



Early intervention and perspectives for children with autism spectrum disorder in Japan

Yuko Yoshimura^{1,2,3}, Sanae Tanaka², Tomoko R. Haramaki³

¹Institute of Human and Social Science, ²Research Center for Child Mental Development, Kanazawa University, Kanazawa, Japan; ³United Graduate School of Child Development, Osaka University, Osaka, Japan

Correspondence to: Yuko Yoshimura. Institute of Human Science, Kanazawa University, Kakuma-machi, Kanazawa, Ishikawa 920-1192, Japan.

Email: yukuchen@staff.kanazawa-u.ac.jp.

Abstract: Early detection and early diagnosis of autism spectrum disorder (ASD) are promoted throughout the world. Early detection and early intervention for children with ASD is known to have certain effects. Consistent with global trends, systems to provide children with appropriate environments and educational opportunities in Japan are improving; features of ASD are being detected by the age of approximately 2 years through health checkups for infants and children. However, the early screening of autistic infants and children in Japan, subsequent follow-up, and early intervention methods differ greatly among residential areas and local governments. In this article, we outline well-constructed models of systems that include aspects such as early detection, early diagnosis, early intervention, parent support, and longitudinal follow-up of ASD and are used in some areas in Japan. Furthermore, we note the current efforts of the Early Start Denver Model (ESDM), which the authors are working to apply in Japan. Early detection and diagnosis systems for children with ASD in Japan will continue to develop, and the validation of their effects through randomized controlled trials (RCTs) is desired in research on early intervention for children with ASD. Furthermore, the brain function research that the author of this article is working on may be one approach for objectively evaluating the effects of early intervention from both behavioral and physiological perspectives.

Keywords: Autism spectrum disorder; children; early intervention; Japan

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Introduction

In recent years, the prevalence of autism spectrum disorder (ASD) has been reported as 1% or more (1). In 2014, the overall prevalence of ASD in 11 states in the United States of America was 16.8 per 1,000 children aged 8 years (one in 59) (2). Consistent with global trends, the number of children diagnosed with ASD has also increased in Japan. Kawamura *et al.* (2008) reported that the prevalence rate of ASD among 5- to 8-year-old was 181.1 per 10,000 population based on research that conducted a direct evaluation of individuals with ASD (3). A recent survey was conducted in nine different size municipalities in Japan that are engaged in early diagnosis (before preschool) of

developmental disorders (4). The author reported that the prevalence of pervasive developmental disorders (PDD) was 3.0% to 6.6% among children aged 6 to 7 years (born from April 2006 to March 2007); two years later, at the age of 8 to 9 years, the prevalence increased to 4.2% to 8.7%. However, these diagnoses were only clinical diagnoses, and no standardized diagnostic evaluation, such as the Autism Diagnostic Observation Scale (ADOS), was used. Although the reported prevalence may differ according to the diagnostic methods used, early identification and subsequent intervention for ASD are considered key issues.

Recent studies have reported that early intensive behavioral intervention and a comprehensive, intensive early intervention approach have resulted in some improvements

in cognition, language, and adaptive functioning in some young children with ASD (5,6). Along with global trends, efforts towards providing early detection, diagnosis and intervention for children with ASD starting early childhood are also developing in Japan. Meanwhile, medical institutions and treatment organizations for children with ASD are in short supply compared with the high prevalence, and the shortage of developmental disorder experts has not been resolved. Against this background, many local communities have begun to work to establish a cooperative network of medical, health, welfare and education services with the goal of efficient collaboration among local healthcare professionals and specialized medical institutions.

Early detection and early intervention in children with autism spectrum disorder

Early intervention for children with disabilities in Japan is called “Ryou-iku” (i.e., “treatment and education”, “developmental support”). As a welfare service, early intervention is generally provided at the local medical center and child development support center, mainly by local governments. In recent years, the number of private institutions and establishments that provide various treatment methods for early intervention has also increased. The Ministry of Health, Labor and Welfare recommends the establishment of an early intervention system by each local government, but there are no specific guidelines on the process and content of early intervention in Japan. Therefore, many regions eclectically incorporate elements, theories and programs from various intervention methods.

The Japanese public health system is one of the world’s most highly developed in its provision of health checkups for infants and children. The “mass health checkups” provided at 3 to 4 months, 1 year 6 months and 3 years include height and weight measurement, examinations by a pediatrician, nutritional counseling, parenting consultation, dental guidance, and visual and auditory examinations.

The rates of participation in health checkups are consistently high in most cities in Japan. According to the data from April 2016 to March 2017, the rates of participation for child health checkups in Japan were 95.6% for the 3- to 5-month checkup, 96.4% for the 18-month checkup and 95.1% for the 36-month checkup (7). Several municipalities are working to provide early diagnosis and construct early intervention systems for children with ASD utilizing this public health system. Honda *et al.* named the model of community care from infancy to adulthood

for people with developmental disorders such as ASD SAUCIAL (Support for people with AUtism and other developmental disorders in Community from Infancy to Adult Life) and introduced an early support system based on this model in Yokohama City, Japan (8). SAUCIAL is composed of DISCOVERY (Detection and Intervention System in the COMMunity for VERY Young children with developmental disorders), which is responsible for early detection; CHOICE (Community and Home Oriented Instruction, Counseling and Exercises), which is responsible for early intervention; and VISION (VItal Skills, Information, Occupation and Networking). In particular, DISCOVERY establishes interfaces between detection and diagnosis and between diagnosis and treatment to ensure consistent support; it is responsible for smoothing and tightening cooperation (9,10). In addition, the early intervention program (CHOICE), in which preschool children can participate, provides early intervention that meets the diversity of needs among children, from those with intellectual disabilities to those who are high functioning; CHOICE is a multiaxial care model that provides “reinforcement for supporting inclusion” to preschools and kindergartens in the community in addition to “intervention for children”, “support for parents” and “development of advanced technology” (11). Iwasa *et al.* (2010) reported that in 13 infants with ASD who could participate in an intelligence test, the IQs of those who received early intervention based on the CHOICE model increased significantly after early intervention (12).

Kamio *et al.* revealed that the Modified Checklist for Autism in Toddlers (M-CHAT) is an effective screening tool for detecting the risk of ASD in general groups, such as children seen at public health checkups, and clinical groups, such as children seen at medical sites (13). The authors recommend screening for ASD at the 18-month public health checkup using the M-CHAT; if ASD is suspected at that time, medical staff should encourage parents to see a specialist as soon as possible, without a follow-up observation period.

As present, screening for early features of ASD using the M-CHAT is performed at the 18-month checkup in a municipality in Ishikawa prefecture, where the author (Y.Y.) served as a developmental counselor. According to the results from 2013 to 2016, among infants who received an 18-month checkup, 8.6% (2013), 3.8% (2014), 3.7% (2015) and 4.7% (2016) were judged to be at risk of ASD. When children are judged to be at risk of ASD, they and their parents are provided opportunities to

attend parent-child activities led by public health nurses, undergo behavioral observations by public health nurses and educational counselors during group activities, and share their concerns and questions with a counselor. Public health nurses are specialists in regional nursing who receive prescribed specialized education and perform public health activities such as disease prevention and health promotion via district activities, health education and health guidance. In cases where it is desirable to begin medical care as soon as possible, parents visit medical institutions after receiving child development counseling from a specialist and clinical psychologist or speech therapist; there, they receive a diagnosis and start intervention. Furthermore, a public mass health checkup is conducted at the ages of 3 and 5 years, and a longitudinal evaluation system has been constructed to follow children with ASD without intellectual delay. Most ASD children with intellectual disabilities tend to be referred to medical institutions and educational interventions relatively quickly due to an obvious delay in language and mental development. On the other hand, for ASD children without intellectual delay, longitudinal evaluation is necessary because it is difficult to evaluate social development delay in a short period of time.

As described above, ASD screening through public health checkups and early detection have been addressed in Japan; however, little evidence regarding the effects of early intervention for ASD has been reported. This is due to the lack of research on early intervention for ASD.

Early intervention for children with autism spectrum disorder in Japan

Kamio and colleagues surveyed 29 papers on early treatment published in Japan before 2013 (14). They found that the intervention methods that were most frequently used in Japan were intervention studies using applied behavior analysis (ABA), low-frequency interventions, and nonintensive interventions. Many universities and local governments were involved in this intervention research, and the research involved different intervention designs at each institution. In Japan, educational and developmental studies have used a wide variety of early intervention methods. For instance, approaches reported at academic societies and research meetings have included Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH); ABA; ESDM; discrete trial training (DTT); Pivotal Response Treatment (PRT); the script model; the Picture Exchange Communication

System (PECS); social skill training; the Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) program; the National Autistic Society (NAS) Early Bird program; parent training; dietary approaches; intestinal environment approaches; joint attention training; imitation training; and the sensory integration approach. Interventions are conducted by pediatric doctors, psychologists, clinical nurses, physical therapists, occupational therapists, speech therapists, public health nurses and experts in special needs education at each institution. However, as mentioned above, few reports have verified the effectiveness of early interventions and outcomes for children with ASD in Japan using scientific methods, such as RCTs. It is necessary to accumulate evidence regarding the effect of early intervention in Japan. It is also important to clarify the relationship between early intervention and long-term outcomes by conducting follow-up studies of children who have received early intervention. Furthermore, it is necessary to thoroughly evaluate individual developmental stages in multiple domains that reflect children's development, such as language development, cognitive development, and social skills; set teaching goals; and implement interventions.

ESDM in Japan

There are 11 ESDM therapists in Japan as of March in 2019. Most of their backgrounds are in clinical psychology, clinical developmental psychology, and/or speech pathology, and some of them are medical doctors. The first ESDM Introductory and Advanced Workshop was held in 2010 in Japan. This workshop was hosted by Tomoko Haramaki (third author in this manuscript) and the collaborative work of ANOTHER PLANET, which is an organization that provides clinical services for individuals with ASD and their families, and ASD Publishing, Ltd., which produces the Japanese translation of the ESDM Manual. Since then, ESDM implementation has started. There are more than 5 ESDM sites throughout the country. In particular, the sites in the cities of Saga and Taku in Saga Prefecture were the earliest sites. Those two sites are uniquely set up with an early ASD detection system (as early as 18 months of age) and provide ESDM as an early intervention program. These two ESDM early intervention programs are funded by the local governments and by all of the parents who are residents of these cities and wish to receive ESDM therapy sessions. Sessions are provided by certified ESDM therapists from ANOTHER PLANET. These sessions

are offered free of charge to children under 4 years old. To date, more than 50 children with ASD have received ESDM and ‘graduated’; the ratio of boys to girls is approximately 3:1. Currently, 36 children with ASD are receiving ESDM therapy sessions in the cities of Saga and Taku in Saga Prefecture. To date, efforts have been focused on training ESDM-certified therapists to provide clinical services, although the data in ESDM intervention and results are currently being collected, but certain preliminary data are available for inclusion in this manuscript.

We conducted early interventions that included ESDM sessions for 105 children with ASD. Among them, 49 participants (12 females and 37 males) who were able to obtain data before and after the ESDM were included in the current analyses. The mean age of month at the start of ESDM was 25.3 months and the age of month at the end was 37.4 months. An ESDM session by a certified therapist was conducted for 1 hour during week. ESDM sessions were provided for each child for approximately one year. We investigated the differences of development between before and after the ESDM intervention using the Kyoto Scale of Psychological Development (KSPD), the Vineland Adaptive Behavior Scales-Second Edition (Vineland-II), the Autism Diagnostic Observation Schedule-2 (ADOS-2).

We investigated the differences of development and parenting stress before and after the ESDM intervention using the Parenting Stress Index-Short Form (PST-SF).

The KSPD is a standardized test to assess the overall mental and motor development of children. The developmental quotient (DQ) for chronological age is calculated from subtests in the motor development, cognitive development, and language and social development domains. The Vineland-II measures the adaptive functioning of individuals from birth to adulthood (15). In a semi-structured interview, a parent or caregiver is asked to describe the child’s typical performance in everyday activities, including with respect to communication, daily living skills, socialization, and motor skills. Standard scores ($M = 100$, $SD = 15$), percentile ranks, adaptive levels, and age-equivalent scores are generated for the 4 global domains and the Adaptive Behavior Composite; v -scale scores ($M = 15$, $SD = 3$), adaptive levels, and age equivalents are also determined for 11 subdomains. The Vineland-II has been used widely in clinical, educational, and research settings, including with populations as diverse as ASD patients (16). The ADOS-2 is an instrument for diagnosing and assessing ASD. The ADOS is a semi-structured, standardized assessment designed for use with individuals referred for possible

ASD (17). Four ADOS modules accommodate various developmental and language levels. We used the ADOS to assess severity in children with ASD. The PST-SF is a self-report screening tool that helps providers and families identify the sources and different types of stress associated with parenting (18).

A pre/post comparison using a paired t -test revealed a significant difference in DQ ($P < 0.001$) on the KSPD. The Vineland-II showed significant differences between pre- and post-intervention scores for adaptive behavior ($P < 0.001$). A pre/post comparison of ADOS-2 results using the Wilcoxon signed-rank test revealed a significant difference in total ADOS score ($P < 0.001$). Furthermore, more than 70% of program ‘graduates’ eventually attended regular schools. The PST-SF indicated a trend of decreasing parenting stress. These efforts have resulted in our program obtaining additional funding for another 3 years from local governments.

ESDM perspective in Japan

Currently, in Japan, a system for the early detection and early diagnosis of ASD is being developed through a public health checkup system for newborns and young children. Evidence-based early intervention, such as ESDM therapy, will be increasingly required in Japan. Moreover, several experienced clinicians in Japan are currently working on ESDM certification procedures. As the importance of early detection and early intervention in young children with ASD becomes increasingly understood, there will be a growing number of clinicians who wish to be ESDM-certified therapists. Furthermore, the “Public Psychologist” system was launched in 2018 as the first national certification system for psychologists in Japan. “Public Psychologist” is a certification to support mental health based on collaboration with other specialists (i.e., doctors, teachers and therapists). It is hoped that this national qualification system will foster the development and maintenance of a large number of professionals with certain qualities and will be widely used. On the other hand, in Japan, there are situations in which it is difficult to receive public medical services at medical institutions and other facilities at the stage when a patient is at risk but a definitive diagnosis has not yet been obtained. To detect children with autism characteristics earlier and to administer early treatment such as ESDM therapy, it is necessary to foster specialists involved in early treatment and to develop a system that connects early detection to support.

Future directions in ASD intervention research/ response monitoring in Japan

A previous study has physiologically examined the effects of ESDM therapy. Dawson *et al.* (2012) investigated the brain response to human face stimuli using electroencephalograms (EEGs) after a two-year ESDM intervention. The authors reported that children who received ESDM intervention showed increased cortical activation in response to human face stimulation, and greater cortical activation while viewing faces was associated with improved social behavior (19). In our previous studies, we focused on the development of auditory processing in early childhood through auditory evoked magnetic fields (AEFs) using child-customized magnetoencephalography (MEG) and on language development in typically developing children and children with ASD. We reported the differences in brain responses evoked by human voices between typically developing children and children with ASD (20), the relationship between language development and brain activity in young children (21,22), and the different developmental patterns of auditory response to voice between typically developing children and children with ASD (23) In the future, we would like to evaluate the effects of ESDM intervention not only in terms of behavioral indicators but also in terms of physiological indicators in Japan.

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