up items, was conducted at the centre as mass screening. Six participants did not answer this question.

Table 3-4 summarises the approach and instruments used for autism screening at the statutory 18-month check-up at the 233 Public Health Centres. More than half of the Centres ($n = 119$, 51.1%) used a set of screening items gathered by either the Public Health Centre or Prefecture, with use of a validated, standardised autism screener being uncommon. The Japanese M-CHAT was used by 50 centres (21.5%), with an additional four centres reporting partial use of this tool, bringing at least some use of the M-CHAT to 23.2%. The use of an eye-tracking device (Gazefinder®; Tsuchiya et al., 2015) was reported by two centres (0.9%) and the SACS-J (Social Attention and Communication Surveillance- Japan; Okuno et al., 2014) was used by two centres (0.9%). Notably, 56 participants (24.0%) responded that they had no autism-specific screening undertaken at their centre at the 18-month check-up.

Two developmental assessment measures, the New Kyoto Scale of Psychological Development (Kyoto Scale; Koyama et al., 2010) and the Enjoji Analytical Developmental Scale for Infants and Children (Enjoji Scale; Enjoji & Yanai, 1961) were reported as being used for autism screening by a small number of participants ($n = 11$, 4.7%), with written comments indicating that only part of the developmental measure was used. It remains unknown whether the entire assessment was conducted within the limited time frame of a check-up in other cases. Three municipalities (1.3%) also

reported that they had check-up items that were not autism-specific but assessed general developmental delay or irregularities.

The 50 centres using the M-CHAT-JV provided details of its implementation, suggesting wide deviation from standardised use of the tool (Table 3-5). Only four (8.0%) use all 23 screening items while 20 centres (40.0%) used self-chosen ones with the number of items ranging from two to 17. Nineteen centres (38.0%) adopted 10 key items identified in the Japanese version (Kamio & Inada, 2006) despite this selection set not being validated. Twenty centres reported that they used a certain number of items that they selected, which ranged from two to 17 items. Other responses included items selected by their prefecture ($n = 2$), a 6-item short version ($n = 1$), and one failed to report any detail ($n = 1$). Nearly half of the users (46.0%) reported they did not utilise the supplementary illustrations that had been added to the Japanese version to assist in screening (Kamio & Inada, 2006). Only one respondent reported using the M-CHAT as a parent-report, where a parent provides answers to the M-CHAT yes/no questionnaire and cut-off criteria are applied to the result to determine autism risk. Most of the respondents (88.0%) also conducted an interview to review answers provided by the parent, and four respondents (8.0%) simply interviewed parents at the check-up, resulting in 96.0% of the M-CHAT users not solely relying on independent parent report. Finally, most respondents (84.0%) reported that they conducted the follow-up interview either on the phone or in person. Only a few respondents (3.0%) had no knowledge of the follow-up interview, which is part of formal procedures of the M-CHAT.

Table 3-4*Autism Screening Method Used at the 18-month Check-up Within Public Health Centres (N = 233, multiple choice)*

Tool/items	<i>n</i>	%	Instrument type	Reference
Items developed at Public Health Centre	104	44.6		
Items set by Prefecture	15	6.4		
M-CHAT-JV ¹	50	21.5	Level 1 autism screener	Kamio & Inada, 2006
M-CHAT-JV partial use	4	1.8		
Gazefinder®	2	0.9	Level 1 autism screener	Tsuchiya et al., 2015
SACS-J ²	2	0.9	Level 1 developmental surveillance	Okuno & Kezuka, 2016
Kyoto Scale (including partial use) ³	7	3.0	Developmental assessment measures	Koyama et al., 2010
Enjoji Scale (including partial use) ⁴	4	1.7	Developmental assessment measures	Enjoji & Yanai, 1961
Items on overall development	3	1.3		
No autism screening	56	24.0		

Note. ¹Japanese version of Modified Checklist for Autism in Toddlers; ²Social Attention and Communication Surveillance-Japan; ³New Kyoto Scale of Psychological Development; ⁴Enjoji Analytical Developmental Scale for Infants and Children. One participants reported the use of the Parental-Interview ASD Rating Scale (PARS; Tsujii et al., 2006). However, PARS was designed for use in children older than 3 years of age and hence omitted from the table.

Table 3-5*Details of the M-CHAT-JV Administration at the 18-month Check-up (N = 50)*

		<i>n</i>	%
Number of items	All 23 items ¹	4	8.0
	10 key items	19	38.0
	Self-report ²	20	40.0
	Other	4	8.0
	Missing	3	6.0
Use of supplementary	Yes	23	46.0
Illustrations	No	23	46.0
	Missing	4	8.0
		<i>n</i>	%
Administration style	Parent report	1	2.0
	Parent report followed by interview	44	88.0
	Only interview	4	8.0
	Missing	1	2.0
Follow-up interview	Telephone	18	36.0
	In person	9	18.0
	Telephone or in person	15	30.0
	No follow-up intervention	5	10.0
	No knowledge of follow-up	3	6.0
	Missing	1	2.0

Note. ¹Using M-CHAT threshold (2/23 or 1/10) *n* = 2; 2/23 only *n* = 1; Detail unreported *n* = 1.

²Eleven or more items *n* = 4; 10 items *n* = 2; 9 items or less *n* = 11; Detail unreported *n* = 3.

Table 3-6 below shows the percentages of children who became the subject of follow-up services due to developmental concerns, including display of autism signs, identified through the 18-month check-up. The responses varied greatly: while nearly half of the municipalities (48.5%, $n = 113$) followed up less than 5% to 15% of the target population, another half (46.4%, $n = 108$) followed up more than 15%, with the mean percentage being 34.0% ($n = 91$, $SD = 14.94$, range = 15.3—80.0).

Table 3-6

Percentage of Children Referred for Follow-up After the 18-month Check-up ($N = 233$)

	<i>n</i>	%
More than 15%	108	46.4
10-15%	43	18.5
5~10%	37	15.9
Less than 5%	33	14.2
Missing	12	5.2

Question 2: What Are the Foci and Challenges Within the Follow-up Services for Children and Parents Identified at 18-month Check-up?

The range of follow-up services provided by the participating Public Health Centres is summarised in Table 3-7, with children able to be offered more than one option from the suite of services. Both face-to-face and phone consultations were more prevalent than other types of services (85.5% and 77.2% respectively), followed by “wait until next check-up” (70.1%). The mean wait until the next check-up was 8.18 months ($SD = 5.22$, range = 1—24). Referral to parent-child group intervention (66%) was less

common than to specialist consultation (85%). The direct referral to a medical or intervention facility after the 18-month check-up was offered by 62.7% and 61.0% of the participants, respectively. Preschool visit was the least endorsed service (55.6%).

Table 3-7

Follow-up Options (N = 239, multiple choice)

	<i>n</i>	%
Specialist consultation	206	85.5
Phone consultation	186	77.2
Wait until next check-up (in X months)	169	70.1
Home visit	160	66.4
Parent-child group intervention	159	66.0
Referral to medical institution	151	62.7
Referral to intervention institution	147	61.0
Preschool visit	134	55.6
Other	19	7.9

Challenges of Referral to Medical Institutions

To examine referral to medical institutions, participants were asked to choose three of the most important challenges and rank them 1 to 3. Their selection of challenges and the overall priority ranking is shown in Table 3-8. Of the 151 centres that selected referral to medical institutions, six were excluded from the analysis as they did not provide answers.

“Long wait until the first appointment” was ranked highest (first: 42.4%; second: 39.1% respectively) and “Lack of medical institutions to refer to” ranked next (first:

31.3%; second: 31.8%). “Difficulty in obtaining parent consent to see a doctor” was chosen third (first: 29.1%) and chosen the most as a third priority (29.8%). The overall ranking that these three were the most prioritised challenges regarding referral to a medical institution, with the remaining options, including “Long wait until diagnosis” and “Unreliable diagnosis”, were chosen by fewer centres. Thus, the central barriers to successful and timely referral were the limitations in local medical resources (i.e., insufficiency of medical institutions and long waiting) and parental factors (i.e., parents are reluctant to see a doctor).

Objectives of Parent-child Group Intervention and Specialist Consultation

To explore prioritised objectives of parent-child group intervention and specialist consultation, participants were, again, required to choose three options for each service and rank them from 1 to 3. The selection of objectives and the overall rankings are summarised in Table 3-9. Of the 159 Public Health Centres that selected parent-child group intervention as a follow-up option, 31 centres were excluded from the analysis as they reported that the programme was conducted outside their centre. Similarly, of the 206 centres that selected specialist consultation as a follow-up option, 30 centres were excluded.

In the group intervention ranking, although “Developmental support for children” was chosen most as the first priority (30.5%), the total percentage of the options selected among the top three priorities remains 64.1%, outranked by “Parenting support” (89.1%) and “Support for parental acceptance of child’s disability” (69.5%). None of the centres selected “Encouraging parents to visit a diagnostic institution” and “Provision of play space” as the first priority, and the total percentages of being chosen among top three priorities were notably lower than the rest (i.e., the top three options and “Comprehension of child’s developmental traits”).

Table 3-8*Participant Identified “Top 3” Challenges Associated With Referring to Medical Institution (N = 151)*

Challenges	Priority ranking ¹			Top 3 percentage ²
	1	2	3	
1. Long wait until first appointment	64 (42.4%)	59 (39.1%)	19 (12.6%)	94.0
2. Lack of medical institutions to refer to	47 (31.1%)	48 (31.8%)	29 (19.2%)	82.1
3. Difficulty in obtaining parent consent to see a doctor	44 (29.1%)	23 (15.2%)	45 (29.8%)	74.1
4. Long wait until diagnosis	1 (0.7%)	16 (10.7%)	19 (12.6%)	23.8
5. Unreliable diagnosis	1 (0.7%)	3 (2.0%)	4 (2.6%)	5.3
6. Other	0	2 (1.3%)	4 (2.6%)	4.0

¹Priority ranking refers to the percentages an option was chosen as the first, second, or third option. ²Percentage of an option chosen within the top three priorities.

Table 3-9*Participant Identified “Top 3” Objectives of Parent-child Group Intervention and Specialist Consultation at Public Health Centres*

Objectives	Priority ranking ¹			Top 3 percentage ²
	1	2	3	
Parent-child group intervention (<i>N</i> = 128)				
1. Parenting support	36 (28.1%)	52 (40.6%)	26 (20.3%)	89.1
2. Support for parental acceptance of child's disability	13 (10.2%)	32 (25.0%)	44 (34.4%)	69.5
3. Developmental support for children	39 (30.5%)	25 (19.5%)	18 (14.1%)	64.1
4. Comprehension of child's developmental traits	33 (25.8%)	22 (17.2%)	19 (14.8%)	55.1
5. Encouraging parents to visit a diagnostic institution	0	2 (1.6%)	7 (5.5%)	7.0
6. Provision of play space	0	1 (0.8%)	6 (4.7%)	5.5
7. Other	2 (1.6%)	0	1 (0.8%)	2.3

Objectives	Priority ranking			Top 3 percentage
	1	2	3	
Specialist consultation (N = 176)				
1. Comprehension of child's developmental traits	26 (14.8%)	71 (40.3%)	41 (23.3%)	78.4
2. Support for parental acceptance of child's disability	88 (50.0%)	26 (14.8%)	14 (8.0%)	72.7
3. Developmental support for children	21 (11.9%)	39 (22.2%)	36 (20.5%)	54.5
4. Parenting support	30 (17.0%)	28 (15.9%)	30 (17.0%)	50.0
5. Support for parent’s problems	4 (2.3%)	15 (8.5%)	20 (11.4)	22.2
6. Encouraging parents to visit a diagnostic institution	1 (0.6%)	1 (0.6%)	27 (15.3%)	16.5
7. Other	3 (1.7%)	0	2 (1.1%)	2.8

¹Priority ranking refers to the percentage an option was chosen as the first, second, or third option. ²Percentage of an option chosen within the top three priorities.

For specialist consultation, “Support for parental acceptance of child's disability” was selected by half of the centres as the first priority although outranked by “Comprehension of child's developmental traits” in the overall ranking, which was selected most as the second and third priorities (40.3% and 23.3% respectively). These two and “Developmental support for children” and “Parenting support” were the top four options selected. “Support for parent’s problems” and “Encouraging parents to visit a diagnostic institution” were selected notably less.

Hence, the central objective of both services (group intervention and specialist consultation) was to provide support to children and their parents, and referral to a medical institution was perceived as less important. Further, as a general trend, group intervention placed more emphasis on developmental support for the child while specialist consultation on assessment of the child and parental support.

Challenges of Parent-child Group intervention and Specialist Consultation

To examine prioritised challenges of parent-child group intervention and specialist consultation participants were asked to choose the three most important challenges and rank them from 1 to 3. The overall priority rankings based on the percentage in which a certain option was chosen among the top three priorities are shown in Table 3-10. The exclusion criterion was the service being conducted outside the Public Health Centre, leaving 128 and 176 centres, respectively.

The percentages of being selected among top three priorities of the group intervention were closer to each other, with no single option selected by more than half of the centres. “Obtaining parent consent for participation” was selected most as the first priority (25.0%) and also ranked first in the overall ranking, followed by “Assessment of programme outcome in children” and “Frequency of programme”. The rest of the options were only selected by less than 30% of the respondents as top three priorities although

“Capacity of programme” was the second most chosen option as the first priority (14.8%; ranked fourth in overall ranking) and “Development of programme” was the third (12.5%; ranked sixth). Compared to “Deciding when child leaves the programme” and “Increasing staff”, which were selected by approximately a quarter of the respondents, “Comprehension of child's developmental traits” and “Geographical accessibility to programme” were selected by less than 20% of the respondents.

Among the challenges of specialist consultation, two options, “Making timely appointments” and “Obtaining parent consent for participation”, were selected by more than half of the centres as in the top three priority (58.5% and 56.3% respectively) and ranked first and second as the first priority (chosen by 33.5% and 22.2% respectively). “Increasing staffing” and “Encouraging parents to visit a diagnostic institution” were both selected by more than 40% of the centres. In comparison, “Assessment of child's developmental traits” and “Geographical accessibility to programme” were selected by notably fewer centres.

Overall, there were two common themes in the prioritised challenges of the two services: parental resistance to the use of the service and the limited capacity of the service. Challenges related to assessment of children were also chosen in parent-child group intervention while encouraging parents to see a doctor was prioritised more than assessment of children in specialist consultation.

Table 3-10*Participant Identified “Top 3” Challenges Associated With Specialist Consultation at Public Health Centres*

Challenges	Priority ranking ¹			Top 3 percentage ²
	1	2	3	
Parent-child group intervention (N = 128)				
1. Obtaining parent consent for participation	32 (25.0%)	16 (12.5%)	12 (9.4%)	46.9
2. Assessment of programme outcome in children	14 (10.9%)	19 (14.8%)	23 (18.0%)	43.8
3. Frequency of programme	16 (12.5%)	21 (16.4%)	12 (9.4%)	38.3
4. Capacity of programme	19 (14.8%)	9 (7.0%)	7 (5.5%)	27.3
5. Deciding when child leaves programme	7 (5.5%)	13 (10.2%)	13 (10.2%)	25.8
6. Development of programme	16 (12.5%)	7 (5.5%)	8 (6.3%)	24.2
7. Increasing staff	6 (4.7%)	13 (10.2%)	12 (9.4%)	24.2
8. Comprehension of child's developmental traits	4 (3.1%)	11 (8.6%)	9 (7.0%)	18.8
9. Other	10 (7.8%)	4 (3.1%)	5 (3.9%)	14.8
10. Geographical accessibility to programme	3 (2.3%)	8 (6.3%)	7 (5.5%)	14.1

Challenges	Priority ranking ¹			Top 3 percentage ²
	1	2	3	
Specialist consultation (<i>N</i> = 176)				
1. Making timely appointments	59 (33.5%)	24 (13.6%)	22 (12.5%)	58.5
2. Obtaining parent consent for participation	39 (22.2%)	33 (18.8%)	27 (15.3%)	56.3
3. Increasing staffing	32 (18.2%)	30 (17.0%)	18 (10.2%	45.5
4. Encouraging parents to visit a diagnostic institution	18 (10.2%)	29 (16.5%)	24 (13.6%)	40.3
5. Assessment of child's developmental traits	13 (7.4%)	14 (8.0%)	8 (4.5%)	19.9
6. Other	7 (4.0%)	9 (5.1%)	8 (4.5%)	13.6
7. Geographical accessibility to programme	2 (1.1%)	11 (6.3%)	8 (4.5%)	11.9

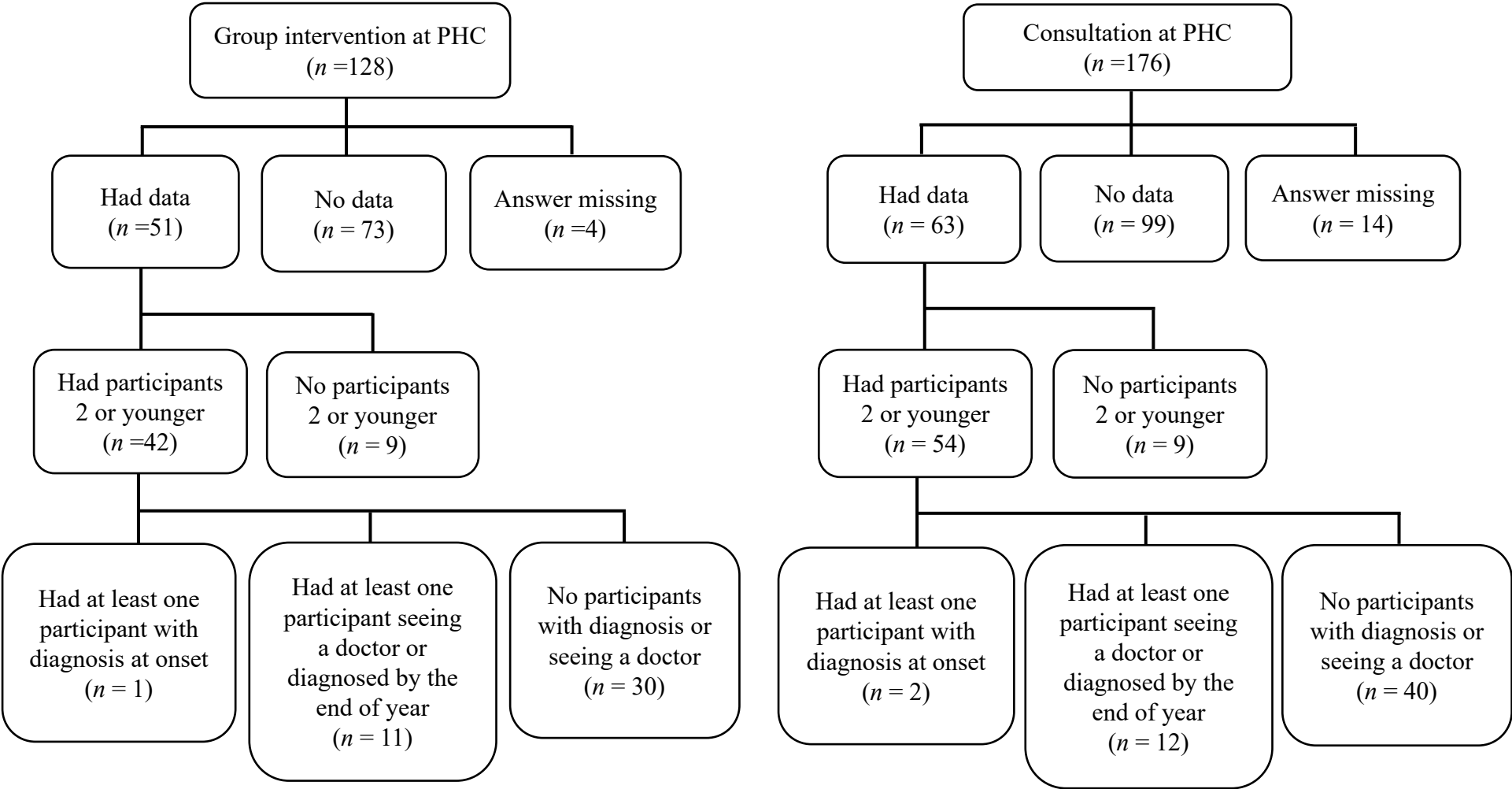
¹Priority ranking refers to the percentages an option was chosen as the first, second, or third option. ²Percentage of an option chosen within the top three priorities.

Diagnosis Among Children Using Follow-up Services

To ascertain the prevalence of diagnoses among children younger than three years of age who use the follow-up services, participants were asked to provide information on the children who joined either parent-child group intervention or specialist consultation at the age of two or younger in the fiscal year of 2018. Specifically, the questions asked the numbers of children (1) who already had a diagnosis related to developmental disorders including autism and (2) who started seeing a doctor for developmental concerns and/or were diagnosed within one year of attending the follow-up service.

As illustrated in Figure 3-1, similar results were found for both services. First, more than half of the centres did not have such data (57% for group intervention and 56.3% for specialist consultation). Of those who shared data, some did not have service users aged under two years. The majority of the remaining centres (30 out of 42 and 40 out of 54, respectively) did not have any children who fell into category (1) or (2) described above. Only one centre (0.8%) confirmed that they had at least one child with a diagnosis at the time of participation in group intervention, and two centres (1.1%) in specialist consultation. Only a few centres had at least one child who started seeing a doctor or was diagnosed within a year since participation (8.6% and 6.8% respectively).

Figure 3-1.
Prevalence of Diagnosis Among Children Aged Under Three in Group Intervention and Individual Consultation at Public Health Centres



Question 3: What Are the Screening and Assessment Practises and Tools Undertaken Within the Follow-up Services Within Public Health Centres?

Use of Screening and Assessment Instruments

The respondents were asked to provide details of any screening and assessment instruments used within the follow-up services conducted at their Public Health Centre. Tools designed for use in children aged three or older were excluded from the analysis. Table 3-11 summarises the types of instruments used within parent-child group intervention and specialist consultation.

Overall, use of assessment instruments, including secondary autism screeners, were uncommon, except for developmental assessment measures. Every centre that reported the use of an adaptive behaviour measure or an autism screener also used developmental assessment measures. No centres used assessment measures of sensory processing patterns that are applicable for children younger than three years. Only two centres (1.1%) reported the use of an autism screener within the specialist consultation, and no centre used an autism screener within the group intervention. When the group intervention and specialist consultation responses are compared, less instrument use was reported in the former, including developmental assessment tools (21.9% in the former and 72.7% in the latter).

Table 3-11

Use of Assessment Instruments Appropriate for Children Aged Under Three Within Parent-child Group Intervention and Specialist Consultation at Public Health Centres

	Parent-child group intervention (<i>N</i> = 128)		Specialist consultation (<i>N</i> = 176)	
Use of assessment instruments	<i>n</i>	%	<i>n</i>	%
No	100	78.1	48	27.3
Yes (multiple choice)	28	21.9	128	72.7
Developmental assessment	28		128	
Adaptive skill assessment	1		10	
Sensory processing profile	0		0	
Autism screening	0		2	

Staffing and Administrators of Assessment Instruments

To explore the relationship between staffing and the professional expertise of those who administer the assessment instruments, participants were asked to provide the (a) details of staffing in the service and (b) professions of assessors using any instruments within the service.

As summarised in Table 3-12, more than 90% of the centres reported they had public health nurse(s) and preschool teacher(s) in parent-child group intervention. Approximately 70% of the centres had psychologists, but other professionals including speech, occupational and physical therapist(s) were only reported by less than 20% of

centres. In contrast, the most common profession for specialist consultation was psychologist (83.5%), followed by public health nurse (74.4%) and speech therapist (32.4%). Other professions were only reported by less than 17% of the centres.

For both services, assessment instruments were mostly administered by a psychologist and, in fewer cases, by public health nurses. Involvement of other allied health professionals such as speech or occupational therapists were uncommon.

Table 3-12

Staffing (numbers outside parenthesis) and Profession of Administrators of Assessment Instruments (numbers in parenthesis) in Parent-child Group Intervention and Specialist Consultation (multiple choice)

	Parent-child group intervention (N=128)		Specialist consultation (N= 176)	
	<i>n</i> [*]	%	<i>n</i> [*]	%
Psychologist	91 (17)	71.1 (13.4)	147 (112)	83.5 (63.6)
Public health nurse	121 (12)	94.5 (9.4)	131 (23)	74.4 (13.1)
Preschool teacher	116 (1)	90.6 (0.8)	30 (2)	17.0 (1.1)
Speech therapist	25 (4)	19.5 (3.1)	57 (12)	32.4 (6.8)
Occupational therapist	20 (3)	15.6 (2.4)	18 (5)	10.2 (2.8)
Physical therapist	8 (0)	6.3 (0)	15 (0)	8.5 (0)
Other	44 (3)	34.4 (2.4)	37 (11)	21.0 (6.3)

Non-use of Assessment Instruments

The 48 Public Health Centres that reported not using screening or assessment measures in any of their follow-up services were asked to provide reasons of non-use (Table 3-13). Two prominent reasons were “Outsourcing of assessments” and “difficulty in securing assessors”, both of which were selected by half of the respondents, followed by “Difficulty in securing time for assessment” (18.8%). The rest of the choices were only selected by four or less centres. Although chosen by eight centres, none of “other” answers formed a theme.

Table 3-13

Reasons of Non-use of Screening and Assessment Instruments in Follow-up Services at Public Health Centres (N = 48, multiple choice)

	<i>n</i>	%
Assessments are outsourced	24	50.0
Difficulty in securing assessors	24	50.0
Difficulty in securing time for assessment	9	18.8
Other	8	16.7
Difficulty in obtaining parent consent	4	8.3
No budget	4	8.3
No need for assessment	2	4.2

Discussion

The findings from the current study provide insights into follow-up practises for young children identified with developmental concerns, including likelihood of autism,

following the 18-month check-up at Public Health Centres in Japan, and the use, or lack thereof, of screening instruments during follow-up. It is important to understand the current processes in place prior to making recommendation for improvements in follow-up service practices so that the centres can make the most of their limited resources before diagnosis (Yamazaki et al., 2016).

Autism screening at the 18-month check-up, when it occurred, was mostly not reliant on use of an autism-specific screening instrument. Rather, the results indicated that the focus was on identifying children with a broader range of developmental conditions. When an autism screener was used, the tool of choice was usually the M-CHAT-JV, as previously reported (JSCCP, 2014; Ministry of Health, Labour and Welfare, 2016). However, a wide range of deviations in instrument use was found, particularly in the number of items used and the administration format. Further research is needed to ascertain why the M-CHAT-JV was not used according to instruction, as well as to determine a Level 1 autism screener that is appropriate and feasible for use within statutory 18-month health check in Japanese Public Health Centres.

The high rate of referrals to follow-up (an average of 34%) from around half of the centres is notable (Honda et al., 2009). Referral of children following their 18-month check-up to a medical facility was associated with three major challenges. Consistent with previous research (Takahashi et al., 2015), the paucity of medical facilities to refer to was indicated by respondents. The current study also revealed that parental resistance to see a doctor and a long waiting list until the first appointment were other significant factors that hinder referral to a medical institution that would enable subsequent diagnosis. The finding indicates that the central challenge for Public Health Centres lies not simply in obtaining a diagnosis, but in the steps prior whereby challenges were identified in convincing and connecting parents to a first appointment with a doctor with

proper expertise. Supporting this position, “Long waiting until diagnosis” and “Unreliable diagnoses” were only chosen by few centres as a priority.

Public Health Centres identified two prominent objectives for their follow-up services. First, in referring for a specialist consultation and/or intervention, active provision of support to children and parents (i.e., “Developmental support for children” and “Parenting support”) were highly ranked as priorities ahead of referral to a medical facility (i.e., “Encouraging parents to visit a diagnostic institution”) which was among the least prioritised objectives in both cases. The absence of a diagnosis among follow-up users was also supported by the very low percentage of centres that had children who participated in either service before two years of age and started seeing a doctor or were diagnosed within a year. These results confirmed that community-level support before diagnosis (Yamazaki et al., 2016) was indeed taking place in many local Public Health Centres across Japan.

Second, promoting parental acceptance of the child’s disability was identified as important within the follow-up services. Parental resistance was not only one of the main challenges facing medical referral as mentioned above, but also a central challenge for both the specialist consultation and parent-child group intervention services. This finding reflects the complex emotional experiences of parents of young children displaying signs of developmental disabilities (Futagi & Yamamoto, 2002; Nagai & Hayashi, 2004) where they may deny their child’s developmental concerns in the hope that these will attenuate over time (Matsunaga & Hiroma, 2010). The high ranking of “Support for parental acceptance of child’s disability” as a prioritised objective in both services suggest that professionals working in Public Health Centres aim to provide supports required for a parent to become resolved with their child’s developmental condition, albeit undiagnosed. Further, although medical referral was not a prioritised objective,

“Encouraging parents to visit a diagnosis facility” was chosen among the top three challenges by 40% of the centres that offer specialist consultation. Together with the findings discussed above, this indicates that a slower approach is taken towards a medical referral, by waiting for parents to adjust while providing the necessary supports to both them and their children. This is an important finding in the current study. Previous Japanese research on parental acceptance of their child’s disability has focused on their stress and anxiety before the diagnosis, and their emotional experiences after the diagnosis (Futagi & Yamamoto, 2002; Matsunaga & Hiroma, 2010; Mizuta S., 2009; Nagai & Hayashi, 2004). None to date have examined the role that the follow-up service provided in between the two phases.

The high percentage of the children referred to the follow-up services, coupled with the lack of early diagnosis supports the need for secondary screening within these services. Consistent with a previous report (Yamazaki et al., 2016), the current data founds that the only type of assessment measure commonly used in follow-up services was a developmental assessment instrument. Autism screeners were largely absent from the practices reported by the respondents from the Public Health Centres.

The data further revealed that assessments, primarily that of general development, were primarily undertaken within specialist consultations, with notably fewer assessments conducted at parent-child group interventions. Nonetheless, in the prioritised challenge ranking, “Assessment of child's developmental traits” ranked low in specialist consultation, and “Comprehension of child's developmental traits” was ranked low in the parent-child group intervention. Highly prioritised challenges of the group intervention included, “Assessment of programme outcome in children” (ranked second of ten), “Deciding when child leaves programme” (fifth), and “Development of programme” (sixth), are considered benefits of secondary assessment.

In the majority of the cases, assessment instruments, when used, were administered by psychologists, followed by a small number of public health nurses. Other allied health professionals, such as speech pathologists and occupational therapists were rarely reported as assessors. These results mostly reflected the staffing at the follow-up services. Although preschool teachers were the most common professionals in the parent-child group intervention, they were not involved in the assessment of children. “Difficulty in securing assessors” was one of two most common reasons of non-use of assessment measures within the follow-up services (the other was outsourcing of assessment), followed by “Difficulty in securing time for assessment”, as reported previously (Matsumoto et al., 2013).

These results surrounding instrument use within the follow-up services have several implications. First, use of a Level 2 autism screener may be beneficial given the high rates of follow-up so that children with autism can be identified from those with other developmental challenges, and intervention and other supports can be tailored to them. Second, use of an autism screener within the parent-child group intervention may directly address some of the prioritised challenges reported in this study such as the assessment of programme outcome in children and development of programme. Third, given that securing of assessors and assessing time were major obstacles in introducing assessment instruments to the follow-up service, an autism screening instrument that is brief and easy to administer, even by non-specialists, such as public health nurses and preschool teachers, may be desirable.

Limitations

One limitation in the study was the limited number of questions used in the survey. To increase the response rate, question number was minimized to fit onto two sides of a single sheet of A3 paper. Consequently, the collection of more detailed

information was compromised, such as the rate of successful referral to a medical institution after the 18-month check-up, and the reasons of non-use of an autism screener at follow-up services. It was also not possible to examine the factors contributing to the difference in the follow-up rate based on the 18-month check-up result (i.e., around half of the responding Public Health Centres followed up less than 15% of the children while the other half followed up an average of 34%). Furthermore, the limited number of questions inhibited a more in-depth exploration of parental hesitancy in obtaining an early diagnosis, or utilising the offered follow-up service. Further research is needed to examine this important issue.

Another limitation was the low response rate and anonymity of the respondents. One possible explanation of the low return rate may be a perceived “lack of authority”. Similar Japanese surveys targeting Public Health Centres and reporting a higher response rate were often undertaken by a national institute or a widely known organization (e.g., Gokami, 2007; JS CCP, 2014; Sasamori et al., 2010). Since Public Health Centres are public institutions, many of them may have been more cautious about participating in the current study, which was not supported by a governmental institution or local research fund. Indeed, the survey did not require specific information on the responding centres and their municipalities because of this potential caution being taken into consideration. The ensuing sample size affected the data analysis. That is, given that the current thesis placed emphasis on autism screening in low resource settings, it would have been ideal to conduct subgroup analyses based upon the different levels of resource setting. However, the sample size was too small to ensure sufficient statistical power. Thus, due to the anonymity of respondents and the relatively small sample size, the results from the survey should be interpreted with some caution, and any conclusions from the findings remain tentative.

Lastly, the scope of this study was limited to questions about specialist consultation and parent-child group intervention. The high prevalence of the “wait and see until next check-up” approach needs be further investigated, as well as other common follow-up options such as phone consultation and home visits, to fully understand the follow-up pathways at Japanese Public Health Centres.

Conclusion

The current study indicates that the screening and follow-up pathway of young children found at risk of developmental concerns, including autism through the 18-month check-up in Japan lacks secondary screening. In the absence of a medical diagnosis, further assessment of the children at follow-up is essential to effectively utilise the available services and to prioritise supports for each child and parent, especially for the parent-child group intervention, a valuable first opportunity for early behavioural intervention. The limited time and human resources within the follow-up services at Public Health Centres point to the necessity of a brief, easy to train and administer autism screening tool so that the secondary assessment becomes more feasible within the existing follow-up services.

Chapter 4

Cultural Adaptation of the Autism Detection in Early Childhood (ADEC) for Japan

In the absence of reliable biological markers for autism, screening and diagnosis remain reliant on developmental history and behavioural presentation (Abrahams & Geschwind, 2008; Klin & Jones, 2015; Zwaigenbaum et al., 2015). The development of various early screening instruments over the last decades reflect concerted efforts to facilitate earlier identification of autism based on presenting behavioural characteristics. As presented in Chapter 2, a review of early autism screening instruments in Japan identified a lack of Level 2 screeners that are applicable for, and have been validated with, children aged under 3 years. As noted in Chapter 3, the statutory 18-month health check-up at the local Public Health Centres in Japan serves as an opportunity for universal Level 1 screening. The follow-up service which ranges from specialist consultation to mother-child group intervention is offered to those who screen positive. This follow-up stage is particularly important in the Japanese maternal and child health context because this is often where the earliest support for children with developmental disabilities, including autism, and their families begins.

The results from the survey on autism screening practices and use of assessment instruments at Japanese Public Health Centres presented in Chapter 3 revealed: (a) very little, if any, use of Level 2 autism screening tools within specialist consultation or parent-child group intervention at Public Health Centres. This was the case despite the apparent diversity in nature and degree of developmental concerns amongst those referred for follow-up; (b) some of the prioritised challenges surrounding the group intervention indicating the potential benefit from use of a Level 2 autism screening tool; and (c) the limited time and human resources available within the follow-up services

which pointed to the necessity of any Level 2 tool being brief, easy to train on and administer; this would enable the tool to be administered by a range of professionals including public health nurses and preschool teachers, as well as psychologists and other allied health professionals.

Rationale Behind Instrument Selection

Informed by the findings from the Survey Study, and the literature review, a Level 2 autism screener was selected: Autism Detection in Early Childhood (ADEC; Young, 2007). The ADEC is an interactive behaviour observation instrument developed in Australia for use with children aged between 12 to 36 months. It consists of 16 items that are considered to reflect the purest manifestations of early behavioural indicators of autism (Young, 2007), and has demonstrated good screening properties (Hedley et al., 2015; Nah et al., 2014). Although developing an entirely new tool specifically designed for use within Japanese Public Health Centres may be ideal, it was not very realistic given the extensive resources and effort required to test and validate a brand-new tool. Importantly, the ADEC has now been used in different cultural settings, with good psychometric properties reported (Hedley et al., 2010; Sidjaja, 2015; Young & Nah, 2016). Considering the extremely rare use of an autism screening tool within the follow-up service, evaluating the ADEC in a Japanese setting for expeditious adoption was considered to be more time-efficient and economical.

An important point regarding selection of the ADEC is that it is an interactive behaviour observation tool, as opposed to a parent report. As presented in Chapter 2, concerns have been raised regarding discrepancy between Japanese specialists' and parents' observations of a child's behaviour (e.g., Tamai et al., 2014). The low use rate of the M-CHAT, a parent report, at the 18-m check-up at Japanese Public Health Centres may be partially accounted by this concern if the centres are aware of the unreliability of

parent report. The only direct observation tools available in Japan are the Childhood Autism Rating Scale-Tokyo Version (CARS-TV; Kurita et al., 1989) and the Japanese adaptation of Autism Diagnostic Observation Schedule-Second Edition (ADOS-2). However, their limitations were already discussed in Chapter 2, and the hurdles of introducing the ADOS-2 to low-resource settings are very high (e.g., a Japanese ADOS-2 kit costs over 7,500 AUD as of 2020). The ADEC can provide a new, more feasible method of secondary autism screening that allows direct observations by personnel involved in the follow-up service, which may motivate and increase the use of Level 2 autism screening instrument at Public Health Centres.

The Autism Detection in Early Childhood (ADEC)

Compared to Japan, more instruments have been validated in English speaking countries as Level 2 autism screeners that are suitable for children under three years of age (Zwaigenbaum et al., 2015). The Baby and Infant Screen for Children with aUtism Traits: Part 1 (BISCUIT; Matson et al., 2011) is a parental report instrument developed to assess autistic and related characteristics in children aged 17 to 37 months. The preschool part of Social Responsiveness Scale-Second Edition (SRS-2; Constantino & Gruber, 2012) is also a parent (and teacher) report measure that can be used for children as young as 2 years old. A direct behaviour observation tool, the Childhood Autism Rating Scale, Second Edition (CARS-2; Schopler et al., 2010) is also designed for use with children aged 2 years and above, while an interactive behaviour observation tool, the Screening Tool for Autism in Two-Year-Olds (STAT; Stone et al., 2000, 2004) is suitable for children aged 24 to 36 months. Among these instruments, BISCUIT and older versions of CARS (Schopler et al., 1980) and SRS (Pine et al., 2006) have been adapted and validated in Japan (Kamio, Honda, et al., 2015; Kurita et al., 1989; Stickley et al., 2017), whose limitations have already been noted in Chapter 2. As of 2020, there is no Japanese

adaptation of STAT although limitations of the original instrument, such as the lack of validation with very young samples, have been discussed (Nah et al., 2014).

The ADEC has several advantages over the other Level 2 screeners mentioned above. First, it can be used to detect autistic traits in children as young as 12 months; none of the aforementioned tools are designed to address children as young as this. Indeed, the ADEC was designed to operationalise the earliest and purest behavioural markers of autism in very young children, rather than secondary symptoms that may appear later in development (Young, 2007). Hence, the ADEC items are developed to elicit preverbal behaviours, with little reliance on receptive language abilities, making it appropriate for use with very young children. Second, similar to the STAT, the ADEC is an interactive behaviour observation measure where the assessor tries to elicit target behaviours from the child through fun play-based interactions. Research has reported that parental report measures, such as BISCUIT and SRS-2, may be less reliable than direct observation measures possibly due to compensatory strategies parents may use to achieve desired outcomes (Baranek, 1999) or due to the very young age of their child (Barton et al., 2012; Wiggins et al., 2007). Discrepancies between parent and specialist assessments have been reported even when the same screening instrument was used (Ishii et al., 2013; Stone et al., 1994; Takei et al., 2010; Tamai et al., 2014).

The ADEC Items, Scoring, and Interpretation

The 16 behaviours in the ADEC were identified based on a retrospective parental survey (Young et al., 2003) and home video analysis (Clifford et al., 2007). These items are: (1) response to name, (2) imitation, (3) ritualistic play, (4) joint attention and social referencing, (5) eye contact, (6) functional play, (7) pretend play, (8) reciprocity of smile, (9) reaction to common sounds, (10) gaze monitoring, (11) following verbal commands, (12) use of words, (13) anticipation of social advances, (14) nestling, (15) use of

gestures, and (16) task switching.

The diagnostic criteria for ASD within the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5; American Psychiatric Association, 2013) has two sets of criteria: impairments in social communication and interaction (e.g., lack of eye contact, pointing, or facial expressions) and the presence of restricted and repetitive behaviours, interest and activities (e.g., finger-flicking, fixation on order of things), with the latter including hyper- and hypo-reactivity to sensory stimuli and unusual sensory interests (e.g., mouthing or smelling objects). As shown in Table 4-1, ADEC behaviours correspond well with the current DSM-5 criteria reflecting good clinical consistency. The imbalance of the number of items in each domain is justifiable as repetitive and stereotyped behaviours, interests, and activities and sensory and atypical motor mannerisms are not frequently observed during infancy and toddlerhood (Gray & Tonge, 2001; Young & Brewer, 2002), only becoming more evident later in development.

Table 4-1*Categorization of 16 ADEC Behaviours*

DSM-5 domains*	ADEC manual domains**	ADEC items (Number in the manual)
Deficits in social communication and interaction	Disturbance in interacting with others and with objects	(1) Response to name (2) Imitation (4) Joint attention and social referencing (5) Eye contact (6) Functional play (7) Pretend play (8) Reciprocity of smile (10) Gaze monitoring (11) Following verbal commands (12) Use of words (13) Anticipation of social advances (14) Nestling (15) Gestures
Presence of restricted and repetitive behaviours, interest, and activities	Stereotyped, repetitive movements Bizarre responses to environmental stimuli	(3) Ritualistic play (16) Task switching (9) Reaction to common sounds

Note. *From American Psychiatric Association (2013). **Revised from Young (2007).

Each ADEC item is scored on a three-point scale where zero (0) signifies a developmentally appropriate behaviour or response and two (2) a developmentally inappropriate behaviour or response. A score of one (1) is given when the child partially fulfills the requirements when prompted by the administrator, or spontaneously performs the desired behaviour or response at other times during the testing session. This scoring approach enables the child to receive partial credit for their behaviours throughout the session, rather than simply fail or pass on each testing item, leading to a better characterisation of the child's strengths and manifestation of autistic traits. The total score thus ranges from 0 to a maximum of 32, with a score of 0 to 10 indicating a low risk of autism, 11 to 13 a moderate risk, 14 to 19 a high risk, and 19 and above a very high risk (see Table 4-2).

Table 4-2

Score Interpretation of the ADEC

Total score	Interpretation
>19	Very high risk of AD
14-19	High risk
11-13	Moderate risk
0-10	Low risk

Although the ADEC was developed based on the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DMS-IV-TR; American Psychiatric Association, 2000), Hedley and colleagues (2015)

conducted a clinical study on the ADEC at a paediatric hospital in the United States (US) using DSM-5 diagnostic criteria (APA, 2013). They found the ADEC demonstrated adequate screening against best estimate clinical (BEC) diagnoses using the recommended cut-off of 11.

Accessibility of the ADEC

The ADEC also offers a number of advantages for clinical use. Although it is an interactive observation measure, administration only takes around 15 minutes including the adaptation period. Moreover, the official ADEC kit that comprises a manual, 10 scoring sheets, toys used to elicit some of the target behaviours and responses (Figure 4-1), and a training DVD is relatively inexpensive compared to other observation measures. Available substitute toys may also be used as long as they elicit the required effects and functions (Young, 2007), with the manual and DVD alone costing AUD \$225.00.

The ADEC items and scoring system are designed such that even non-ASD specialists can reliably administer the tool, and without extensive training (i.e., careful and thorough reading of the manual and watching of the training DVD is the minimal requirement). This accessibility of the ADEC was the motivation behind the two cultural adaptations undertaken to date: the Spanish (ADEC-SP; Hedley et al., 2010) and Indonesian (ADEC-IND; Sidjaja, 2015) versions were both intended to be utilised in low-resource clinical settings, where there is minimal access to specialised tools for an ASD diagnosis, and few multidisciplinary specialists available to undertake a comprehensive diagnosis.

Figure 4-1*Toys and Materials Used in the ADEC***Psychometric Properties of the ADEC**

Preliminary studies on the ADEC (Young, 2007) reveal good internal consistency (Cronbach's $\alpha = .85\text{---}.93$), test-retest reliability ($r = 0.83$), and inter-rater reliability (intra-class correlation, $ICC = .83$). Other studies have also reported moderate to high internal consistency (Hedley et al., 2015; Nah et al., 2014) and high inter-rater reliability ($ICC = .95$; Hedley et al., 2015). In a validity study with 192 children, the ADEC excelled at identifying children with autism (Sensitivity = 1.0) but over-identified some without autism (Specificity = .74—.90) (Nah et al., 2014). A clinical study in the US also reported good sensitivity (.93—.94) and moderate specificity (.62—.64) (Hedley et al., 2015). Moreover, the ADEC scores were found to be strongly correlated with international “gold standard” tools: the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994) (r ranging from .47 to .86; Nah et al., 2014) and the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2; Lord et al., 2012) (r ranging from .60 to .70; Hedley et al., 2015).

The ADEC-SP and ADEC-IND also have good psychometric properties to

support the applicability of the ADEC in different cultural and language settings. The sensitivity and specificity of the ADEC-SP with 115 children aged 15 to 73 months were .79—.94 and .88—1.00 respectively, with a subgroup of children aged 19 to 36 months demonstrating better screening outcomes than the whole sample (Hedley et al., 2010). A study with 82 children aged 14 to 72 months on the ADEC-IND reported excellent sensitivity (.92—.96) and specificity (.85—.92). The total score of the ADEC-IND was strongly correlated with the that of ADI-R ($r = .64$) (Sidjaja, 2015).

Japanese Translation and Adaptation of the ADEC

To address the issues in many previous cultural adaptations of autism screeners (i.e., lack of conformity with guidelines, rigorous cultural adaptation, or detailed reporting of the process; Soto et al., 2015), the ADEC tool and manual were translated and adapted into Japanese in accordance with the World Health Organization guideline (World Health Organization, n.d.) which comprises four steps: forward translation, expert panel, back translation, and pre-testing. Since the ADEC was not a questionnaire, the cognitive interviewing procedure was omitted. The following sections describe each of the four steps.

Forward Translation

The ADEC manual and scoresheet were translated into Japanese by the candidate who is a native Japanese speaker with previous experience of translation in the field. During this initial process, questions and ambiguities regarding interpretation of the language and instructions were discussed to reach a consensus with a bilingual Japanese psychologist who had extensive experience in developmental psychology and the early identification of autism. In translating, the candidate noted two differences in the play of Peek-a-Boo (Item 5) and the Japanese equivalent, *Inai-inai baa*. In the former, an adult hides their face and reveals it while saying “Peek-a-boo!”. In the latter, an adult says

“*inai inai...*” while hiding their face and reveal it with the phrase “*baa!*”. Additionally, the use of a towel is less common in Japanese who more often use their hands. This point was presented in the Expert Panel.

Expert Panel

The same Japanese psychologist who aided the forward translation assumed the “editor-in-chief” position in this next step and reviewed the forward translation for any misinterpretations and misleading expressions. Five other psychologists, one public health nurse and one social worker also reviewed the translation, all of whom were well-versed in the field. The main objective of their review was to ensure appropriate use of terminology and readability, as well as cultural relevance of the toys and tasks described in the manual. They were all monolingual in Japanese, and on those occasions where the original English texts needed to be referred to, either the candidate or the editor-in-chief psychologist provided help with comprehension. Following feedback from the panel, the translator made minor amendments to the wording of the translation. Additionally, the panel expressed concern regarding the use of the toy shaped as an old-fashioned phone with a dial (Item 6: Functional Play) since these phones are no longer used in Japan. As the original ADEC has replaced this toy with one that imitates a smartphone, the panel agreed to follow this change. Regarding the game of Peek-a-Boo, it was concluded that the aforementioned differences in the use of a towel did not interfere with the instructed administration of the task. No other concerns based on cultural differences were raised regarding the design or administration of each ADEC item.

Back-translation

A bilingual Japanese translator (PhD in biological and environment sciences) who had no previous knowledge of the ADEC translated the manual and scoresheet back to English. One American psychologist (PhD in Psychology) and one bilingual psychologist

(PhD in psychology), both of whom had extensive experience in the administration of the ADEC, independently reviewed the back-translation, comparing it with the original manual, to exclude any misunderstanding in the Japanese translation. Consequently, the following misinterpretation was pointed out for item 15 (gestures/ wave a goodbye):

Japanese: そのほかの別れの挨拶を表す身ぶり手ぶりには、すべて 1 をつける。

(Reading: Sonohoka-no wakare-no aisatsu-wo arawasu miburi-niwa subete 1-wo tsukeru.)

Back-translation: Score “1” should be given when (the administrator) observed any other gestures that are meant to be farewell greetings.

Original: “Any other demonstration of these types of gestures can be scored here.”

During the forward translation, the candidate and editor-in-chief psychologist had a discussion on whether “these types of gestures” refers to various social gestures or gestures for farewell. The translation settled on the latter interpretation. However, review revealed that the former interpretation was correct. With this feedback, the translator revised the sentence as follows:

Japanese: そのほかの身ぶり手ぶりがいずれかの場面で見られたら、1 をつける。

(Reading: Sonohoka-no miburi-teburi-ga izureka-no bamen-de miraretara 1-wo tsukeru.)

Translation: "If any other gestures are observed on any occasion, score 1 will be given."

In this context, the reading of “on any occasion” is reasonably considered to be restricted to “on any occasion during the assessment” in Japanese. No other revisions were requested by the reviewers. The backtranslation, including the amendment, received approval from the developer of the ADEC (Young). The details of the ADEC items and coding guideline are presented in Appendix B.

Pre-testing

The pre-test was approved by the Research Ethics Committee of Nihon Institute of Medical Science, Japan (#2018029) with reciprocal approval from the Human Ethics Committee of La Trobe University.

Participants

Participants comprised ten children (five males; *Mage* = 19.2 months, *SD* = 4.7, range = 16—30) who were raised in a Japanese-speaking household and whose first language was Japanese. Although there was one bilingual (Japanese and English) participant, it was confirmed by the parent that her dominant language was Japanese. The ADEC was administered solely in Japanese. Participants were recruited through a maternal and child health network in Gunma, Japan. Written consent was obtained from parents of all participants prior to the testing.

Procedures

The ADEC-J was administered to all participants by the candidate using the Japanese manual. Prior to the pre-test, the candidate was trained on the ADEC administration by an expert ADEC assessor across three practice sessions. All testing sessions were held in a small space partitioned within a larger room, with the child seated on the floor together with the candidate. The child’s parent was present during the administration, also seated on the floor to observe the ADEC administration. The sessions were video-recorded, and the recordings sent to an external English-speaking

expert assessor (PhD in Psychology) experienced in ADEC administration. English translations of the dialogue were added to each recording to aid the expert assessor who independently scored the ADEC from observing the videotapes. The Japanese psychologist who assumed the editor-in-chief role in the Expert Panel also watched the recordings to examine any adjustment from the Japanese instructions (e.g., prompting words different from those described in the manual) made during the testing.

Analysis

An Intraclass correlation coefficient (ICC) was used to determine agreement between the scores rated by the candidate (using the Japanese manual) and those by the expert assessor (using the original manual). The expert assessor was also required to provide feedback on the applicant's administration in case of deviations from the original manual.

Results

A high ICC was found between the applicant's and expert assessor's scores (ICC = .93). No deviations were identified by the expert ADEC assessor regarding the candidate's administration of the ADEC using the Japanese manual. However, two linguistic adjustments were observed by the Japanese psychologist: (1) In Reciprocity of Smile (Item 8), the candidate used expressions such as "*niko-niko shite?*" and "*nikotto dekiru-kana?*" using onomatopoeias for smiling (*niko* or *niko-niko*), instead of the straightforward translation of "Smile" (i.e., "*waratte?*") to elicit a reciprocal smile; (2) In Response to a Verbal Command (Item 11), parents often selected "Give me something" as a simple command that their child would understand and follow; however, the verbal instruction "*chodai*" (Please give me) was usually accompanied a gesture of showing their hand with the palm up. The candidate thus asked them to administer the item without gesturing.

Discussion

Although the administration and scoring of the ADEC based the Japanese manual was consistent with those based on the original manual, two persistent linguistic adjustments were found. The use of onomatopoeic expressions to prompt a reciprocal smile may be because the Japanese imperative expression sounds too strong to use with a young child. Further, as young Japanese children may show more difficulty in socializing with a stranger compared to Western children (Rothbaum et al., 2000), use of more friendly wording may be needed to reduce the natural shyness of Japanese children. The second adjustment relates to the habit of accompanying a gesture with the Japanese phrase “Give me something”. Although many parents first chose this command when asked, use of a gesture should be avoided in the task because the ADEC Item assesses the child’s receptive language capacity. Hence, explicitly instructing parents not to accompany a gesture or use other commands in this case is necessary. It is important to note, however, that both adjustments are well within the scope of the original instructions where modifications are allowed insofar that the objective of the task was maintained. Therefore, as a conclusion, no revision was required to the Japanese adaptation of the ADEC (ADEC-J) although addition of practical notes to the ADEC-J may be useful when formerly published in Japanese.

Summary

A Level 2 screening instrument, the ADEC, was selected as an autism screener, based on its accessibility and strong psychometric properties for use with children referred for follow-up after their 18-month check-up at Public Health Centres in Japan. The process of translation and adaptation undertaken, that followed the WHO guidelines, was outlined. The pre-test with ten Japanese children showed a strong correlation between the ADEC and ADEC-J ratings undertaken independently by two administrators,

suggesting that the translation of the Japanese tool and manual was accurate, and instructions for administration of the ADEC-J did not deviate from the instructions within the original ADEC manual.

The ADEC-J is proposed as a new tool to address both the lack of Level 2 autism screening instruments designed for use in children aged younger than three years in Japan, and the lack of secondary screening practices within the follow-up services. As a next step, validation of the ADEC-J is described, with the aim of determining its capacity as a Level 2 screen for autism with the intended population.

Chapter 5

Validation of the Japanese Adaptation of the Autism Detection in Early Childhood (ADEC-J)

In their recent summary of recommendations for statutory check-up and follow-up practices at Public Health Centres in Japan, Yamazaki et al. (2016) highlight the necessity of further assessment of the children in the follow-up services so that Public Health Centres can ensure early identification of disabilities and improve the quality of early support. However, their survey confirmed that while developmental tests (such as the New Kyoto Scale of Psychological Development; Koyama et al., 2009) were used at some of the centres, screening tools specific to developmental disorders, including autism, were rarely used. The survey study conducted and presented in Chapter 3 confirmed these findings, thereby recommending the use of an autism screening tool for secondary assessment within the follow-up service.

Chapter 4 introduced the Autism Detection in Early Childhood tool (ADEC; Young, 2007), which was translated, piloted and presented as the ADEC-J. The objective in the current study was to validate the ADEC-J in a sample of Japanese preschool children who participate in the follow-up service at their local Public Health Centres due to developmental concerns identified at the 18-month statutory check-up. To do so, the ADEC-J was compared against the Japanese ADOS-2 (Lord et al., 2015), which is a gold standard tool commonly used to diagnose children with ASD. The ADOS was used as an index of likely ASD in the absence of comprehensive medical diagnosis undertaken of children.

In undertaking the current study, it was hypothesised that the ADEC-J total score would be highly correlated with the ADOS-2 total and severity scores. It was also

hypothesized that children who were using the follow-up services would generally score higher on both the ADEC-J and ADOS-2 than those not using these services. It was also expected that children within the follow-up service would score lower in developmental and adaptive behaviour assessments administered to them compared to those who were not referred to such services. Finally, it was also hypothesised that not all children using the follow-up services would show developmental concerns including signs of autism as the services were available to children and their parents with a broad range of challenges and concerns.

Methods

The study was approved by the Research Ethics Committee of the Nihon Institute of Medical Science, Japan (#2018023) with reciprocal approval from the Human Ethics Committee of La Trobe University.

Participants

Participants were 60 children (31 males, 52%) and their caregivers recruited into the study through flyers distributed at Public Health Centres, Child Developmental Support Centres and other institutions related to maternal and child health services in Gunma, Japan. Twenty-nine participants (48%) were using one or more follow-up services (hereafter FU group) while 31 were not (NFU group). The FU group is considered as a pseudo high-risk group because, in the most common scenario in Japan, they were offered the follow-up service by their local Public Health Centres based on developmental concerns identified during health check-ups. In contrast, the NFU group constitutes a pseudo low-risk group who were not offered the follow-up service by the local Public Health Centre. It is possible, however, that the NFU group includes children from families (a) who rejected the offer of using the follow-up service (i.e., despite developmental concerns identified) and (b) whose developmental concerns were not

properly screened for at health check-ups (i.e., “false-negatives” in screening at local Public Health Centre). Descriptive information about the participants is summarised in Table 5-1.

Table 5-1

Descriptive Characteristics of participants

	Overall	FU ^a	NFU ^b
<i>n</i> (male, female)	60 (31, 29)	29 (22, 7)	31 (9, 22)
<i>M</i> _{age} (SD), months	28.87 (7.13)	32.52 (5.59)	25.45 (6.78)
	Overall	FU ^a	NFU ^b
Age range	15—42	19—42	15—36
ASD	2	2	0
Intellectual disabilities	1	1	0
Suspected autism ^c	2	2	0

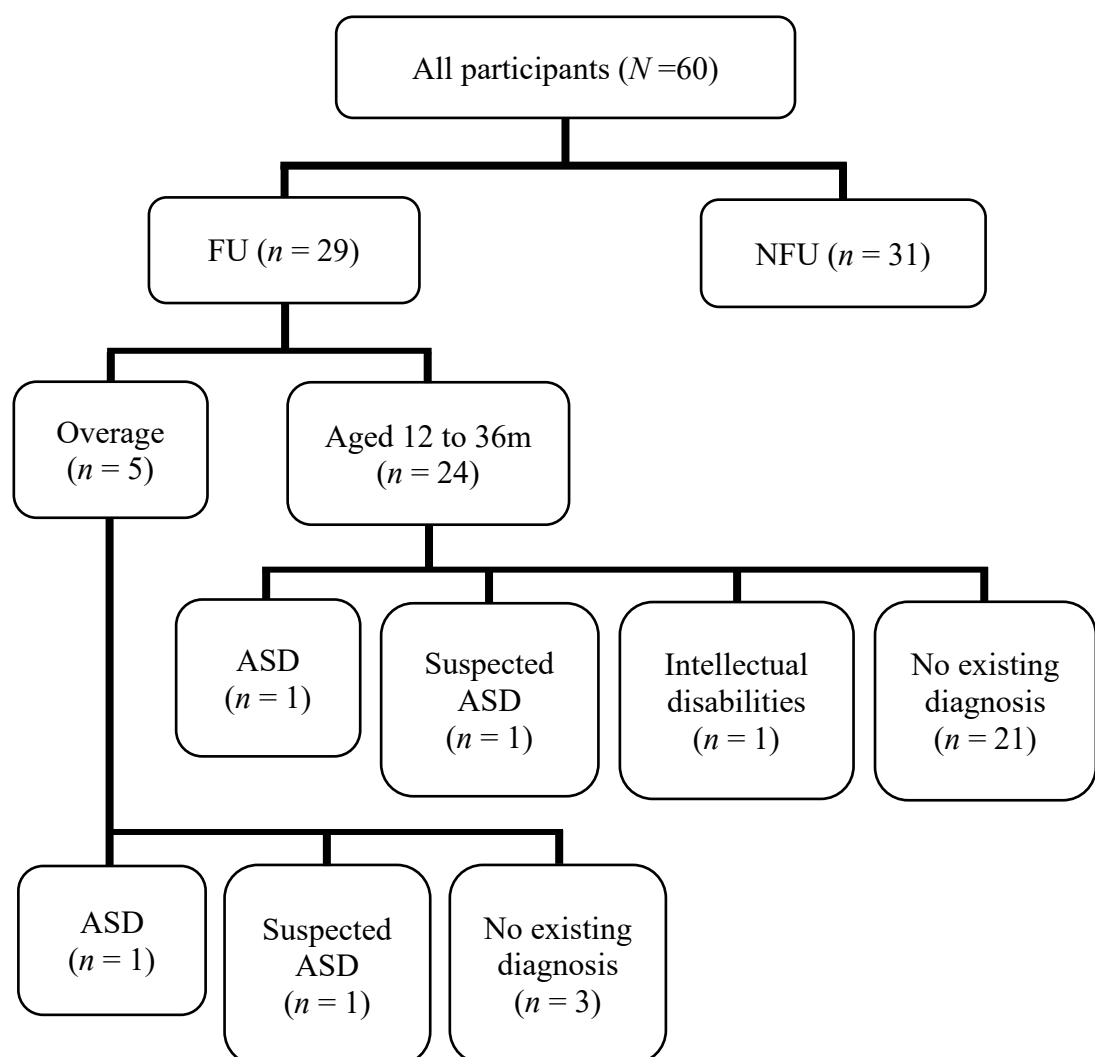
Note. ^aFU = Follow-up service users. ^bNFU = Non follow-up service users. ^cSuspected autism = Not formally diagnosed but notified of the high likelihood of developing autism.

Initial inclusion criterion for the study was child age needing to be between 12 to 36 months of age. However, five overage FU children (*M*_{age} = 39.40 months, *SD* = 2.30, range = 37—42, four male) were included to increase the number of FU participants because the number of FU children as young as 12 to 36 months was limited in the population who responded to the recruitment. Three of the FU children had been diagnosed with a neurodevelopmental disability prior to participation: two with ASD and

one with an intellectual disability. An additional two participants were not formally diagnosed with ASD due to their young age, but parents had been notified by a medical practitioner that their child was likely to be developing autism. They were categorised as “suspected autism” so that the doctor’s observation could be compared with their assessment results undertaken in this study. All children with a diagnosis or suspected autism were in the FU group which also comprised two of the five overage participants (see participant flowchart in Figure 5-1).

Figure 5-1

Participant Flowchart



Instruments

The Japanese Version of the Autism Detection in Early Childhood. The Autism Detection in Early Childhood-Japanese (ADEC-J) is a Japanese adaptation of the ADEC (Young, 2007), a 16-item interactive behaviour observation instrument designed to identify autism in children aged 12 to 36 months. Each item is scored on a three-point scale where 0 implies a developmentally appropriate response and 2 a developmentally inappropriate response. Score 1 is given when the child partially fulfills the requirements when prompted by the administrator, or spontaneously performs the desired behaviour or response at other times during the testing session. The total score thus ranges from 0 to a maximum of 32, with a score of 0 to 10 indicating a low likelihood of ASD, 11 to 13 a moderate likelihood, 14 to 19 a high likelihood, and 19 and above a very high likelihood. The factor structure of the ADEC is consistent with the latest diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5; American Psychiatric Association, 2013) (Nah et al., 2014), and the tool has been validated as an autism screener with a clinically referred sample (Hedley et al., 2015). Studies on the original ADEC have reported moderate to high internal consistency ($\alpha = .80—.91$; Hedley et al., 2015; Nah et al., 2014) and high inter-rater reliability (ICC = .95; Hedley et al., 2015). The sensitivity ranged .93—1.0 and specificity .62—.90, with strong correlation found with international “gold standards”, the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994) and the ADOS-2 (Hedley et al., 2015; Nah et al., 2014).

The Japanese Version of the Autism Diagnostic Observation Schedule-Second Edition. The Japanese version of the Autism Diagnostic Observation Schedule-Second Edition (Lord et al., 2015) is an adaptation of Autism Diagnostic Observation Schedule-Second (ADOS-2; Lord et al., 2012), a semi-structured standardized play-based

instrument regarded as a “gold standard” diagnostic tool for ASD. Of five modules that cover different age groups and developmental levels, the Toddler Module (for children aged 12 to 30 months), Module 1 (for children aged 31 months and above who do not use three-word sentences), and Module 2 (for children aged 31 months and above who use three-word sentences) were used in this study. Thirty-one participants were assessed with the Toddler Module (*All Younger/Older with Few to Four Words: n = 17, Older with Five or More Words: n = 14*), 27 with Module 1 (*Few to Four Words: n = 4, Five or More Words: n = 23*) and two with Module 2 (*Younger than Five Years*).

The ADOS-2 provides Social Affect (SA), Restricted and Repetitive Behaviours (RRB), and total scores. The symptom severity across different modules can be compared using Comparison Scores (CS; Esler et al., 2015; Gotham et al., 2009). Comparison Scores of 4 and 6 on the ADOS-2 correspond to clinical cut-offs of AD and ASD respectively on Module 1 and 2 (Gotham et al., 2009) and the same scores correspond to “Little-to-No Concern” and “Mild-to-Moderate Concern” ranges respectively on Toddler Module (Esler et al., 2015). Although there is no publication on the psychometric properties of the Japanese ADOS-2, the original ADOS-2 manual (Lord et al., 2012) reports good to excellent sensitivity (.77—.98) and moderate to excellent specificity (.50—.94) for the three modules.

New Kyoto Scale of Psychological Development. The New Kyoto Scale of Psychological Development (Kyoto Scale: Koyama et al., 2009) is a Japanese instrument that assesses the general development of children from birth to 14 years of age in three domains: (1) posture and movement, (2) cognitive and adaptive skills, and (3) language and social skills. The score of each subscale is converted to a developmental age (DA) and calculated to obtain a developmental quotient (DQ). Overall DA and DQ are also obtained from the results of subscales.

Social Maturity Scale Third Edition. The Social Maturity Scale Third Edition (S-M Scale-3; Ueno et al., 2016) is a Japanese adaptive behaviour assessment tool utilising parent report. The first edition of S-M Scale (Miki, 1959) was developed based on the Vineland Social Maturity Scales (Doll, 1953). In the third edition, the language and conversion tables were revised for currency. The S-M Scale-3 assesses a child's adaptive skills in six domains: (1) Self-help, (2) Locomotion, (3) Occupation, (4) Communication, (5) Socialization, and (6) Self-direction in infants to children aged 15 years. The subdomain scores are calculated to obtain an overall social quotient (SQ).

Procedures

Each recruited child and their parent were scheduled for a half-day assessment session. Assessments were undertaken in a small space partitioned within a larger room, with the child seated either on a chair at a table or on the floor, depending on the needs of assessment (Figure 5-2). The child's parent was present throughout the session, also seated on a chair or the floor to observe the assessments. The sessions were all video recorded for future reference. At intake, parents were asked to provide basic information including history of follow-up service use at their local Public Health Centre and presence of a diagnosis related to developmental disabilities. Engagement with follow-up service(s) was used as an index of high-risk and low-risk populations. Informed consent was obtained from caregivers of all participants included in the study.

Figure 5-2*An Example of the Testing Room Setting*

The child was first assessed with the Kyoto Scale while the parent answered the S-M Scale-3 questions, and subsequently with the ADEC-J and Japanese ADOS-2 during which the parent was present. The Japanese ADOS-2 was administered first instead of the Kyoto Scale when the child was upset or nervous because the Japanese ADOS-2 offered more play- and toy-based tasks that were fun and engaging to a young child. No participant was excluded from data analysis.

The ADEC-J was administered by the candidate, who completed ADEC training under supervision of an experienced ADEC assessor (certified Psychologist with PhD in Psychology) and achieved over 90% agreement in a pilot sample of 10 children (5 male, $Mage = 19.2$ months, $SD = 4.7$, range = 16—30 months) with another experienced ADEC assessor (also a certified Psychologist with PhD in Psychology). The Japanese ADOS-2 was administered by a certified Japanese Psychologist who had long years of clinical experience with young children in Japan and had completed training on the Japanese ADOS-2. Both assessors were blind to intake results and each other's assessment results.

The Kyoto Scale was administered by either the Japanese ADOS-2 assessor or one of two other certified Japanese Psychologists, each with extensive clinical experience with young children. The parent response on the S-M Scale-3 was reviewed and scored by the candidate after the assessment session.

Data Analysis Plan

Where appropriate to do so, and due to the relatively small sample size, bootstrapping using 1000 resamples was employed to provide more robust statistics. T-tests were conducted to compare performance between the FU and NFU groups on the assessment measures, and effect size and BCa 95% confidence intervals were examined to determine significance. To explore concurrent validity of the ADEC-J and ADOS-2, bivariate correlations between the ADEC total scores and ADOS-2 SA, RRB, total, and comparison scores, and partial correlations controlling for age were calculated. Finally, a descriptive analysis of the distribution of participants based on the ADEC-J and ADOS-2 results, use of follow-up service, and existing diagnoses, was conducted.

Results

Group Comparison

Group performance on autism specific measures, and the developmental and adaptive assessments, are provided in Table 5-2. Significant differences were found on all assessment results between the FU and NFU groups, including chronological age, where children in the FU group were significantly older than those in the NFU group. As apparent in Table 5-2, the ADEC-J total scores and Japanese ADOS-2 SA, RRB, total scores and CS were all significantly higher in the FU group compared to the NFU group. The Kyoto Scale overall and subscale DQs as well as S-M Scale-3 overall SQ were significantly lower in the FU group, indicating delays in development, language, social and adaptive skills respectively. The overall and subscale DQs and overall SQ of children

in the NFU group suggested age-appropriate development.

Concurrent Validity

Pearson's correlation and partial-correlation coefficients for the autism, developmental, and adaptive skill assessments are provided in Table 5-3. ADEC-J total scores were strongly correlated with ADOS-2 SA, total and comparison scores while correlation between ADEC-J and ADOS-2 RRB scores were moderate. Partial correlations were also examined with chronological age as a control variable, resulting in slightly stronger correlations between ADEC-J total scores and ADOS-2 total and comparison scores. Moderate to strong negative correlations were found between autism assessment results (the ADEC-J and ADOS-2) and the developmental and adaptive skill assessment results (Kyoto Scale and S-M Scale-3) whereby high scores on the autism measures negatively correlated with (low) scores on these developmental and adaptive skills. This is particularly noticeable for ADEC-J total and ADOS-2 total scores with the Kyoto Scale Language-Social and overall DQs.

Table 5-2*Means, standard deviations, and bootstrapped t-test results for FU and NFU groups*

	FU (<i>n</i> = 29)		NFU (<i>n</i> = 31)		t test				Cohen's <i>d</i> [95% CI]
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>	<i>P</i> ^a	BCa 95% CI ^b	
Chronological age	32.52	5.49	25.45	6.78	57.11	-4.42	.002	-10.09, -4.12	1.16 [-0.84, 3.55]
ADEC-J	10.76	5.53	4.00	2.99	42.42	-5.83	.001	-9.36, -4.40	1.56 [-0.45, 2.61]
ADOS-2 SA	8.52	3.56	2.45	1.59	38.15	-8.42	.001	-7.45, -4.69	2.27 [0.97, 2.83]
ADOS-2 RRB	1.62	1.27	.23	.425	33.87	-5.65	.001	-1.90, -0.88	1.51 [1.05, 1.66]
ADOS-2 total	10.14	4.10	2.63	1.72	37.07	-9.09	.001	-9.10, -5.82	2.46 [0.97, 3.06]
ADOS-2 CS	4.41	1.52	1.48	.626	36.67	-9.62	.001	-3.54, -2.32	2.60 [2.04, 2.82]
Kyoto Scale P-M	84.55	13.97	95.45	13.01	58	3.13	.003	4.17, 17.48	-0.82 [-5.91, 3.76]
Kyoto Scale C-A	75.21	16.59	97.42	12.24	58	5.93	.001	14.96, 30.00	-1.56 [-7.60, 2.75]
Kyoto Scale L-S	68.28	22.06	99.26	14.26	47.42	6.41	.001	21.88, 39.80	-1.71 [-9.74, 3.31]
Kyoto Scale Overall	74.52	15.21	97.74	11.29	58	6.74	.001	15.99, 30.43	-1.77 [-7.31, 2.20]
S-M Overall	70.66	21.09	93.74	17.43	58	4.63	.001	13.72, 33.06	-1.22 [-8.89, 4.92]

Note. ^a1000 samples bootstrapped *p*-value. ^dBCa 95% confidence intervals that do not cross zero are bolded. ADOS-2 SA: Social Affection; RRB: Restricted and Repetitive Behaviours; CS: Comparison Score. Kyoto Scale P-M: Posture-Movement; C-A: Cognitive-Adaptive; L-S: Language-Social.

Table 5-3

Pearson's bootstrapped correlations (top diagonal) between assessment results and partial correlations (bottom diagonal) controlling for age

	2	3	4	5	6	7	8	9	10	11
1. Chronological age	.173	.293*	.459**	.356**	.351**	-.145	-.388**	-.349**	-.393**	-.222
2. ADEC-J	—	.827**	.643**	.848**	.798**	-.476**	-.684**	-.767**	-.756**	-.646**
3. ADOS-2 SA	.825***	—	.592**	.981**	.951**	-.440**	-.592**	-.725**	-.672**	-.541**
4. ADOS-2 RRB	.644***	.538***	—	.736**	.684**	-.265*	-.568**	-.555**	-.590**	-.536**
5. ADOS-2 total	.855***	.982***	.690***	—	.963**	-.433**	-.633**	-.741**	-.705**	-.582**
6. ADOS-2 CS	.800***	.948***	.629***	.957***	—	-.410**	-.590**	-.702**	-.665**	-.543**
7. Kyoto Scale P-M	-.463***	-.420**	-.225	-.412**	-.388**	—	.630**	.639**	.700**	.603**
8. Kyoto Scale C-A	-.680***	-.542***	-.477***	-.574***	-.526***	.629***	—	.766**	.943**	.647**
9. Kyoto Scale L-S	-.766***	-.695***	-.474***	-.705***	-.661***	.635***	.730***	—	.916**	.699**
10. Kyoto Scale Overall	-.760***	-.633***	-.501***	-.658***	-.612***	.707***	.933***	.904***	—	.703**
11. S-M Overall	-.633***	-.510***	-.501***	-.552***	-.509***	.592***	.624***	.680***	.687***	—

Note. ADOS-2 SA: Social Affection; RRB: Restricted and Repetitive Behaviours; CS: Comparison Score. Kyoto Scale P-M: Posture-Movement; C-A: Cognitive-Adaptive; L-S: Language-Social. * $p < .05$; ** $p < .01$; *** $p < .001$.

Distribution of Participants

The distribution of participants based on the ADEC-J total scores, ADOS-2 classifications, use of the follow-up service and existing diagnosis are shown in Table 5-4. In the NFU group, all children except one fell into non-ASD category on the ADOS-2 and scored below cut-off in the ADEC-J. The one child who met the ADEC cut-off (i.e., a score of 11 or above) was one of the youngest participants (male, 15 months, score = 12). The results from the other measures suggested that this child had borderline developmental delay across all subscale DQs and overall DQ, and his adaptive skills were also delayed. Among the children who did not meet both the ADEC and ADOS-2 cut-offs, one participant showed developmental delay, and three showed borderline developmental delay in overall DQ on the Kyoto Scale.

In the FU group, a total of 22 participants (76%) scored above the ASD threshold on the ADOS-2, with 14 (48.4%) and eight participants (27.6%) classified as ASD and AD respectively. Among these children, 14 met the ADEC cutoff of 11, including one participant with an ASD diagnosis, two with suspected autism, and one with intellectual disabilities. In contrast, the remaining eight children scored below cutoff in the ADEC, with two scoring 10, one 9, two 8, two 7, and one 5. One child who scored 8 was an overage participant (male, 41 months) with an ASD diagnosis, and showed borderline delay in both overall development and adaptive skills, with Cognitive-Adaptive domain of the Kyoto Scale scoring below 70. The other child who scored 8 was also an overage child (male, 42 months), but with no known diagnosis. The child showed borderline delay in Language-Social domain and overall development. Of the non-overage six children, one (score = 10) showed developmental delay and two (scores = 7 and 5) showed borderline delay in all subcategories and overall DQ in Kyoto Scale. Two children (scores = 10 and 7) showed borderline developmental delay in some

subcategories, but not in overall development. The remaining child was relatively young (21 months, score = 9) and only showed borderline delay in Cognitive-Adaptive DQ.

Five of these six children were all classified as ASD rather than AD on the ADOS-2.

Seven children (24.1%) in the FU group were classified as Non-ASD on the ADOS-2 and did not meet the ADEC cut-off. Of these seven children, two showed developmental delay, two borderline developmental delay, and three had age-appropriate development on Kyoto Scale overall DQ. Adaptive skill levels mostly paralleled overall developmental levels, except for one child whose SQ showed delay in adaptive skills, but not in overall development.

Table 5-4

Distribution of participants based on the ADEC-J, ADOS-2, use of follow-up services, and diagnosis

		ADEC-J total score			
		11+		10 or less	
		FU [diagnosis]	NFU	FU [diagnosis]	NFU
ADOS-2 Classification	AD	7 [3 ^a]	0	1	0
	ASD	7 [1 ^b]	0	7 [1 ^c]	0
	Non-ASD	0	1	7	30

Note. ^aTwo with suspected autism and one with intellectual disabilities. ^bOne with ASD. ^cOne with ASD.

Discussion

The overall objective in this study was to validate the ADEC-J, and scores on this measure were found to be strongly correlated with those from the ADOS-2. This finding is consistent with those from previous validation studies on the original ADEC (Hedley et al., 2015; Nah et al., 2014) and the Indonesian adaptation (Sidjaja, 2015). Of participants with existing ASD diagnosis ($n = 2$) or strong concerns of autism ($n = 2$), three met cut-offs on both instruments, and one only on the ADOS-2. This latter case may have been due to his older age (41 months) given that the ADEC was designed for children aged 12- to 36 months to operationalise core autism behaviours that may ameliorate with age (Young et al., 2003; Young, 2007). The association between older age and a lower ADEC score despite an ASD diagnosis was also reported in a validation study of the Spanish ADEC (Hedley et al., 2010). Another overage child (42 months) without an existing diagnosis also met cut-off on the ADOS-2, but not on the ADEC. One child with intellectual disability in the FU group met cut-off on both instruments; however, it remains unknown whether he was misclassified by the autism assessment or whether his autism traits were overlooked at the time of his diagnosis or, indeed, whether the doctor intentionally avoided mentioning autism to his parents given his young age.

The use of follow-up services was confirmed to serve as an index of high developmental risk, as expected in the present study. When compared with children in the NFU group, those in the FU group demonstrated significantly higher scores on the autism measures and significantly lower scores on the developmental and adaptive skill assessments. The negative correlations found between autism related scores and scores on the developmental and adaptive skill assessments are consistent with this finding. All but one child in the NFU group did not meet cut-off either on either the ADEC-J or ADOS-2 while half of the FU group met both cut-offs. One NFU child who scored above

the ADEC-J cut-off was very young (15 months) and showed borderline developmental delay. The reason of the high ADEC score may be performance failure during the session due to his young age and/or lower DQ.

As expected, there were some participants in the FU group who scored below cut-off on both the ADEC-J and ADOS-2, with some of these participants being developmentally delayed. As already noted, the follow-up service is available to children with various developmental concerns, and is not exclusive to those with a suspected autism; it is also available to children without development concerns whose parents are directed to the service for different reasons, such as concerns about their attachment relationship (Gokami, 2007; Kono & Ito, 2011). Our data confirmed the mixed nature of follow-up service users (Yamazaki et al., 2016). Similarly, there were some participants in the NFU group whose DQs suggested borderline or marked developmental delay. This was not entirely unexpected since there might have been children (1) who were identified with developmental concerns by their local Public Health Centre but whose families refused to use the follow-up service or (2) whose developmental concerns were not properly screened for at the centre.

Several study limitations need to be addressed. First, the sample size was relatively small. This is partially because the current study was conducted independently from any ongoing project or established research network in Japan. Consequently, the study was designed to be feasible with available resources and a limited time frame, resulting in a smaller group of participants than desired. Should the sample size be larger, for instance, further analyses of those who only met the ADOS-2 cut-off and not the ADEC-J cut-off would have been made possible. Due to this limitation, the observations offered in the current study are preliminary, and future research with a larger sample is necessary to draw statistically stronger conclusions regarding the screening capacity and

characteristics of the ADEC-J.

Second, the lack of access to detailed data of the participants hindered more in-depth analyses of the characteristic of the children. For instance, data such as the age when the child first screened positive at a check-up, screening items and results, the time of participation to a follow-up service and/or successful referral to a medical institution would have enriched the analyses. Collaboration with local governments and their Public Health Centre is essential to achieve this in future studies. Another limitation was that comprehensive medical diagnoses were not available to study participants. As a result, it was not possible to ascertain the psychometric properties of the ADEC-J, especially sensitivity and specificity, nor was it possible to ascertain the optimal cut-off of the ADEC-J in a Japanese sample. Although the original cut-off of 11 was reported as sound based on best estimate clinical diagnoses using the latest DSM-5 criteria (Hedley et al., 2015), the result needs to be replicated with a Japanese sample.

The unavailability of diagnoses for the participants was because cooperation from a child psychiatrist experienced in early diagnosis of ASD was not obtained for the study and otherwise a diagnosis of ASD in the participants' age group was rare in the country as has been discussed in Chapter 2 and 3. To overcome this challenge in Japanese autism research, introducing the notion of the best estimate clinical (BEC) diagnosis may be beneficial. A BEC diagnosis can be formed by a single or a group of health and/or allied-health professional(s) experienced in examining young children with autism, using all assessment results, developmental history, expert opinions, and other relevant information available for the examined child (e.g., Nah et al., 2014). This contrasts with the diagnosis in Japan, which is only attainable from a medical practitioner. Consequently, when diagnosis is discussed in Japanese studies involving children with ASD, it refers to a medical diagnosis and usually requires involvement of an experienced

paediatric psychiatrist or a paediatrician well versed in early signs of autism. The concept of BEC diagnosis may facilitate autism research and practice in Japan, particularly those targeting very young children.

Despite the noted limitations, the current study findings confirmed the observations made in Chapter 3 regarding early identification of autism within the Japanese local Public Health Centres. Most children using a follow-up service within their local maternal and child health service were, unsurprisingly, found to have developmental concerns, including autism and developmental delays, while only very few non-follow-up users showed such concerns. This suggests that the Level 1 developmental screenings undertaken at 18-months is effective in identifying children in need of follow-up. At the same time, the mixed nature of the follow-up users was also confirmed, emphasizing the importance of utilising Level 2 autism screening to prioritise those at a high likelihood of autism and in need of targeted behavioural intervention.

Although a comprehensive medical diagnosis was unavailable, our data suggest that the ADEC-J may have good screening capacity given its comparable performance to that of a “gold standard” diagnostic instrument, the ADOS-2. Given its brief administration time, and low cost in terms of training and scoring, the ADEC-J is a promising Level 2 autism screener to introduce into the existing follow-up services at Public Health Centres in order to identify those children developing autism. Future studies are desired to investigate the psychometric properties of the ADEC-J, as well as the feasibility and validity of the implementation of the ADEC-J at Public Health Centres.

Chapter 6

General Discussion

The objective in undertaking the studies reported in this thesis was to promote earlier identification of autism within Public Health Centres in Japan. A key criterion was that the approach would be appropriate and feasible within the existing practices at these centres.

Following a comprehensive review of autism screening instruments utilised in Japan, a survey study was undertaken to examine screening practices at the statutory 18-month check-up and subsequent follow-up services within Public Health Centres. Based on the review and the findings from this first study, a Level 2 autism screener, Autism Detection in Early Childhood (ADEC; Young, 2007), was chosen as a possible tool for use at the follow-up services at Public Health Centres to fill a gap identified by the literature review and survey.

A core component of the research presented in the thesis was the translation and pilot testing of the ADEC and the validation of this new Japanese adaptation of the ADEC (ADEC-J). The validation study examined the screening capacity of the ADEC-J with young Japanese children compared to the Japanese adaptation of the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2-JV; Lord et al., 2015), an international gold standard diagnostic instrument. The following sections summarise the key research findings and the clinical implications from these for improved autism screening and follow-up practices at Public Health Centres in Japan.

Early Autism Screening and Support Pathways in Japan

Despite significant heterogeneity in outcomes, it has been established that children with autism make greater gains from early intervention when they start at

younger ages (Dawson et al., 2012; Vivanti et al., 2016). In particular, onset of intervention at around 24 months of age predicted better cognitive and language abilities as well as lower levels of restricted and repetitive behaviours at school age (Clark et al., 2017) and better cognitive abilities in young adulthood (Anderson et al., 2014), compared to later onset of intervention. Hence, identification and subsequent access to intervention by 24 months of age is highly recommended to improve the likelihood of better developmental outcomes for children with autism. The current screening framework utilised in Japan, as identified in the present research, was not fully successful in achieving this goal.

The data presented in Chapter 2 and Chapter 3 indicated that the intention of the Public Health Centres is to identify a broader range of developmental irregularities (i.e., not specifically autism) at the 18-month check-up. This results in a high portion of children identified with unspecified developmental concerns who require follow-up services. The identified children might be autistic and developmentally delayed, autistic with mild- or low-level developmental delays, or non-autistic but with developmental delays or concerns due to a multitude of reasons. A general hesitancy on the side of professionals and parents to refer to and access a medical diagnosis was identified, in addition to the paucity of such services, particularly in smaller prefectures.

The lack of diagnostic specification leads to delivery of general intervention practices for all identified children within the follow-up services in Public Health Centres, despite considerable evidence that *early*, *intensive* and *targeted* intervention is required to alter the developmental trajectories of children with autism. This is due partly to the high level of heterogeneity in autism which necessitate individualised intervention approaches that specifically identify developmental skills needing attention, and that target these skills. Such intervention requires the accurate detection of autism, which is

not currently achieved within the Japanese system.

The results from the survey study indicated that a formal diagnosis of developmental disorder including autism, or even a visit to a medical institution for a diagnostic assessment, was rare among children in the follow-up group who were mostly aged below three years. The strength of the Japanese system was that various supports, including low-intensity intervention, was readily provided both to the children and their parents, with access not necessitating a diagnosis. However, to achieve reliable identification of autism prior to age 3 years and deliver more targeted early intervention and other supports, more refined, secondary screening of autism (and other conditions) is needed within Public Health Centres.

Japanese Adaptation of the ADEC

The adaptation procedures and initial validation of the Japanese version of the ADEC and ADEC-J, respectively were successful, fulfilling the needs of rigorous cultural adaptation and validation. The Japanese translation of administration and scoring instructions in the ADEC manual did not require much alternation for cultural adaptation. This may partially be attributed to the ADEC mostly focusing on pre-verbal behaviours (Young, 2007) such that linguistic differences only have minimal influence on the assessment process. Further, assessments are made strictly based on the behaviours observed during administration of the ADEC, in contrast to the parental report format needed in the Japanese adaptation of the Modified Checklist for Autism in Toddlers (M-CHAT-JV; Kamio & Inada, 2006); this latter tool has been subject to concerns due to the cultural characteristic among Japanese parents who tend to avoid giving clear or direct answers to questions (Kamio et al., 2014).

The finding of strong and significant associations between the ADEC and the more comprehensive diagnostic instrument, ADOS-2, identified in the validation study

undertaken here is consistent with a previous validation study of the original ADEC (Hedley et al., 2015). In validating the ADEC-J, of the four participants with an existing diagnosis of ASD, three scored above the ADEC cut-off and one scored below, with this child being older than the recommended age range for the ADEC (i.e., > 36 months); the ADEC specifically targets behavioural signs of autism that are evident in very young children and which may ameliorate with age. The association between older age and a lower ADEC score despite an ASD diagnosis was also reported in the validation study of the Spanish ADEC (Hedley et al., 2010). Thus, the preliminary validation data reported here are supportive of the screening capacities of the ADEC-J with very young Japanese children suspected of autism (or developmental disabilities).

Recommendations for Autism Screening Practices at Public Health Centres in

Japan

Based on the current findings reported in this thesis, the following recommendations are suggested for improved screening practices for autism within Japanese Public Health Centres (see Figure 6-1 for a visual supplement):

- (1) *Conceptualising autism screening within Public Health Centres as a two-stage practice in the absence of immediate diagnostic assessment.* When immediate access to a formal medical diagnosis is unattainable, better outcomes may be achieved by implementing a Level 2 screening (i.e., for the high-risk population), following the existing Level 1 autism or general developmental screening (i.e., for general population) undertaken at the 18-month check-up. This Level 2 autism-specific screening can increase reliability in the identification of autism as in the Extraction and Refinement Strategy undertaken in Yokohama, Japan (Honda et al., 2009).
- (2) *Reviewing of screening instruments.* The selection of instrument may be an

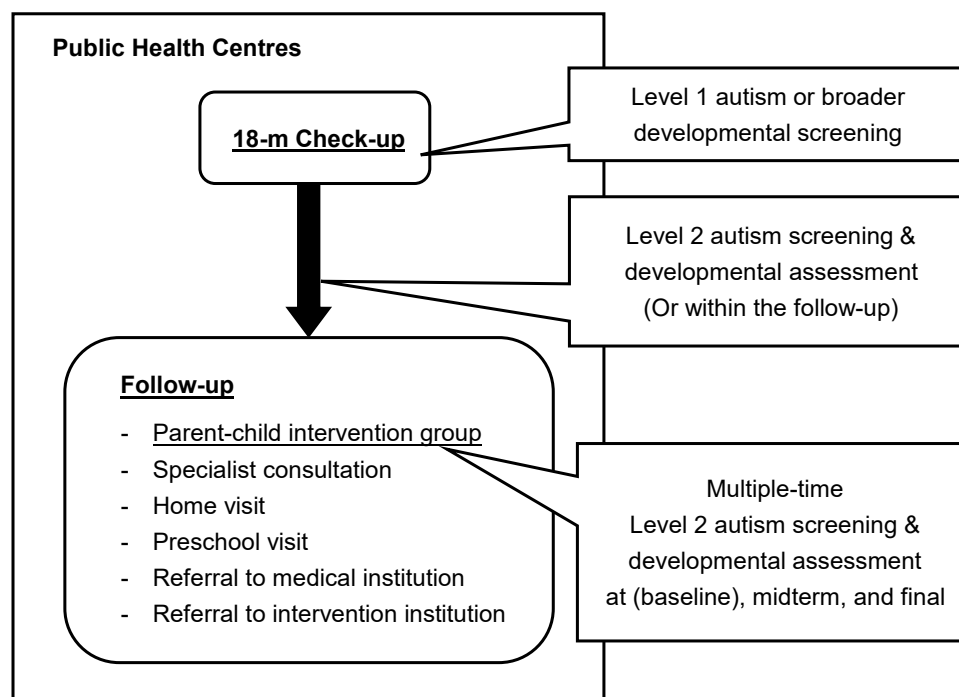
important enabler to improved screening outcomes given widely varied financial, temporal, and human resources for Level 1 and 2 screenings within Public Health Centres.

- (3) *Pairing Level 2 autism screening with a developmental assessment.* The followed-up population identified through Level 1 screening comprise children with various and broad-ranging developmental concerns. To confirm or rule out the presence of autism and/or other developmental issues, implementation of a robust developmental assessment along with Level 2 autism screening may be beneficial. It will enable improved characterisation of children's strengths and needs.
- (4) *Basing the decision-making regarding follow-up strategies on assessment and screening results.* A potential setting for the developmental assessment and Level 2 autism screening is the follow-up service (e.g., immediately after Level 1 screening at the 18-month check-up). Indeed, it will be more beneficial if the follow-up assessment and screening are provided immediately to every child who screens positive or has any developmental concerns identified at the 18-month check-up because these results can inform decision making regarding access to the follow-up services. Such an approach would enable determination of who is in higher need referral for a diagnosis and/or more intensive intervention, who should be recommended for the parent-child intervention group, and what support and advice may be needed for which parent. Furthermore, if every identified child is assessed immediately after the 18-month check-up, the baseline assessment for parent-child intervention group suggested below may not be needed.
- (5) *Introducing multiple assessments into parent-child intervention groups.*

Multiple times of assessment (i.e., developmental assessment and Level 2 autism screening) of participants during a programme period may bring several advantages to parent-child intervention groups: (a) better characterisation of each child's developmental profile will inform the development and delivery of the intervention programme in a more targeted way which is suited to the needs of children within the programme; (b) multiple-time assessments enables tracking of changes in participants and sharing of the outcomes with their parents; and (c) the developmental gains will inform the decision making of which child should leave the programme, so that new participants may join, given the limited resources within these programmes. The first (baseline) assessment should be conducted either prior to or at the time of entry into the programme, followed by a second assessment mid-way through the programme (e.g., after three- or six-months) and the third and final assessment at programme end.

Figure 6-1

Recommendations for improved screening practices at Public Health Centres in Japan



Future Directions

It is important to remember that Level 2 screening at Public Health Centres is particularly important within the Japanese context as an immediate medical diagnosis may not be available for the majority of children identified with developmental concerns at the 18-month check-up, particularly in low-resource communities. Improving screening practice should coincide with the effort to promote early diagnosis. As part of the effort, future research should examine how the follow-up service at Public Health Centres can better address parental hesitance in accessing medical institutions for a diagnosis. Research has reported that parental psychological readiness to be notified of a diagnosis (Iwasa et al., 2014) and younger age of the child (Fujiwara et al., 2011) were two of the factors associated with a later diagnosis of autism in Japan. Such findings suggest that

providing appropriate support to parents may facilitate earlier diagnoses, and Public Health Centres are the primary source of such support following the detection of developmental risk. Similarly, although lack of knowledge on appropriate medical institutions amongst parents was another factor associated with later diagnosis (Fujiwara et al., 2011). Such issues may be circumvented if Public Health Centres successfully build a positive and supportive relationship with their clients. Importantly, however, the findings from the current thesis also indicated some parental hesitancy in participating in the offered follow-up service (e.g., parental consultation and parent-child group intervention). Public Health Centres appear to be facing a challenge in obtaining parent understanding and consent for their child to be referred and assessed for developmental concerns. Research on the role of Public Health Centres as a bridge between parents of high-risk children and an early diagnosis, which focuses on parental “psychological” barriers to obtaining diagnosis and support for their young child, will inform the discussion on the promotion of early diagnosis of ASD in Japan.

While the findings presented in this thesis are promising, they are also preliminary due to a number of limitations within the reported studies. Adoption of the ADEC-J requires further research to examine its psychometric properties and derive an accurate cut-off for Japanese children. Although the original cut-off score was used here, which has been found to be appropriate across diverse populations and cultures, verification of this score with the Japanese translation is required for it to be useful clinically. Further, the feasibility and effectiveness of the use of the ADEC-J within Public Health Centres should be tested to realistically adopt its wider introduction into these centres. A clinical study of the ADEC-J at a larger number of Public Health Centres than possible here is strongly recommended, with strict adherence to the ADEC target age-range and use of a BEC diagnosis.

Conclusions

The findings reported in this thesis demonstrate the necessity of Level 2 autism screening within lower resourced Public Health Centres in Japan and indicate the promise of the ADEC-J as an appropriate Level 2 autism screening instrument for use at these centres. The statutory 18-month health check-up and subsequent follow-up operations at Public Health Centres can play a significant role in early identification of developmental conditions including autism and provision of support for these children and their caregivers, when referral for a formal diagnosis and specialised intensive intervention are not immediately attainable. To promote successful identification of autism prior to two years of age even with limited resources, it will be beneficial to conceptualise screening at Public Health Centres as a two-stage process where Level 2 screening follows Level 1 screening or general developmental assessment at the 18-month check-up. Furthermore, the use of an autism-specific screening instrument at this latter stage will achieve better screening outcomes.

Although an ideal intervention for young children with autism needs to be intensive and targeted, providing an ideal form of intervention to every high-risk child may not be realistic in lower resourced municipalities in Japan. In such cases, the parent-child intervention group at Public Health Centres, though low in intensity, still provides a valuable opportunity for early intervention that can be provided in a timely manner to children with developmental concerns prior to a confirmed diagnosis. It is for this reason that it is recommended that the Level 2 autism screening using the ADEC-J be paired with developmental assessments undertaken at multiple timepoints so that assessment results can inform the decision making of follow-up strategies and improve the quality of intervention programmes. The importance of quality improvement at follow-up services is further highlighted as it provides support to parents as well, which can facilitate

parental acceptance of their child's disability, an important necessity for enabling a visit to a medical institution for a potential diagnosis.

One of the primary goals in undertaking the research reported in this thesis was to develop and validate a Japanese version of the ADEC (Young, 2007). The ADEC is characterised by its brevity, accessibility, and low threshold for reliable administration. The Japanese adaptation of the ADEC-J and preliminary validation study demonstrated its potential for use with young Japanese children. Specifically, the translated instrument displayed strong correlations with the Japanese ADOS-2. The ADEC-J therefore shows potential to address the paucity of a reliable and feasible Level 2 autism screening instrument in Japan, particularly within the follow-up services at Public Health Centres. A large-sample clinical validation study of the ADEC-J is now needed before recommending the ADEC-J for future clinical use.

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Appendices

Appendix A

A-1 Survey Form (English Translation)

Early detection and intervention for ASD from the 18-month check-up: Survey on the use of assessment instruments

A Respondent information (If different staff answers Section D, please also fill in the right column).

	Nurse in charge		Section D respondent	
A-1 Gender	1) Male	2) Female	1) Male	2) Female
A-2 Experience in	1) Over 20yrs	2) 15-20yrs	1) Over 20yrs	2) 15-20yrs
maternal and	3) 10-15yrs	4) 5-10yrs	3) 10-15yrs	4) 5-10yrs
child health	5) 1-5yrs	6) Less than 1yr	5) 1-5yrs	6) Less than 1yr

B Local government information

B-1 What is the population of your local government in the fiscal year of 2018?

- | | |
|--------------------------------|---------------------------------|
| 1) More than 500,000 | 2) 200,000 to less than 500,000 |
| 3) 50,000 to less than 200,000 | 4) 10,000 to less than 50,000 |
| 5) Less than 10,000 | |

B-2 What is the number of births in the fiscal year of 2018?

- | | | |
|-------------------------|-----------------------------|---------------------------|
| 1) More than 5,000 | 2) 1,000 to less than 5,000 | 3) 500 to less than 1,000 |
| 4) 100 to less than 500 | 5) Less than 100 | |

C Use of ASD screening instruments at 18-month check-up

C-1 Does your 18-month check-up take place in mass screening style at your centre?

- 1) Yes 2) No (Please specify: _____)

C-2 If you answer "Yes" in C-1, please go on to the questions below. If you answer No, please go on to Section C.

Please circle all ASD screening methods at your 18-month check-up.

- | | |
|--|-------------------------|
| 1) M-CHAT | 2) Gazefinder |
| 3) Other screening tool (name: _____) | |
| 4) Parent report or behaviour observation items developed at your centre | |
| 5) Other (_____) | 6) No screening for ASD |

C-3 If you choose M-CHAT in C-2, select how you administer M-CHAT.

1. No. of items

1) All 23 items	2) 10 key items
3) Selected items (how many: _____)	4) Other (_____)
2. Illustration

1) Use illustrations	2) Do not use illustrations
----------------------	-----------------------------

3. Administration
 - 1) Parent report
 - 2) Interview based on parent report
 - 3) Interview
 - 4) Other ()
4. Cut-off score
 - 1) Fail 3 items out of 23
 - 2) Fail 1 item out of 10 key items
 - 3) When either 1 or 2
 - 4) Other ()
5. Follow-up telephone interview (FUI)
 - 1) Conduct FUI
 - 2) Conduct FUI in person
 - 3) Do not conduct FUI
 - 4) Did not know about FUI

※The FUI is part of the original M-CHAT protocol after the parent questionnaire.

M-CHAT FUI manual: <https://www.ncnp.go.jp/nimh/jidou/aboutus/aboutus.html>

D Follow-up of 18-month check-up and its challenges

- D-1 What is the percentage of children followed-up due to developmental concerns at an 18-month check-up?
- 1) More than 15% (%)
 - 2) 10 to less than 15%
 - 3) 5 to less than 10%
 - 4) Less than 5%
- D-2 What follow-up methods do you provide to children in D-1? (Please elect all that is applied)
- 1) Wait till next check-up (held in _____ months)
 - 2) Home visit
 - 3) Phone interview
 - 4) Group intervention
 - 5) Individual consultation
 - 6) Preschool visit/consultation
 - 7) Referral to intervention programmes
 - 8) Referral to diagnostic institutions
 - 9) Other ()
 - 10) No follow-up
- D-3 If you choose “4) Group intervention” in D-2, what is the operating body of the programme?
- 1) Public Health Centre
 - 2) Other organization (please specify:)
- D-4 If you choose “1) Public Health Centre” in D-3, please answer the following questions.
1. Choose top three priorities as objectives of the group intervention.
 - 1) Comprehension of children’s developmental characteristics
 - 2) Developmental support for children
 - 3) Parenting support and consultation for parents
 - 4) Aid for parents to understand and accept their child’s developmental characteristics
 - 5) Aid for parents to get ready to visit diagnostic institutions
 - 6) Provision of play space and opportunities
 - 7) Other ()

Priority order First () Second () Third ()

2. Choose occupations of staff members (including part-timers) in the fiscal year of 2018

1) Public health nurse	2) Preschool teacher
3) Psychologist	4) Occupational therapist (OT)
5) Physical therapist (PT)	6) Speech therapist (ST)
7) Other ()	
3. Choose top three priorities as challenges of group intervention.
 - 1) Difficulty in obtaining understanding of child's participation from parents
 - 2) Problems with convenience (e.g., site is too far, no transportation)
 - 3) The number of available spots is too small for the follow-up population
 - 4) Difficulty in developing programme (as needs and challenges vary)
 - 5) Unable to increase the programme frequency (e.g., monthly to fortnight)
 - 6) Difficulty in comprehending each child's developmental characteristics
 - 7) Difficulty in assessing changes in children (outcomes of the programme)
 - 8) Difficulty in deciding when children finish and leave the programme
 - 9) Difficulty in increasing staff (Please circle occupations that apply)

(1. Public health nurse	2. Preschool teacher	3. Psychologist
4. OT	5. PT	6. ST
7. Other:)		
 - 10) Other ()

Priority order First () Second () Third ()

D-5 If you choose "5) Individual consultation in D-2, what is the operating body of the programme?

- 2) Public Health Centre 2) Other organization (please specify:)

D-6 If you choose "1) Public Health Centre" in D-5, please answer the following questions.

1. Choose top three priorities as objectives of the individual consultation.
 - 1) Comprehension of children's developmental characteristics
 - 2) Developmental support for children
 - 3) Parenting consultation for parents
 - 4) Facing individual challenges and difficulties of parents (regardless of their awareness)
 - 5) Aid for parents to understand and accept child's developmental traits
 - 6) Aid for parents to get ready to visit diagnostic institutions
 - 7) Other ()

Priority order First () Second () Third ()

4. Choose occupations of staff members (including part-timers) in the fiscal year of 2018

1) Public health nurse	2) Preschool teacher
------------------------	----------------------

- 3) Psychologist
 5) Physical therapist (PT)
 7) Other ()
- 4) Occupational therapist (OT)
 6) Speech therapist (ST)
2. Choose top three priorities as challenges of group intervention
- 1) Difficulty in obtaining understanding of child's participation from parents
 2) Problems with convenience (e.g., site is too far, no transportation)
 3) Difficulty in providing timely consultation because of limited availability
 4) Difficulty in objectively assessing children's traits (Circle the specific reason(s).)
1. No tool available
 2. Not time for tool use
 3. Lack of skills in counsellors
 4. Different assessment methods among counsellors
 5. Other :)
- 5) Difficulty in increasing the number of staff (Please circle occupations that apply)
- (1. Public health nurse 2. Preschool teacher 3. Psychologist
 4. OT 5. PT 6. ST 7. Other:)
- 6) Difficulty in connecting the parent to diagnostic institutions
 7) Other ()
- Priority order First () Second () Third ()

D-7 Please provide approximate percentages of children described below for both group intervention and consultation in the fiscal year of 2018. (Circle unknown when data is not available.)

	Intv. group	Consultation
1) Those who already had a diagnosis of developmental disorders at the time when they joined the programme	%	%
2) Those who received a diagnosis of developmental disorders by the end of the fiscal year, or those who are seeing a doctor for a suspect developmental disorder	%	%
3) Those who are not fell under 1 or 2	%	%
4) All unknown (No data available)	Unknown	Unknown

D-8 If you choose "referral to diagnostic institutions" in C-2, please select top three priorities as challenges regarding referral.

1) Difficulty in convincing parents 2) Lack of diagnostic institutions
 3) Long waiting lists (Takes time till appointment) 4) Takes time until diagnosis

5) Diagnosis is not reliable 6) Other ()

Priority order First () Second () Third ()

D-9 Please choose all assessment tools used in services selected in C-2, and answer specific services (e.g., group intervention, consultation) and profession of the assessor(s) (e.g., nurse, psychologist) for each tool.

If no tool is used in any services, please circle 0) in the bottom row.

	Tool	Used in	Used by
Developmental	1) Enjoji Developmental Scale		
	2) Tanaka-Binet Intelligence Test V		
	3) WPPSI-II		
	4) New Kyoto Developmental Scale		
	5) Other ()		
Adaptive	1) Vineland-II		
	2) Social Maturity Scale Third Edition		
	3) Other ()		
Sensory	1) Infant/Toddler Sensory Profile		
	2) Sensory Profile		
	3) Other ()		
ASD Screening	1) PARS		
	2) SRS-2 (SRS-P)		
	3) CARS (CARS-TV)		
	4) ADI-R		
	5) ADOS-2		
	6) Other ()		
	0) No use of assessment tools in any services		

D-10 If you choose “0) No use of assessment tools in any services”, please select all reasons that are applied.

- | | |
|---|-------------------------------------|
| 1) No need for assessment | 2) Assessments are outsourced |
| 3) No budget for assessment tools | 4) Difficulty in securing assessors |
| 5) Difficulty in securing assessment time | |
| 6) Difficulty in obtaining parental consent | |
| 7) Other () | |

This is the end of the survey. Thank you for your cooperation.

A-2 Survey Form (Japanese)

**一歳半健康診査からの自閉スペクトラム症の早期発見・早期支援
ースクリーニングツール使用実態に関するアンケートー**

A 回答者の方の情報をお聞きします。D パートの回答者が異なる場合は右欄にご記入ください。

	母子保健統括保健師		D パート（健診事後事業関連）回答者	
A-1 性別	1) 男性	2) 女性	1) 男性	2) 女性
A-2 母子保健分野での経験年数	1) 20 年以上 3) 10～15 年未満 5) 1～5 年未満	2) 15～20 年未満 4) 5～10 年未満 6) 1 年未満	1) 20 年以上 3) 10～15 年未満 5) 1～5 年未満	2) 15～20 年未満 4) 5～10 年未満 6) 1 年未満

B 自治体の基本情報についてお聞きします。

B-1 平成 30 年度の人口は何人ですか。あてはまるもの 1 つに○をつけてください。

- 1) 50 万人以上 2) 20 万～50 万人未満 3) 5 万～20 万人未満
4) 1 万～5 万人未満 5) 1 万人未満

B-2 平成 30 年度の出生数を教えてください。

- 1) 5000 人以上 2) 1000～5000 人未満 3) 500～1000 人未満
4) 100～500 人未満 5) 100 人未満

C 一歳半健診での ASD スクリーニングツールの使用状況についてお聞きします。

C-1 一歳半健診は、市町村の保健センター等での集団健診ですか？

- 1) はい 2) いいえ（具体的に： ）

C-2 C-1 で「はい」と答えた方は以下の設問へ、「いいえ」と答えた方は D へお進みください。

一歳半健診での ASD スクリーニングの方法を全て選んでください。

- 1) M-CHAT 2) Gazefinder
3) その他スクリーニングツール（名称： ）
4) 貴機関で独自に作成した質問紙や行動観察項目
5) その他（ ） 6) ASD スクリーニングを行っていない

C-3 C-2 で「1) M-CHAT」を選んだ場合、実施方法として該当するものを全て選んでください。

- 使用項目数
 - 全 23 項目
 - 重要 10 項目
 - 独自に選んだ項目（数： ）
 - その他（ ）
- イラスト
 - イラストを使用している
 - イラストは使用していない
- 使い方
 - 保護者が回答した質問紙を預かる
 - 保護者の回答を見て問診も行う
 - すべて問診での聴き取り
 - その他（ ）
- フォローアップ基準の設定
 - 3/23 項目不通過
 - 1/10 重要項目不通過
 - 3/23 項目または 1/10 重要項目不通過
 - その他（ ）
- フォローアップ電話面接
 - 電話面接を実施している
 - 直接面接を実施している
 - 実施していない
 - 電話面接が必要と知らなかった

※本来 M-CHAT では、質問紙のフォローアップとして電話面接を行います。

（M-CHAT 電話面接マニュアル：<https://www.ncnp.go.jp/nimh/jidou/aboutus/aboutus.html>）

D 一歳半健診のフォローアップ率とフォローアップ方法、その課題についてお聞きします。

D-1 一回の健診における、発達に課題があると思われるフォローアップ対象児の割合を教えてください。

- 1) 15%以上 (%) 2) 10～15%未満 3) 5～10%未満 4) 5%未満

D-2 D-1のフォローアップ対象児に行っている支援をすべて選んでください。

- 1) 次の健診 (か月後) で確認する 2) 家庭訪問 3) 電話相談
4) 事後教室 (遊びの教室、親子教室など) 5) 個別相談 (発達相談、心理相談など)
6) 園巡回 (コンサルテーションも含む) 7) 療育機関への紹介
8) 診断機関への紹介 (医療機関、児童相談所、発達支援センターなど)
9) その他 () 10) 特になにもしない

D-3 D-2で「4) 事後教室」を選んだ場合、事後教室の実施主体を教えてください。

- 1) 保健センターが実施 2) 他機関に委託 (機関名:)

D-4 D-3で「1) 保健センターが実施」を選んだ場合、以下の質問にお答えください。

1. 事後教室の目的として優先順位の高いものを3つ選び、番号を記入してください。
 - 1) 子どもの発達特性の把握
 - 2) 子どもへの発達支援
 - 3) 保護者への子育て支援・相談
 - 4) 保護者が子どもの現状 (課題や特性) を理解し受容する手助け
 - 5) 保護者が診断機関の受診を受け入れるための支援
 - 6) 遊び場の提供
 - 7) その他 ()

優先順位 1 番 () 2 番 () 3 番 ()
2. 平成 30 年度の事後教室の従事者の職種 (雇い上げも含) として当てはまるものを全て選んでください。

1) 保健師 2) 保育士 3) 心理士 4) 作業療法士 (OT)
5) 理学療法士 (PT) 6) 言語聴覚士 (ST) 6) その他 ()
3. 事後教室の課題として優先順位の高いものを3つ選び、番号を記入してください。
 - 1) 参加について保護者の理解が得られない
 - 2) 会場が遠い、交通手段がないなど、利便性に問題がある
 - 3) 枠に対して対象者が多過ぎる
 - 4) プログラム作りが難しい (さまざまな課題を抱えた子どもたちがいるため)
 - 5) 教室開催の頻度を増やせない (月一回を隔週にする等)
 - 6) 子ども一人ひとりの発達特性を把握するのが難しい
 - 7) 子どもの伸び (教室参加の効果) の評価が難しい
 - 8) 子どもの卒業 (参加終了) ラインを決めるのが難しい
 - 9) 従事者を増やせない (該当する職種に○をつけてください。)
(1. 保健師 2. 保育士 3. 心理士 4. OT 5. PT 6. ST 7. その他:)
 - 10) その他 ()

優先順位 1 番 () 2 番 () 3 番 ()

D-5 D-2で「5) 個別相談」を選んだ場合、個別相談の実施主体を教えてください。

- 1) 保健センターが実施 2) 他機関に委託 (機関名:)

D-6 D-5 で「1) 保健センターが実施」を選んだ場合、以下の質問にお答えください。

3. 個別相談の目的として優先順位の高いものを3つ選び、番号を記入してください。

- 1) 子どもの発達特性の把握
- 2) 子どもへの発達支援
- 3) 子育て相談
- 4) 保護者自身の課題への対応
- 5) 保護者が子どもの現状（課題や特性）を理解し受容するのを助ける
- 6) 保護者が医療機関等への受診を受け入れる手助け
- 7) その他（ ）

優先順位 1 番（ ） 2 番（ ） 3 番（ ）

4. 平成 30 年度の個別相談の従事者の職種（雇い上げも含）として当てはまるものを全て選んでください。

- 1) 保健師 2) 保育士 3) 心理士 4) 作業療法士（OT）
- 5) 理学療法士（PT） 6) 言語聴覚士（ST） 6) その他（ ）

5. 個別相談の課題として優先順位の高いものを3つ選び、番号を記入してください。

- 1) 参加について保護者の理解が得られない
- 2) 会場が遠い、交通手段がないなど、利便性に問題がある
- 3) 予約から相談までに時間がかかり、タイムリーな相談に応じることが困難
- 4) 子どもの発達特性を客観的に評価するのが難しい
（該当する理由に○をつけてください）
 - （1. 検査ツールがない 2. 検査ツールを使用する時間がない
 3. 相談員にスキルがない 4. 相談員によって評価が異なる
 5. その他： ）
- 5) 相談員の確保が難しい（該当する職種に○をつけてください。）
 - （1. 保健師 2. 保育士 3. 心理士 4. OT 5. PT 6. ST 7. その他： ）
- 6) 相談から診断機関へつなげるのが難しい
- 7) その他（ ）

優先順位 1 番（ ） 2 番（ ） 3 番（ ）

D-7 平成 30 年度の事後教室および個別相談に月齢 24 か月以下で参加した子どもについて、以下の割合を大まかに教えてください。（わかる項目をご記入ください。すべてのデータがない場合には不明に○をつけてください。）

	事後教室	個別相談
1) 参加した時点で発達障害の診断があった子どもの割合	%	%
2) 年度末までに新たに発達障害の診断がついた子ども、または発達障害の疑いで受診中の子どもの割合	%	%
3) その他の子どもの割合	%	%
4) すべてわからない（データなし）	不明	不明

D-8 D-2 で「8) 診断機関への紹介」を選んだ場合、課題として優先順位の高いものを3つ選んでください。

- 1) 受診について保護者の理解が得られない 2) 紹介先が少ない
- 3) 予約から初診までに時間がかかる 4) 初診から診断までに時間がかかる

- 5) 信頼性のある診断を得られない 6) その他 ()
- 優先順位 1 番 () 2 番 () 3 番 ()

D-9 D-2 で選んだ各種事業で使用している検査ツールがあれば全てに○をつけ、使用している事業（相談、教室など）と検査者の職種（保健師、心理士など）を教えてください。すべての事業で検査ツールの使用がない場合は、最下段の 0) に○をつけてください。

	ツール名	使用事業（例：相談）	検査者職種（例：心理士）
発達／知能	1) 遠城寺式発達診断検査		
	2) 田中ビネー知能検査		
	3) WPPSI-III 知能検査		
	4) 新版 K 式発達検査		
	5) その他 ()		
社会適応性	1) Vineland-II 適応行動尺度		
	2) S-M 社会生活能力検査		
	3) その他 ()		
感覚	1) ITSP 乳幼児感覚プロフィール		
	2) SP 感覚プロフィール		
	3) その他 ()		
ASDスクリーニング	1) PARS		
	2) SRS-2 (SRS-P)		
	3) CARS (CARS-TV)		
	4) ADI-R		
	5) ADOS-2		
	6) その他 ()		
	0) どの事業においても検査ツールの使用なし		

D-10 D-9 で「0) どの事業においてもツールの使用なし」を選んだ場合、その理由をすべて選んでください。

- 1) 評価する必要性を感じない 2) 評価は他機関に依頼している
- 3) 検査用具や検査用紙を購入する予算がない 4) 検査者の確保が難しい
- 5) 検査時間の確保が難しい 6) 保護者の同意を得るのが難しい
- 7) その他 ()

アンケートは以上です。ご協力ありがとうございました。

Appendix B

B-1 Details of ADEC Items and Scoring Protocol (English)

ADEC Item	Operationalisation	Scoring Protocol
1. Response to name	<p>Example:</p> <ul style="list-style-type: none"> • Child turns head and looks at tester's face and makes eye contact <p>Non-examples:</p> <ul style="list-style-type: none"> • Child does not look up from activity • Child looks around but not at tester's face 	<p>0: child turns head towards tester immediately following name call on first or second trial</p> <p>1: child turns head towards tester immediately following name call on third, fourth or fifth trial; or behaviour is seen to occur spontaneously at other times during the testing session</p> <p>2: child does not respond to name on any of the 5 trials and this behaviour is not demonstrated spontaneously during the testing session</p>
2. Imitation (drum hands on box)	<p>Example:</p> <ul style="list-style-type: none"> • Child drums on box with both hands <p>Non-examples:</p> <ul style="list-style-type: none"> • Child drums on box with just one hand • Child does not respond • Child looks away 	<p>0: child drums on box with both hands on at least one trial</p> <p>1: child makes clear attempt to imitate the gesture but is impeded by lack of motor co-ordination or some spontaneous imitation occurs during testing but not on command (score '1' if child imitates any actions during the testing session)</p> <p>2: child makes no attempt to imitate gesture on any of the 3 trials</p>

<p>3. Stereotypical Behaviour (upset when line of blocks disturbed)</p>	<p>(a) Child becomes distressed when the blocks are disturbed Example:</p> <ul style="list-style-type: none"> • Child cries or screams <p>Non-examples:</p> <ul style="list-style-type: none"> • Child disturbs the line-up of blocks on their own initiative • Child does not respond to the disturbance of the line of blocks <p>(b) Child makes attempts to realign the blocks Example:</p> <ul style="list-style-type: none"> • Child attempts to place one or more of the moved blocks back into a linear arrangement • Child builds blocks in some order (colour) and is upset when it is disturbed <p>Non-examples:</p> <ul style="list-style-type: none"> • Child disturbs the line of blocks on their own • Child does not respond to the disturbance of the line of blocks • Child starts to align the blocks in a non-linear fashion (e.g., building a tower in a non-structured format) • Spontaneous alignment of objects other than blocks or some rigidity in positioning of objects should be scored as '1' here. That is, if the child makes any attempt to line up or stack objects other than the blocks, or is disturbed by the tester's repositioning of objects placed by him/her this should be scored as '1' here. In addition, any stereotypical behaviours (including body movements) should score '1'. 	<p>0: child unconcerned by disturbance of line-up of blocks or disturbs them him or herself</p> <p>1: child becomes upset at disturbance of line-up of blocks or demonstrates some linear alignment of other objects such as cars during the adaptation or testing sessions</p> <p>2: child becomes upset <i>and</i> attempts to realign the blocks</p>
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4. Gaze Switching	<p>Example:</p> <ul style="list-style-type: none"> • Child points at toy and also looks at adult's face (either caregiver's or tester's) • Child turns head and eyes to look at toy then turns head and eyes to look at the tester's face (and back at the toy again) • Child looks at adult's face <p>Non-examples:</p> <ul style="list-style-type: none"> • Child does not look up • Child becomes upset (cries) without looking at adult's face • Child is completely uninterested 	<p>0: child turns head and eyes to look at toy then turns head and eyes to look at adult, then turns back to look at toy; (may combine eye gaze with pointing/vocalisations/reaching)</p> <p>1: child may look at either toy or adult but with no gaze switching between the toy and adult (i.e., he/she makes no attempt to look or engage adult)</p> <p>2: child makes no attempt to look at or engage adult; child may be just fixated on toy and indifferent to surroundings or may be indifferent to toy</p>
5. Eye Contact (in a game of peek-a-boo)	<p>Example:</p> <ul style="list-style-type: none"> • Child engages in game and shows good eye contact • Child displays signs of interest in the game (e.g., child smiles; child laughs) • Child becomes excited and looks in the tester in the eye <p>Non-examples:</p> <ul style="list-style-type: none"> • Child displays signs of no interest in the game • Child looks away; child does not engage in eye contact 	<p>0: on each of the 5 trials, child engages in game and looks into tester's eyes</p> <p>1: on at least one, but not all 5 trials, child looks into tester's eyes</p> <p>2: child does not look into tester's eyes on any of the 5 trials or deliberately tries to avoid eye contact</p>
6. Functional Play (toy telephone)	<p>Example:</p> <ul style="list-style-type: none"> • Child pushes car along • Child picks up receiver and holds it to their ear • Child picks up receiver and holds it to their ear and vocalises • Child dials telephone 	<p>0: child engages in <i>more than one</i> of the Example behaviours</p> <p>1: child engages in <i>only one</i> of the Example behaviours throughout the time period/or functional play was observed throughout the session using other toys</p> <p>2: child does not engage in any of the Example behaviours</p>

	Non-examples: <ul style="list-style-type: none"> • Child plays with only one feature of the toy (e.g., spinning the wheels) • Child engages in sensorimotor play (e.g., banging, waving, sucking, throwing, sniffing) 	
7. Pretend Play (pretend phone)	Example: <ul style="list-style-type: none"> • Child holds the piece of foam to ear, as if it is a telephone receiver Non-examples: <ul style="list-style-type: none"> • Child takes the piece of foam from tester but does not hold it against ear (e.g., holds it, bangs it against table, throws it, eats it) • Child does not take the piece of foam from tester • Child looks away from the tester 	0: child holds foam to ear, as if it is a telephone receiver and vocalises 1: child takes phone, maybe he/she vocalises but does not clearly demonstrate an understanding that it is a pretend phone 2: child displays any of the Non-example behaviours
8. Reciprocity of Smile	Example: <ul style="list-style-type: none"> • Child smiles Non-examples: <ul style="list-style-type: none"> • Child looks at tester but does not smile • Child looks away from tester's face 	0: child smiles immediately after one of first 2 trials, and there is a clear change in expression from a non-smiling expression to smile 1: delayed smile or smile occurs spontaneously during the testing session 2: child does not smile; avoids social contact with tester throughout the testing session
9. Response to Everyday Sounds	Example: <ul style="list-style-type: none"> • Child turns head towards CD player • Child points to CD player • Child looks at caregiver or tester 	0: child engages in any of the Example behaviours and there are no Non-example behaviours demonstrated 1: child ignores sound, continues with his or her activity 2: child engages in any one of the Non-example behaviours

	Non-examples: <ul style="list-style-type: none"> • Child covers ears with hands • Child attempts to remove self • Child cries or screams 	
10. Gaze Monitoring (following point/pointing)	Example: <ul style="list-style-type: none"> • Child turns head to look in the direction tester is pointing • Child points to something in the room Non-examples: <ul style="list-style-type: none"> • Child looks at tester's face, hand or arm but does not follow point or point themselves • Child does not respond 	0: child turns head and looks in the direction tester is pointing or child points to something spontaneously to engage tester 1: child does not look at object of interest, instead focuses on the tester (i.e., the tester's face, or pointing hand or arm) 2: child does not look up at the tester; child looks away or no pointing is observed
11. Response to a Verbal Command	Example: <ul style="list-style-type: none"> • Child responds appropriately to a verbal command (e.g., 'clap hands', 'blow kiss') 	0: child demonstrates the behaviour to the standard normally achieved according to the caregiver 1: child responds to the command (looks up at caregiver, approaches caregiver) but does not demonstrate the behaviour he/she was asked to do 2: child does not respond or looks away from caregiver; or caregiver states that child is unable to respond to a verbal command
12. Demonstrates Use of Words	Example: <ul style="list-style-type: none"> • For child 12-18 months of age: child demonstrates use of at least one word, clearly pronounced, and is not a made-up word • Child demonstrates at least 6 words (18 months to 2 years) 	0: child clearly pronounces one word or more (12-18 months of age); child demonstrates at least 6 words (18 months to 2 years); child demonstrates more than 12 words (more than 2 years of age)

	<ul style="list-style-type: none"> • Child demonstrates more than 12 words (more than 2 years) 	<p>1: child makes an attempt, but the word is not pronounced clearly; or child just babbles; or fewer words are spoken than is desirable for the child given their age</p> <p>2: child does not use any words</p>
13. Anticipatory Posture (for being picked up)	<p>Example:</p> <ul style="list-style-type: none"> • Child leans forward towards caregiver • Child raises one or both elbows/arms to make armpits available for caregiver to grasp • Child displays anticipation of being picked up but appears to reject it – this might be by squeezing his/her arms against their own body as if to prevent the caregiver from gaining access to their armpits <p>Non-examples:</p> <ul style="list-style-type: none"> • Child looks at caregiver but does not raise arms • Child looks away from caregiver or child continues activity without responding 	<p>0: child demonstrates one of more of the Example behaviours making it clear they realise the intent of the caregiver</p> <p>1: child displays one of more of the Example behaviours after much prompting (either verbal or physical)</p> <p>2: child does not display any of the Example behaviours</p>
14. Nestling into Caregivers	<p>Example:</p> <ul style="list-style-type: none"> • Child nestles into caregiver by resting body on caregiver's body and leaning head on caregiver's shoulder (may put arms around caregiver) <p>Non-examples:</p> <ul style="list-style-type: none"> • Child assumes rigid posture • Child assumes limp posture (needs to be held up by caregiver) • Child struggles • Child arches back 	<p>0: child displays the Example behaviour (nestling into caregiver)</p> <p>1: child displays some indications of discomfort but none of the Non-example behaviour; or child will only nestle at their initiative not when responding to parent/caregiver; or behaviour is seen to occur spontaneously at other times</p> <p>2: child displays one or more of the Non-example behaviours</p>

	<ul style="list-style-type: none"> • Child pushes caregiver away 	
15. Use of Gestures (wave goodbye)	<p>Example:</p> <ul style="list-style-type: none"> • Child waves at tester at least once while waving (arm or hand is extended towards tester and waved side to side and/or up and down repeatedly, or hand is opened and closed, palm facing towards the tester) <p>Non-examples:</p> <ul style="list-style-type: none"> • Child extends arm towards tester but does not move it up and down in a waving action • Child does not respond 	<p>0: child displays the Example behaviour</p> <p>1: child makes clear attempt to wave (e.g., child extends arm towards tester but does not move it up and down in a waving action). Any other demonstration of these types of gestures can be scored here</p> <p>2: child does not respond or looks away</p>
16. Ability to Switch from Task to Task	<p>Example:</p> <ul style="list-style-type: none"> • Child shifts from one task to another with little resistance <p>Non-examples:</p> <ul style="list-style-type: none"> • Child becomes fussy if activity is changed • Child becomes fixated with one particular task • Child does not engage sufficiently in any activity that enables a shift to be observed 	<p>0: child readily changes from one activity to another</p> <p>1: child may become fixated on one task but generally is happy to change tasks</p> <p>2: child does not respond to tester's requests to change tasks or will not engage in tasks as required preferring to do their own thing</p>

B-2 Details of ADEC Items and Scoring Protocol (Japanese Translation)

ADEC 項目	例	評価基準
1. 呼名反応	<p>該当する例：</p> <ul style="list-style-type: none"> 顔を向け、検査者の顔を見てアイコンタクトをする <p>該当しない例：</p> <ul style="list-style-type: none"> 自分がしていることから顔を上げない 周囲は見るが、検査者の顔は見ない 	<p>0：1回か2回目に名前を呼んだ直後に検査者の方に顔を向ける。</p> <p>1：3回から5回目に名前を呼んだ直後に検査者の方に向ける。または、検査中の別の場面で自発的に名前に反応する。</p> <p>2：5回の試行の中で名前に反応することがなく、検査中の別の場面で自発的に反応することもない。</p>
2. 模倣（箱を太鼓のように叩く）	<p>該当する例：</p> <ul style="list-style-type: none"> 両手で箱を叩く <p>該当しない例：</p> <ul style="list-style-type: none"> 片手だけで箱を叩く 反応しない よそ見をする 	<p>0：3回のうち1回でも両手で箱を叩く。</p> <p>1：模倣しようとしたことは明らかだが、運動協調性の不足により達成できない。または、検査中にいくらか自発的な模倣が見られたが、指示に従ったものではない。（検査中にどんな行動であれ模倣が見られた場合は1をつける。）</p> <p>2：3回とも模倣しようとししない。</p>
3. 常同行動（ブロックの列が乱れると動揺する）	<p>(a) 列が乱れると動揺する</p> <p>該当する例：</p> <ul style="list-style-type: none"> 泣いたり叫んだりする <p>該当しない例：</p> <ul style="list-style-type: none"> 自分から進んで列を崩そうとする 列が崩れても反応しない <p>(b) ブロックを並べ直そうとする</p> <p>該当する例：</p> <ul style="list-style-type: none"> 列から外れたブロックを一つ以上動かして、列の形に戻そうとする。 	<p>0：列が崩れても気にしない。または、自分も列を崩そうとする。</p> <p>1：ブロックの列が崩れると動揺する。または、慣らし時間内や検査の他の場面で、車などブロック以外の物を列の形に並べる。 常同行動が、身体の動き（例：つま先で歩く、回る、体を揺らす、手をひらひらさせる）または物の使用（例：物を並べる、回す）で見られる。</p> <p>2：動揺し、且つブロックの並びを直そうとする（aとbの両方に該当する）。</p>

	<ul style="list-style-type: none"> ・ブロックを一定の形や色に従って並べ、それが崩されると動揺する <p>該当しない例：</p> <ul style="list-style-type: none"> ・自分から進んで列を崩そうとする。 ・列が崩れても反応しない。 ・ブロックを列以外の形に並べ始める（例：雑然と積み上げてタワー型にする）。 ・ブロック以外の物を自発的に並べる、物の置き方にこだわりを持つといった状態が見られたら、1をつける（例：ブロック以外の物を並べたり積み上げたりし、検査者にその位置を動かされると動揺する）。常同行動（身体の動きも含む）も1をつける。 	
4. 視線の行き来／社会的参照	<p>該当する例：</p> <ul style="list-style-type: none"> ・おもちゃを指さし、大人（養育者または検査者）の顔を見る。 ・顔と目を動かしてまずおもちゃを見、その後大人の顔を見る（その後再びおもちゃを見る）。 ・大人の顔を見る。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・顔を上げない。 ・大人の顔を見ず、動揺する（泣く）。 ・まったく興味を示さない。 	<p>0：顔と目を動かしてまずおもちゃを見、それから大人の顔を見る。その後再びおもちゃを見る。（注視と同時に指をさしたり声を出したり手を伸ばしたりすることもある。）</p> <p>1：おもちゃか大人の一方は見るが、二つの間で視線を行き来させることはない（大人を見ようとししない、大人の注意を引こうとししない）。</p> <p>2：大人を見ようとししないし、注意を引こうともしない。おもちゃに集中して周りを気にしない、または、おもちゃに興味を示さない。</p>
5. アイコンアクト（いないいないばあ）	<p>該当する例：</p> <ul style="list-style-type: none"> ・遊びに参加し、しっかり目を合わせる。 ・遊びに興味を示す（例：微笑む、声を上げて笑う）。 ・わくわくした様子で検査者の目を見る。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・遊びに興味を示さない。 ・よそ見をする、目を合わせない。 	<p>0：5回とも遊びに加わり、検査者の目を見る。</p> <p>1：1回以上5回未満の試行で検査者の目を見る。</p> <p>2：5回とも検査者の目を見ない。または、意図的にアイコンタクトを避けようとする。</p>

<p>6. 機能的遊び（おもちゃの電話）</p>	<p>該当する例：</p> <ul style="list-style-type: none"> ・車をごろごろと走らせる。 ・受話器を取って耳に当てる。 ・受話器を取って耳に当て、声を出す。 ・ダイヤルを回す。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・おもちゃの一部分だけを使って遊ぶ（例：車輪を回す）。 ・感覚運動的な遊びを行う（例：叩きつける、振り回す、しゃぶる、投げる、においを嗅ぐ）。 	<p>0：該当行動を2つ以上見せる。</p> <p>1：時間内に1つだけ該当行動を見せる。または、検査の別の場面で他のおもちゃを使って機能的な遊びを行う。</p> <p>2：該当行動を1つも見せない。</p>
<p>7. ふり遊び（電話するふり）</p>	<p>該当する例：</p> <ul style="list-style-type: none"> ・発砲スチロールを受話器のつもりで耳に当てる。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・発砲スチロールを受け取るが、耳には当てない（例：握る、叩きつける、投げる、口に入れる）。 ・発砲スチロールを受け取らない。 ・検査者から視線をそらす。 	<p>0：発砲スチロールを受話器のつもりで耳に当て、声を出す。</p> <p>1：発砲スチロールを受け取り、場合によっては声も出すかもしれないが、受話器のつもりであることを理解している様子が、行動からははっきりとは伝わらない。</p> <p>2：該当しない例の行動を見せる。</p>
<p>8. ほほ笑み返す</p>	<p>該当する例：</p> <ul style="list-style-type: none"> ・微笑む。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・検査者を見るが微笑まない。 ・検査者の顔から視線をそらす。 	<p>0：最初の2回の試行のどちらかで、すぐに微笑み返す。そのとき、笑っていない顔から笑顔へと、明らかに表情が変化する。</p> <p>1：やや遅れて微笑み返す。または、検査の他の場面で自発的に微笑む。</p> <p>2：微笑まない。検査中ずっと検査者との接触を避ける。</p>
<p>9. 日常的な音への反応</p>	<p>該当する例：</p> <ul style="list-style-type: none"> ・CD プレイヤーの方に顔を向ける。 ・CD プレイヤーを指さす。 ・養育者や検査者を見る。 <p>該当しない例：</p>	<p>0：該当する例にある行動をとり、該当しない例にある行動はとらない。</p> <p>1：音を無視して自分のしていることを続ける。</p> <p>2：該当しない例にある行動をとる。</p>

	<ul style="list-style-type: none"> ・CD プレイヤーの方に顔を向ける。 ・CD プレイヤーを指さす。 ・養育者や検査者を見る 	
10. 視線のモニタリング（指さしを追う／指さしをする）	<p>該当する例：</p> <ul style="list-style-type: none"> ・顔を動かして検査者の指さす方を見る。 ・部屋にある何かを指さす。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・検査者の顔や手、腕を見るが、指差しは追わない。または、自分を指さす。 ・反応しない。 	<p>0：顔を動かして検査者の指さす方を見る。または、検査者の注意を引くために自発的に何かを指さす。</p> <p>1：対象物を見ず、検査者に注意を向ける（例：検査者の顔や指さしている手、腕を見る）。</p> <p>2：検査者の顔を見ない、よそ見をする、指さしをしない。</p>
11. 言葉での指示に反応する	<p>該当する例：</p> <ul style="list-style-type: none"> ・言葉での指示に適切に反応する（例：「手を叩こう」、「ちょうだい」）。 	<p>0：養育者が言うような普段のレベルで指示を実行する。</p> <p>1：指示に対して反応を見せる（養育者を見上げる、近づく）が、指示の内容は実行しない。</p> <p>2：養育者の指示に反応しないか、視線をそらす。または、言葉での指示に反応できないことが養育者から伝えられる。</p>
12. 言葉を使う	<p>該当する例：</p> <ul style="list-style-type: none"> ・12 から 18 か月：意味をなす言葉を少なくとも 1 つ、はっきり発音して使う。 ・18 か月から 2 歳：少なくとも 6 語使う。 ・2歳以上：13語以上使う。 	<p>0：12から18か月：1つ以上の言葉をはっきりと発音する。18 か月から2歳：少なくとも6つの言葉を使う。2歳以上：13以上の言葉を使う。</p> <p>1：言葉を言おうとするが、はっきり発音できない、喃語のみ、使う言葉の数が年齢基準よりも少ない。</p> <p>2：言葉をまったく使わない。</p>
13. 行動を先読みした姿勢をとる（抱っこ先の読み）	<p>該当する例：</p> <ul style="list-style-type: none"> ・養育者の方に身体を傾ける。 ・片方または両方の腕や肘を上げて、抱き上げられやすくする。 ・抱き上げられることを予想して、それを拒む態度をとる（例：手を入れられないよう、腕を身体にぴったりくっつける）。 	<p>0：該当例にある行動を1つ以上見せ、養育者の意図を理解していることがはっきりと伝わる。</p> <p>1：養育者が繰り返し（口頭で、または身体的に）働きかけると、該当例にある行動を1つ以上見せる。</p> <p>2：該当例にある行動を1つも見せない。</p>

	<p>該当しない例：</p> <ul style="list-style-type: none"> ・養育者を見るが、腕を上げない。 ・養育者から視線をそらす、反応せず自分のしていることを続ける。 	
14. 養育者に心地よく体を預ける	<p>該当する例：</p> <ul style="list-style-type: none"> ・養育者の体に自分の体を預け、肩に頭をもたせかけ、心地良さそうに身を落ち着ける（養育者に腕を回すこともある）。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・体を硬くする。 ・体がぐにゃぐにゃする（養育者に体を支えられる必要がある）。 ・もがく。 ・のけぞる。 ・養育者を押しのける。 	<p>0：該当する例の行動を示す（養育者に心地よく体を預ける）。</p> <p>1：不快そうだが、該当しない例の行動は見られない。自分から行動したときは体を預けるが、養育者から近づいたときはしない。または、検査中の他の場面で該当行動が見られる。</p> <p>2：該当しない例の行動を1つ以上示す。</p>
15. 身ぶり手ぶりの使用（ばいばいと手をふる）	<p>該当する例：</p> <ul style="list-style-type: none"> ・手をふるように動かす中で、少なくとも一回は検査者に向かってそれを行う（手や腕を検査者に向かって延ばし、上下または左右に動かす。または、手の平を検査者に向けた状態で、握ったり開いたりする）。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・検査者に向かって手を伸ばすが、上下に動かすようなことはしない。 ・反応を示さない。 	<p>0：該当例の行動を示す。</p> <p>1：手をふろうとしていることがはっきりわかる（例：検査者に向かって手を伸ばすが、上下にふるようには動かさない）。そのほかの身ぶり手ぶりがいずれかの場面で見られたら、1をつける。</p> <p>2：反応を示さない。またはよそ見をする。</p>
16. 活動から活動へ切り替える力	<p>該当する例：</p> <ul style="list-style-type: none"> ・一つの活動から別の活動へ難なく切り替わる。 <p>該当しない例：</p> <ul style="list-style-type: none"> ・活動が変わるといらいらする。 ・ある一つの活動に固執する。 ・切り替えが観察できるほど十分な活動への集中が見られない。 	<p>0：一つの活動から別の活動へ難なく切り替わる。</p> <p>1：一つの活動に固執することもあるが、全体的には喜んで活動を替える。</p> <p>2：検査者が活動を替えようと働きかけても応じない。または、自分のやっていることの方を好んで必要な活動に参加しない。</p>