

原因を療育のみに帰することはできないが、2歳から3歳という早い年齢帯においてASD児の生活の支障となりうる複数の症状が有意に改善し、発達が促進されたという事実は家族や療育にかかわる者にとって勇気づけられることは間違いない。さらに、わが国の子どもや家族に最適な療育のあり方を考える上で重要と考えられる。家族支援の観点からは、専門家による療育だけでなく、多くの時間を共にする家族による有効な家庭療育が可能になるような負担の少ない家族支援のあり方も検討されるべきであろう。

### 謝 辞

本研究は、平成16-20年独立行政法人科学技術振興機構社会技術研究システム（脳科学と教育：研究代表者 神尾陽子）、平成20-22年度厚生労働科学研究費補助金障害対策総合研究事業（研究代表者 神尾陽子）の助成の一部を受けて行われました。研究実施に協力いただきました宗像市保健師の大森静佳さんをはじめとする自治体の多くのスタッフの方々、データ収集にご協力いただきました井口英子先生、黒田美保先生、ADI-R実施のスーパービジョンを賜りました土屋賢治先生に感謝申し上げます。本研究にご協力いただきましたお子さまとご家族に、心より御礼申し上げます。

### 引用文献

American Psychiatric Association (2000). Diagnostic and statistical manual of mental disorders, 4th ed text revision. Washington, DC., American Psychiatric Association.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., & Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. *Pediatrics*, 125, e17-23.

Esbensen, A.J., Seltzer, M. M., Lam, K. S., & Bodfish, J. W. (2008). Age-related differences in restricted repetitive behaviors in autism spectrum disorders. *Journal of Autism Developmental Disorders*, 39, 57-66.

Gotham, K., Pickles, A., & Lord, C. (2009). Standardizing ADOS scores for a measure of severity in autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39, 693-705.

Hayward, D., Eikeseth, S., Gale, C., & Morgan, S. (2009). Assessing progress during treatment for young children with autism receiving intensive behavioural interventions. *Autism*, 13, 613-633.

稲田尚子, 黒田美保, 井口英子, 神尾陽子 (2011). 自閉症診断観察尺度 (Autism Diagnostic Observation Schedule: ADOS) 日本語版の信頼性・妥当性に関する研究—モジュール1— (一般児童における発達障害の有病率と関連要因に関する研究①) 平成22年度厚生労働科学研究費補助金 障害者対策総合研究事業 精神障害分野「1歳からの広汎性発達障害の出現とその発達の変化：地域ベースの横断的および縦断的研究 (研究代表者：神尾陽子)」。総括・分担研究報告書, 31-38.

Inada, N., Koyama, T., Inokuchi, E., Kuroda, M., & Kamio, Y. (2011) Reliability and validity of the Japanese version of the Modified Checklist for Autism in Toddlers (M-CHAT). *Research in Autism Spectrum Disorders*, 5, 330-336.

Kamio, Y., Inada, N., & Koyama, T. (in press). A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism*.

神尾陽子, 稲田尚子 (2006) 1歳6か月健診における広汎性発達障害の早期発見についての予備的研究. *精神医学*, 48, 981-990.

神尾陽子 (2010): いま発達障害をどうとらえるか. *地域保健*, 41, 24-31.

小山智典, 神尾陽子, 稲田尚子 (2010) ライフステージにおける種々の要因と長期予後との関連

- に関する検討. 平成 21 年度厚生労働科学研究費補助金(障害保健福祉総合研究事業)「ライフステージに応じた広汎性発達障害者に対する支援のあり方に関する研究：支援の有用性と適応の評価および臨床家のためのガイドライン作成(研究代表者：神尾陽子)」。総括・分担研究報告書, 13-65.
- 小山智典, 神尾陽子, 稲田尚子, 黒田美保, 辻井弘美, 西谷しのぶ, 内藤恵美, 養村さや香, 竹林(武藤)奈奈, 榎原信子 (2009). 早期幼児期における社会性の発達評価に関する研究. 平成 20 年度厚生労働科学研究費補助金(こころの健康科学研究事業)「1 歳からの広汎性発達障害の出現とその発達の变化：地域ベースの横断的および縦断的研究(研究代表者：神尾陽子)」。総括・分担研究報告書, 17-21.
- Kurita, H., Miyake, Y., & Katsuno, K. (1989). Reliability and validity of the Childhood autism rating scale-Tokyo version (CARS-TV). *Journal of Autism and Developmental Disorders*, 19, 389-396.
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H. Jr., Leventhal, B. L., DiLavore, P. C., Pickles, A., & Rutter, M. (2000). The autism diagnostic observation schedule-generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30, 205-223.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*; 24, 659-85.
- Sheinkopf, S. J. & Siegel, B. (1998). Home-based behavioral treatment of young children with autism. *Journal of Autism and Developmental Disorders*, 28, 15-23.
- Sutera, S., Pandey, J., Esser, E. L., Rosenthal, M. A., Wilson, L. B., Barton, M., Green, J., Hodgson, S., Robins, D. L., Dumont-Mathieu, T., & Fein, D. (2007). Predictors of optimal outcome in toddlers diagnosed with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 37, 98-107.

## A Nationwide Survey on Quality of Life and Associated Factors of Adults With High-Functioning Autism Spectrum Disorders

Yoko Kamio, Naoko Inada and Tomonori Koyama

*Autism* published online 7 March 2012

DOI: 10.1177/1362361312436848

The online version of this article can be found at:  
<http://aut.sagepub.com/content/early/2012/02/23/1362361312436848>

---

Published by:



<http://www.sagepublications.com>

On behalf of:



The National  
Autistic Society

The National Autistic Society

**Additional services and information for *Autism* can be found at:**

**Email Alerts:** <http://aut.sagepub.com/cgi/alerts>

**Subscriptions:** <http://aut.sagepub.com/subscriptions>

**Reprints:** <http://www.sagepub.com/journalsReprints.nav>

**Permissions:** <http://www.sagepub.com/journalsPermissions.nav>

>> OnlineFirst Version of Record - Mar 7, 2012

What is This?

---

# A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders

Autism

0(0) 1–12

© The Author(s) 2012

Reprints and permission:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/1362361312436848

aut.sagepub.com



**Yoko Kamio**

National Center of Neurology and Psychiatry, Japan

**Naoko Inada**

National Center of Neurology and Psychiatry, Japan

**Tomonori Koyama**

National Center of Neurology and Psychiatry, Japan

## Abstract

The psychosocial outcomes of individuals with high-functioning autism spectrum disorder (HFASD) appear to be diverse and are often poor relative to their intellectual or language level. To identify predictive variables that are potentially ameliorable by therapeutic intervention, this study investigated self-reported psychosocial quality of life and associated factors for adults with HFASD. All participants ( $n = 154$ ) had a diagnosis of autism spectrum disorder, were over 18 years of age, lived in the community, and had used one or more support services during the survey period. The results demonstrated that psychosocial quality of life was lower than that of the general Japanese adult population. Environmental factors, such as mother's support and early diagnosis, were associated with better quality of life, and aggressive behaviors were associated with poorer quality of life, while expressive language level at preschool years, a conventional outcome predictor, did not predict quality of life. These results emphasize that quality of life measures should be included as outcome indicators in treating individuals with HFASD.

## Keywords

high-functioning autism spectrum disorder, quality of life, adult, outcome, early diagnosis

---

### Corresponding author:

Yoko Kamio, MD, PhD, Department of Child and Adolescent Mental Health, National Institute of Mental Health, National Center of Neurology and Psychiatry, 4-1-1 Ogawa-Higashi Cho, Kodaira-shi, Tokyo 187-8553, Japan.

Email: kamio@ncnp.go.jp

## Introduction

Because autism spectrum disorder (ASD) is a life-long developmental disorder characterized by social and communication impairments and repetitive/stereotyped behaviors, therapeutic intervention for individuals with ASD and their families should be planned for and provided throughout the life span. According to previous outcome studies of autism/ASD, long-term outcomes have repeatedly been shown to be relatively poor when measured by conventionally used indicators, such as employment or independent living, and IQ or expressive language levels during the preschool years, have been thought to be powerful predictors of long-term outcomes (Kobayashi et al., 1992; Howlin et al., 2004; Mawhood et al., 2000). A growing body of literature indicates that children with ASD can be reliably diagnosed in the second year of life (Johnson et al., 2007; Landa, 2008). Furthermore, there is accumulated evidence that early detection and intervention focusing on communication development can lead to substantially better prognosis (Landa, 2008).

Although individuals with high-functioning ASD (HFASD) usually have good intellectual or language development from a very early age, their long-term outcomes are not necessarily desirable and are rather diverse (Kamio et al., 2011). Recent studies have discovered an HFASD subgroup with comorbid psychiatric conditions, which may lead to poor long-term outcomes (Howlin et al., 2004; Tsatsanis, 2003). Counter-examples are also found; some who would have been predicted to do poorly as adults based on their modest intellectual or language development were found to be leading satisfactory lives (Persson, 2000; Ruble and Dalrymple, 1996). Given such diversity in the long-term outcomes of individuals with ASD, it is important to measure long-term outcomes more comprehensively, including subjective aspects such as quality of life (QoL) (Renty and Roeyers, 2006; Ruble and Dalrymple, 1996), and to identify predictive variables that can be changed by therapeutic intervention.

The QoL concept is increasingly being introduced into the health-related science field for children with psychiatric disorders (Bastiaansen et al., 2004). According to the World Health Organization (WHO; The WHOQOL Group, 1995), QoL is defined as 'the individual's perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns', ranging from the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment.

Several studies have investigated QoL during adulthood for people with ASD. Most studies evaluated QoL by proxy (Gerber et al., 2008; Saldaña et al., 2009) or through indirect measures (Persson, 2000) for adults with both intellectual disabilities and ASD, and Renty and Roeyers (2006) investigated self-reported QoL of 58 adults with HFASD. These results showed that the QoL of HFASD populations largely depends on the nature of support services currently being received, suggesting that QoL can be improved by changing environmental factors. Furthermore, Renty and Roeyers (2006) demonstrated that although support characteristics were significantly related to QoL in adults with HFASD, disability characteristics such as IQ or severity of autism were not. This result emphasizes the importance of an available supportive social network, individual needs assessment, and effective professional support for adults with HFASD as well as for ASD adults with intellectual disabilities. However, in the study by Renty and Roeyers (2006) neither informal nor formal support was correlated with QoL, and perceived informal support was positively correlated with it.

In Japan, a new regulation took effect in April 2005 that aims to establish multidisciplinary service systems to improve the function and social participation of individuals with high-functioning autism, Asperger syndrome, and other developmental disorders. Currently, the majority of people with HFASD were not diagnosed as children and only a few people received adequate formal or informal support throughout childhood (Kamio and Inokuchi, 2009). Moreover, mental health

professionals have become increasingly aware of undiagnosed adults with HFASD seeking psychiatric treatment for their comorbid psychiatric symptoms.

The first aim of the present study was to determine the QoL of adults with HFASD living in the community in Japan. The second aim was to identify factors associated with QoL, both in the present and the past. We predicted that ongoing support from early childhood to adulthood is associated with a better QoL in adulthood.

## Methods

In January 2009, we conducted a nationwide survey by mailing questionnaires to 192 specialized facilities that provide consultation and daycare services for local residents with developmental disorders, and to prefectural centers that provide welfare and primary mental healthcare services for local residents. These facilities consisted of 61 Support Centers for Persons with Developmental Disorders, 65 Institutions for Persons with Autism, and 66 Centers for Mental Health and Welfare Services throughout Japan. Clinical staff at each facility helped identify and enroll study participants. Participants were eligible for the study if they had a diagnosis of ASD, were 18 years of age or older, and used any services provided by the facilities during the period 13 January to 13 February 2009. Among 1103 individuals who were identified as eligible, questionnaires were given to the 402 individuals who were willing to participate in the study and whose parents were also willing to participate. By the end of March 2009, 321 questionnaires had been collected from participants at 63 facilities (a response rate of 79.9%).

The protocol of this study was approved by the ethics committee of the National Center of Neurology and Psychiatry in Japan. Written informed consent to participate in our study was obtained from a parent or a guardian, and also from each participant where possible.

## Participants

Out of 202 respondents who returned questionnaires with the self-report portions completed, the final study sample consisted of 154 respondents (123 males and 31 females) with complete information provided by the respondents themselves, their parents, and facility staff who knew the respondents well. For seven ASD participants, information was obtained not from parents but from facility staff who knew the respondents well. Because the self-report questionnaires were distributed only to ASD participants whom facility staff thought could understand and respond appropriately, these participants should be considered to be relatively high-functioning. Although we could not confirm their functioning levels with cognitive test data, this assignment appears to be supported by the fact that 136 of the 154 participants (88.3%) received mainstream education and completed higher education without any support, and that only four participants (2.6%) received special education throughout grades 1 to 12. The mean age of the 154 service user participants was 27.6 years (SD 6.5 years, range 18–49 years), and their characteristics based on the parent-supplied information are outlined in Table 1. In decreasing order of frequency, clinical ASD diagnoses ranged from Asperger syndrome, pervasive developmental disorders, high-functioning autism, autism, to pervasive developmental disorders not otherwise specified (PDD-NOS). Table 2 outlines the past history of the ASD service user participants as completed by the parents.

## Survey questionnaires

The survey questionnaires comprised the following: parent (or staff)-rated items of the ASD service user's demographic information (listed in Table 1), past history (listed in Table 2), and performance

**Table 1.** Characteristics of ASD participants (N = 154)

Characteristics	N (%)
Gender	
Male	123 (79.9)
Female	31 (20.1)
Age categories (years)	
18–24	61 (39.6)
25 +	93 (60.4)
Residential status	
Independent living	11 (7.1)
Living with family	142 (92.2) <sup>e</sup>
Supported living (group home)	1 (0.6)
Marital status	
Married/partnered	9 (5.8)
Unmarried	145 (94.2)
Education	
≤high school <sup>a</sup>	92 (59.7)
Further higher education <sup>b</sup>	62 (40.3) <sup>f</sup>
Employment	
Employed <sup>c</sup>	37 (24.0)
Unemployed <sup>d</sup>	115 (74.7)
Homemaker	2 (0.1)
Comorbid with other medical conditions	
Physical conditions	16 (10.4)
Psychiatric conditions (other than ASD)	58 (37.7)
Challenging behaviors	
Self-injurious behaviors	14 (9.1)
Aggressive behaviors	45 (29.2)

<sup>a</sup>The category '≤high school' includes secondary high school, high school, and special schools for handicapped children.

<sup>b</sup>The category 'further higher education' includes college, polytechnic junior college, and graduate school.

<sup>c</sup>The category 'employed' includes part-time job, full-time job, and self-employed.

<sup>d</sup>The category 'unemployed' includes no occupation, during vocational training, and during leave.

<sup>e</sup>A majority of unmarried Japanese men (70.3%) and women (76.4%) (18-34 years) live with parents according to National Institute of Population and Security Research (2009).

<sup>f</sup>68.6% of new graduates from high school proceed to higher education according to Ministry of Education, Culture, Sports, Science and Technology (2009).

in his/her current environment (described below); self-rated QoL (nine items across two domains); and for staff only, several items concerning current family support.

**Performance in the current environment.** Parent participants were asked to rate the extent of difficulty that the ASD service user participant experienced when doing things related to general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions, and relationships in his/her current environment. Those questions were based on WHO's International Classification of Functioning, Disability, and Health (ICF), and the definition of 'current environment' includes assistive devices or personal assistance whenever the person actually uses them to perform actions or tasks. The parent participants answered questions using a 5-point rating scale (1 = complete difficulty; 2 = severe difficulty; 3 = moderate difficulty; 4 = mild difficulty; 5 = no difficulty).

**Table 2.** Past history of the ASD participants (N = 154)

Early developmental concerns	N (%)
Absent	29 (19.5)
Present	120 (80.5)
Age at first concern (median age)	30 months
Age at referral	48 months
Age at first diagnosis	123 months
Speech level at 6 years	
Words or two-word phrases	34 (24.8)
Sentences with more than three words	103 (75.2)
Early diagnoses before 4 years	
Diagnosed <sup>a</sup>	29 (18.8)
Service utilization <sup>b</sup>	
No utilization at any time	124 (80.5)
Continuous utilization through the entire life stages	22 (14.3)

<sup>a</sup>Includes diagnoses of ASD and other developmental disorders.

<sup>b</sup>Service refers to having professional advice regularly, participating in some therapeutic programs, receiving special educational aid.

*Quality of life.* Subjective QoL was measured using the WHOQOL-BREF, which is derived from the 100-item WHOQOL (The WHOQOL Group, 1995). The WHOQOL was developed to measure individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns, and is used widely and internationally. Its use has been validated for various populations, including psychiatric patients worldwide. Its shorter version, the WHOQOL-BREF, comprises 26 items on four domains of QoL: physical health, psychological health, social relationships, and environment. For the purpose of the present study, the six items of the 'psychological health' domain (bodily image and appearance, negative feelings, positive feelings, self-esteem, thinking, learning, and memory and concentration) and the three items of the 'social relationships' domain (personal relationships, social support, and sexual activity) of the Japanese version of the WHOQOL-BREF (WHOQOL 26) (Nakane et al., 1999; Tazaki and Nakane, 2007) were used. Each item is assessed by an individual diagnosed with ASD on a 5-point scale (1 = very poor/very dissatisfied/not at all; 2 = poor/dissatisfied/a little; 3 = neither poor nor good/a moderate amount; 4 = good/satisfied/very much; 5 = very good/very satisfied/extremely). The mean scores of these two domains were analysed.

*Current family support.* The family support situation was determined by responses to the question, 'Regarding the physical and psychological support provided by his/her family member, do you think it is actually helpful for him/her?' The facility staff who knew the person well answered using a 5-point rating scale (1 = very helpful; 2 = somewhat helpful; 3 = not helpful or unhelpful; 4 = not very helpful; 5 = not at all helpful) for the case of the father, mother, and sibling, respectively (Table 3).

*Demographic characteristics.* Demographic information was obtained through 17 items rated by parents, and included gender, age, residential status, marital status, education, employment, medical conditions, and challenging behaviors. In this study, we asked questions requiring yes or no answers regarding the presence or absence of self-injurious behaviors and aggressive behaviors. Self-injurious behaviors were defined as any kind of behaviors in which the ASD participants hurt themselves. Aggressive behaviors were defined as violent behaviors toward family members or



**Table 3.** Current family support to the ASD participants (N = 154)

	N (%)
Father	
Helpful	60 (39.0)
Not helpful	63 (40.9)
No father or unknown	31 (20.1)
Mother	
Helpful	119 (77.3)
Not helpful	15 (9.7)
No mother or unknown	20 (13.0)
Sibling	
Helpful	35 (22.7)
Not helpful	82 (53.3)
No sibling or unknown	37 (24.0)

other people, verbal aggression as statements such as ‘Die’ or ‘I will kill you’, and destructive behaviors as those causing serious material damage. The most important items are shown Table 1.

*Past history.* Developmental information was obtained through 19 items rated by the parents, and included age at parental concern, age at diagnosis, expressive language level at age 6, and service utilization. The most important items are shown in Table 2.

The self-rating part of the survey questionnaire was pilot tested in several clinical settings to confirm the ease of completion. It was confirmed that individuals with HFASD were able to understand and complete it satisfactorily, at levels similar to other psychiatric patients (Koyama et al., 2009).

### Statistical analysis

First, to compare the QoL domain scores for our ASD participants with those for a healthy Japanese population obtained using stratified sampling methods (N = 828; 410 males; aged 20–49) (Nakane et al., 1999; Tazaki and Nakane, 2007), the raw domain scores were converted to z scores using the mean and standard deviation of the Japanese standardization sample by gender and by age group (20–29, 30–39, 40–49) (Tazaki and Nakane, 2007). To obtain the z scores of participants 18–19 years of age, we applied the mean and standard deviation for the age range of 20–29 years to their raw QoL domain scores. Second, Pearson correlations were calculated to assess associations between performance in the current environment and QoL in both the psychological health and social relationships domains. Third, using two sample *t*-tests, z scores of the QoL domain scores were compared between subgroups of the following demographic characteristics: gender (male vs. female), age ( $\leq 24$ , 25+), residential status (independent living vs. other), marital status (unmarried vs. other), education ( $\leq$ high school vs. additional higher education), employment (unemployed vs. other), medical conditions and challenging behaviors (present vs. absent), sentence level at 6 years of age (present vs. absent), diagnosis before 4 years of age (present vs. absent), and service utilization (none vs. continuous). For current family support, the responses were classified into two categories of ‘helpful’ (1, 2) and ‘not helpful’ (3, 4, 5). Finally, a stepwise multiple regression analysis was used to identify the most important characteristics in predicting QoL domain scores. As independent

**Table 4.** Means and SD for raw scores on psychological and social domains of WHOQOL 26 rated by ASD participants themselves (N = 154), and z scores converted from the raw scores of the ASD participants (N = 154)

QOL domain <sup>a</sup>	Mean (SD)	<i>t</i>	<i>p</i>	95% confidential interval
Psychological health				
Raw score	2.78 (0.74)			
Z score	-.80 (1.24)	-8.0	.0001	-1.0 to -.60
Social relationships				
Raw score	2.71 (0.82)			
Z score	-.63 (1.25)	-6.2	.0001	-.83 to -.43

<sup>a</sup>Psychological domain contains six items (1–5) and social domain contains three items (1–5). The mean raw domain scores of the ASD participants were converted to z scores using the mean and standard deviation of the Japanese standardization sample by gender and by age range (20–29, 30–39, 40–49) (Tazaki and Nakane, 2007).

variables, characteristics that were found to be significant on *t*-tests and all the demographic characteristics were used. A *p*-value < .05 was considered to indicate statistical significance. Statistical analysis was performed using SPSS version 18.0 (SPSS Inc., Chicago, USA).

## Results

### *Psychological and social aspects of QoL in the ASD participants*

The raw score means of the ‘psychological health’ and ‘social relationships’ domains of the WHOQOL 26 as rated by the ASD participants were 2.78 and 2.71, respectively (Table 4), whereas those of the Japanese standardization sample aged 20–49 ranged from 3.26 to 3.32 for the psychological health domain and from 3.19 to 3.25 for the social relationships domain, varying slightly by gender and age (Tazaki and Nakane, 2007). The differences in mean z scores of the ASD participants from those of the Japanese standardization sample were -0.80 for the psychological domain and -0.63 for the social domain, indicating that psychological and social aspects of QoL of the ASD participants were significantly lower (worse) than those of the healthy Japanese population (*p* < .000 for both).

### *Associations between psychological and social QoL and performance in the current environment in the ASD participants*

Pearson correlations revealed that the QoL scores in both psychological and social domains for the ASD participants were not significantly correlated (*r* = 0.06 and *r* = 0.01, respectively, n.s.) with everyday performance in the current environment. This may be interpreted to suggest that the psychological and social domains of QoL capture more of the subjective aspects of QoL, and not objective function or capacity.

### *Factors related to psychological and social QoL in the ASD participants*

As shown in Table 5, *t*-tests revealed that higher QoL was significantly associated with being male (*p* < .05 for psychological domain, *p* < .01 for social domain), having received a diagnosis before 4 years of age (*p* < .05 for psychological domain), and mother’s support being helpful (*p* < .001 for both psychological and social domains). Lower QoL was significantly associated with suffering

**Table 5.** Comparison between two ASD subgroups by demographic characteristics, medical conditions past history, and current family support (N = 154)

	Psychological health domain QoL			Social relationships domain QoL		
	Mean	score	t	Mean	score	t
<b>Demographic characteristics</b>						
Gender (male/female)	2.83	2.56	2.35*	2.73	2.60	2.68**
Age (18–24/25+)	2.76	2.79	0.34	2.80	2.64	0.77
Residential status (living with family/independent living)	2.78	2.73	0.49	2.74	2.27	1.73
Marital status (unmarried/married or partnered)	2.78	2.74	0.37	2.72	2.46	1.37
Education ( $\leq$ high school/further higher education)	2.69	2.90	-1.51	2.64	2.80	-1.14
Employment (unemployed/employed)	2.76	2.85	-0.48	2.69	2.80	-0.40
<b>Medical conditions</b>						
Comorbid psychiatric conditions (absent/present)	2.91	2.58	2.76**	2.85	2.43	3.14**
Comorbid physical conditions (absent/present)	2.76	2.89	-0.38	2.71	2.60	0.42
Self-injurious behaviors (absent/present)	2.81	2.50	1.68	2.74	2.52	1.30
Aggressive behaviors (absent/present)	2.85	2.44	2.58*	2.80	2.36	2.38*
<b>Past history</b>						
Sentence level at 6 years (word or two-word phrases/sentence with more than three words)	3.05	2.71	2.32*	2.93	2.65	1.64
Early diagnoses before 4 years (not diagnosed/diagnosed)	2.71	3.04	-2.02*	2.69	2.86	-1.18
Service utilization (no use at any time/continuous use through all life stages)	2.77	3.04	-1.63	2.71	2.73	-0.13
<b>Current family support</b>						
Father (not helpful/helpful)	2.73	2.81	-0.73	2.66	2.85	-1.25
Mother (not helpful/helpful)	2.14	2.84	-4.01***	1.91	2.84	-4.50***
Sibling (not helpful/helpful)	2.71	2.72	0.00	2.61	2.83	-0.92

\*\* $p < .05$ , \*\*\* $p < .001$ .

**Table 6.** Summary of a stepwise multiple regression analysis investigating the predictive variables of demographic characteristics, medical conditions, past history, and current family support on QoL 'psychological health' domain scores of the ASD participants (N = 154)

Variables entered	Standardized coefficients ( $\beta$ )	t	p-value
Early diagnosis before 4 years	0.22	2.22	.05
Mother's support being helpful	0.32	3.24	.01

Adjusted  $R^2 = 0.16$ . Excluded variables by a stepwise procedure were gender, age, residential status, marital status, education, employment, comorbid psychiatric conditions, aggressive behaviors, speech level at 6 years.

from comorbid psychiatric conditions ( $p < .01$  for both psychological and social domains), behaving aggressively ( $p < .01$  for psychological domain,  $p < .05$  for social domain), and having spoken sentences at 6 years of age ( $p < .05$  for psychological domain).

The results of multiple regression analysis are summarized in Tables 6 and 7. Mother's support being helpful emerged as significantly predictive of higher QoL for both the psychological and social domains ( $\beta = 0.32$ ,  $p < .01$ ;  $\beta = 0.32$ ,  $p < .001$ , respectively). In addition, having received early diagnosis before 4 years of age was also significantly associated with higher psychological

**Table 7.** Summary of a stepwise multiple regression analysis investigating the predictive variables of demographic characteristics, medical conditions, past history, and current family support on QoL 'social relationships' domain scores of the ASD participants (N = 154)

Variables entered	Standardized coefficients ( $\beta$ )	t	p-value
Aggressive behaviors: absent	0.18	2.15	.05
Mother's support being helpful	0.32	3.69	.001

Adjusted  $R^2=0.14$ . Excluded variables by a stepwise procedure were gender, age, residential status, marital status, education, employment, comorbid psychiatric conditions.

QoL ( $\beta = 0.22, p < .05$ ), and not having aggressive behaviors was significantly associated with higher social QoL ( $\beta = 0.18, p < .05$ ).

## Discussion

The present study investigated long-term outcomes for adults with HFASD living in the community in Japan, focusing on subjective aspects such as QoL, and also identified past and current environmental factors that had (pseudo) predictive value. Our major findings are the following.

First, as expected, the self-reported QoL in the psychosocial domain of our sample with HFASD over 18 years of age was found to be significantly lower than the gender- and age-matched healthy Japanese population. The QoL was not found to be related to parent-reported performance level, age, or conventionally used outcome indicators such as residential, marital, educational, and employment status. Although these conventional indicators are certainly important to consider as long-term outcomes, psychosocial QoL in our adults with HFASD appeared not to be related to them. Thus, our findings suggest that the QoL reported by adults with HFASD might be measuring an additional independent aspect that should be considered in judging long-term outcomes in populations with HFASD, which is in line with Renty and Roeyers (2006) and Ruble and Dalrymple (1996).

Second, receiving diagnosis before 4 years of age and mother's support that met current needs were determined to be factors associated with better psychological QoL for adults with HFASD. This finding supports our prediction and is partially consistent with Renty and Roeyers (2006) in that support variables had significant impact on long-term outcomes in HFASD. In Renty and Roeyers (2006), perceived informal support indicative of availability, but not received formal or informal support indicative of actual transfer of advice, aid, and affect, was found to have predictive value; both support characteristics were measured using validated scales. On the other hand, family support characteristics in the current study were not measured using such standard scales, and were instead judged by the facility staff who knew the person well and therefore knew to what degree the family support was actually helpful to the person. This is different from subjectively perceived availability or objectively measured actual transfer of family support. The question was intended to ask how family support met the participant's actual needs from an objective viewpoint. However, validation of this is required.

To our knowledge, the present study is the first to associate early diagnosis with better psychological QoL in adults with HFASD. Only 29 cases out of our sample (18.8%) were diagnosed before 4 years of age, and 22 cases among them used some services during childhood. On the other hand, parental concerns about development were reported for a majority of the sample (66.9%). Why parental concerns did not lead to early diagnosis may be explained by a lack of healthcare or educational professionals with accurate knowledge and wide experience with HFASD at that time in Japan. Moreover, socioeconomic status (SES) could be associated with age of diagnosis: according to birth cohort data from individuals with autism born in California between 1992 and 2001, children

of high SES parents were diagnosed earlier (Fountain et al., 2011). The role of SES in our Japanese participants with HFASD is unknown and this remains a topic for future study.

The finding that mother's support was the best predictor of psychosocial QoL of individuals with HFASD has to be interpreted with caution, because it suggests a bidirectional but not causal association. However, the obvious significance of mother's support but not father's in our study may be related to the Japanese socio-cultural environment in relation to child rearing. For example, Japanese mothers have traditionally been viewed as overprotective and overindulgent toward their children (Doi, 1973). Although it is not clear how such a cultural bias in childrearing practices influences familial attitudes toward a child with HFASD, future intervention must target parenting behavior and assist mothers with formal and informal social support after an early diagnosis of ASD.

Third, our results suggest that adults with aggressive behaviors might experience lower psychosocial QoL. This could be attributable to satisfactory social relationships being disrupted by violent behavior toward others or anger being reflected on others or self, although the causal relationship is not clear.

*Study limitations.* There are several methodological limitations in the present study. First, our sample ( $N = 154$ ) who returned a complete set of self-, parent-, and facility staff-report questionnaires were not representative of all persons with HFASD, although the male:female ratio was 4:1, which is similar to the epidemiological data in Japan (Honda et al., 2005). In regard to the 48 individuals not included in the analyses because of incomplete data, although they were older and more educated than our sample of 154, we confirmed, based on the information that was available, that they did not differ from our sample in psychological and social QoL scores. Moreover, being male, absence of comorbid psychiatric conditions, and mother's support being helpful were significantly associated with higher QoLs, as in our sample. However, whether early diagnosis before 4 years or having aggressive behaviors was similarly predictive of QoL in the 48 individuals not included could not be confirmed. Second, diagnostic status and IQ level of our sample was based on reports by parents and facility staff and was not confirmed using standard procedures. Third, we chose to focus on the domains of 'social relationships' and 'psychological health' because we considered that they best reflected psychosocial QoL, although the 'physical health' and 'environment' domains also reflect psychosocial functioning in everyday life to some degree. We based this decision on the findings of previous studies. Health-related QoL studies on ASD found that individuals with ASD scored lower in most domains than healthy populations (Jennes-Coussens et al., 2006; Kamp-Becker et al., 2010; Kuhlthau et al., 2010), but children with ASD had significantly lower scores for psychosocial health but not physical health than other clinical populations with chronic conditions (Kuhlthau et al., 2010), and adolescents and young adults with HFASD had higher scores than patients with schizophrenia-spectrum disorders except for the 'social relationship' domain (Kamp-Becker et al., 2010). Future research should aim to clarify the relationships between the various QoL domains in ASD. Fourth, past history was retrospectively obtained only from parents and was not based on a review of the clinical records, so there is a chance that the history has been influenced by parents' recall or memory bias.

*Clinical implications.* Despite these methodological limitations, this study points to some important clinical issues. First, clinicians can help children maximize their chances for high long-term QoL by changing environmental factors and treating comorbid psychiatric conditions related to aggressive behaviors, both of which may affect psychosocial well-being and QoL, even if the autistic core symptoms are largely not changeable. Bastiaansen et al. (2005) demonstrated that the QoL of a subgroup of child psychiatric patients improved although the level of psychopathology remained high during a 1-year follow-up period. Therefore, improving QoL should be included as one of the goals in treating individuals with HFASD.

Second, the present study provides evidence for the long-term significance of early detection and intervention for children with HFASD. Although there has been controversy about the positive and negative effects of early diagnosis for parents (Johnson et al., 2007), it may be important for clinicians to convey to parents – and empower them – that prognosis is not deterministic and may be changed by appropriate treatment and family support (Tantam, 2000).

## Conclusions

This study demonstrated that self-reported QoL by adults with HFASD can be an important subjective aspect of long-term outcomes. Environmental factors, such as mother's support being helpful and early diagnosis, were associated with better QoL, and aggressive behaviors were associated with poorer QoL in adulthood, whereas expressive language level in preschool years, a conventional outcome indicator, did not predict QoL levels. To improve long-term QoL, professionals need to detect autistic symptoms in the early years, evaluate the needs of the child and family, provide consistent support, and comprehensively monitor all aspects of mental health. Future outcome studies should be conducted prospectively to determine predictive factors at each developmental stage and at the same time try to determine the mediators and moderators that modify the developmental trajectories for children with ASD.

## Funding

This study was funded in part by the Japanese Ministry of Health, Labor, and Welfare (H19-SHOGAI-008), and an Intramural Research Grant (20B-5) for Neurological and Psychiatric Disorders of NCNP.

## Acknowledgements

We thank all the participants for their co-operation. We also thank to Hisami Nishida and many facility staff and clinicians at the Support Centers for Persons with Developmental Disorders, Institutions for Persons with Autism, and Centers for Mental Health and Welfare Services.

## References

- Bastiaansen D, Koot HM, Ferdinand RF and Verhulst FC (2004) Quality of life in children with psychiatric disorders: self-, parent, and clinician report. *Journal of the American Academy of Child and Adolescent Psychiatry* 43(2): 221–230.
- Bastiaansen D, Koot HM and Ferdinand RF (2005) Psychopathology in children: improvement of quality of life without psychiatric symptom reduction? *European Child and Adolescent Psychiatry* 14(7): 364–370.
- Doi T (1973) *The anatomy of dependence*. Tokyo: Kodansya International.
- Fountain C, King MD and Bearman PS (2011) Age of diagnosis for autism: individual and community factors across 10 birth cohorts. *Journal of Epidemiological Community Health* 65: 503–510.
- Gerber F, Baud MA, Giroud M and Carminati GG (2008) Quality of life of adults with pervasive developmental disorders and intellectual disabilities. *Journal of Autism and Developmental Disorders* 38: 1654–1665.
- Honda H, Shimizu Y, Imai M and Nitto Y (2005) Cumulative incidence of childhood autism: a total population study of better accuracy and precision. *Developmental Medicine and Child Neurology* 47: 10–18.
- Howlin P, Goode S, Hutton J and Rutter M (2004) Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry* 45: 212–229.
- Jennes-Coussens M, Magill-Evans J and Koning C (2006) The quality of life of young men with Asperger syndrome: a brief report. *Autism* 10: 403–414.
- Johnson C, Myers S and the Council on Children with Disabilities of the American Academy of Pediatrics (2007) Identification and evaluation of children with autism spectrum disorders. *Pediatrics* 120: 1183–1215.
- Kamio Y and Inokuchi E (2009) Psychiatric practice's role for individuals with developmental disorders: Current trend and future issues. *Journal of Japanese Association of Psychiatric Hospitals* 28: 14–20.

- Kamio Y, Tobimatsu S and Fukui H (2011) Developmental disorders. In: Decety J and Cacioppo J (eds) *The Oxford Handbook of Social Neuroscience*. Oxford: Oxford University Press, 848–858.
- Kamp-Becker I, Schröder J, Remschmidt H and Bachmann CJ (2010) Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. *GMS Psycho-Social-Medicine* Aug 31; 7: pii: Doc03.
- Kobayashi R, Murata T and Yoshinaga K (1992) A follow-up study of 201 children with autism in Kyushu and Yamaguchi areas, Japan. *Journal of Autism and Developmental Disorders* 22: 395–411.
- Koyama T, Kamio Y, Inada N, Adachi J, Uno Y and Kasahara M (2009) Laifusutêji ni okeru syujyunoyoin to chokiyogo tonon kannren nikansuru kenkyu: Chokiyogo ni kansuru zenkokuchosa wo motoni [Examinations on the association between long-term outcome and related factors across life stage]. In: Kamio Y (ed) [*Annual Report of Research Supported by Health and Labour Sciences Research Grants*]. Tokyo: National Center of Neurology and Psychiatry.
- Kuhlthau K, Orlich F, Hall TA, Sikora D, Kovacs EA, Delahaye J et al. (2010) Health-related quality of life in children with autism spectrum disorders: Results from the Autism Treatment Network. *Journal of Autism and Developmental Disorders* 40: 721–729.
- Landa RJ (2008) Diagnosis of autism spectrum disorders in the first 3 years of life. *Nature Clinical Practice Neurology* 4: 138–147.
- Mawhood L, Howlin P and Rutter M (2000) Autism and developmental receptive language disorder—a comparative follow-up in early adult life. I: Cognitive and language outcomes. *The Journal of Child Psychology and Psychiatry* 41: 547–559.
- Ministry of Education, Culture, Sports, Science and Technology (2009) *School Basic Survey 2009*. Nikkei Insatsu. Available at: [http://www.mext.go.jp/b\\_menu/toukei/001/08121201/1282588.htm](http://www.mext.go.jp/b_menu/toukei/001/08121201/1282588.htm).
- Nakane Y, Tazaki M and Miyaoka E (1999) WHOQOL-BREF survey of general population. *Iryo To Shakai (Journal of Health Care and Society)* 9: 123–131.
- National Institute of Population and Social Security Research (2007) Report on the thirteenth Japanese National Fertility Survey in 2005. Volume II: Attitudes towards marriage and the family among Japanese singles, March 2007. Available at: <http://www.ipss.go.jp/syoushika/bumken/DATA/pdf/132542.pdf>.
- Persson B (2000) Brief report: A longitudinal study of quality of life and independence among adult men with autism. *Journal of Autism and Developmental Disorders* 30: 61–66.
- Renty J and Roeyers H (2006) Quality of life in high-functioning adults with autism spectrum disorder. *Autism* 10: 511–524.
- Ruble L and Dalrymple N (1996) An alternative view of outcome in autism. *Focus on Autism and Other Developmental Disabilities* 11: 3–14.
- Saldaña D, Álvarez RM, Lobatón S, Lopez AM, Moreno M and Rojamo M (2009) Objective and subjective quality of life in adults with autism spectrum disorder in southern Spain. *Autism* 13: 303–316.
- Tantam D (2000) Adolescence and adulthood of individuals with Asperger syndrome. In: Klin A, Volkmar FR and Sparrow SS (eds) *Asperger Syndrome*. New York: Guilford, 367–399.
- Tazaki M and Nakane Y (2007) *WHOQOL26 Tebiki Kaiteiban*. Tokyo: Kaneko Shobo.
- Tsatsanis K (2003) Outcome research in Asperger syndrome and autism. *Child and Adolescent Psychiatric Clinics of North America* 12: 47–63.
- The WHOQOL Group (1995) World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine* 41: 1403–1409.

# 児童精神医学研究の将来展望

神尾陽子

## 1. はじめに

少子高齢化が著しい私たちの社会が、将来、その活力を衰退させることなく、また、国民すべてが心の健康を生涯にわたって長く維持していくためにも、子どものメンタルヘルスの重要性をより強調すべきであると思う。児童期の精神医学は今後より重要となる。それは二人に一人は生涯になんらかの精神障害に罹患するという事実もさることながら、これまで成人の疾患と考えられてきたうつ病や不安障害の約半数が14歳までの児童期に初発することがわかってきたことが大きい<sup>1)</sup>。児童期に発症する精神障害は、自閉症のように生後まもなく明らかとなるものから、注意欠如・多動性障害のように就学後に診断可能となるもの、そして不安障害、うつ病、摂食障害、統合失調症など思春期前後に発症が増えるものまで幅広い。しかも、児童期から成人期にかけての発達過程における診断移行や重複、複雑化、回復など様々な現象の機序はまだ解明されていない。治療を必要としていながら「問題児」、あるいは親のしつけの問題、などとの烙印や誤解を受けてきた多くの子どもとその家族を、長く続く苦痛から解放するための科学的な解決法は、この領域の研究を進展させることである。米国精神保健研究所(NIMH)は、これからの精神疾患研究においては、遺伝と環境の制約の下で経験に依存して「発達」する脳の、神経回路の形成異常やそ

れに基づく学習(記憶の消去を含む)など高次機能の異常を解明するというエビジェネティックな視点を重視する姿勢を打ち出している<sup>2)</sup>。このような発達の観点に立つと、成人の病気と考えられてきた精神疾患も、児童期に始まる脳発達過程の異常として再定義される可能性がある。今日の精神科治療は、発症から受診、そして治療開始までタイムラグがあるため、もっぱら症状の軽減や機能回復を目指す対症療法とならざるを得ず、長期予後に問題を残している。将来、児童期の早期マーカーを手がかりに早期診断が可能となれば、早期治療や予防につながり、成人期における長期予後の向上が期待される。本稿では、わが国における児童精神医学研究の将来を展望するにあたって、克服すべきバリアと、研究やそれを支える体制が目指す方向性について、私見を述べたい。

## 2. 子どものメンタルヘルスへの国民の共通認識と合意の形成

米国オバマ大統領は、自閉症を、がん、心臓疾患と並ぶ主要な研究ターゲットとして、2010年度に1億4100万ドルを予算化し、自閉症の病因解明と治療法開発のための研究に加えて、全国民への2歳でのスクリーニングと早期治療に言及し、国レベルで家族へのサービス向上に取り組む姿勢を明確にしている。眩いばかりの研究推進計画である。さらに米国では、薬物依存



やうつ病などの様々な子どもたちのメンタルヘルスについても、全国子どもメンタルヘルス啓発デーを設け、全国規模で子どもが参加できるイベントを実現させている。そうした米国でも、かつてわが国もそうであったように、誤った自閉症学説がもたらしたスティグマのために、自閉症児の家族は長い間苦しんだ過去があったが、自閉症啓発デーを初めとする官民連携した大規模な社会啓発がスティグマの軽減などに功を奏したことがわかる。

このように、日本においても子どものメンタルヘルスについてエビデンスを生み出すような大規模な研究を推進するには、国全体での取り組みが必要であり、あわせて国民一人一人の意識向上とスティグマ撲滅、そして大人の影響を受けやすい子どもたちへのメンタルヘルス教育が重要である。わが国では、子どもの精神疾患や発達障害に対する偏見はかなり改善されたものの、見えない障害であるだけに誤った思い込みはまだ根強い。子どものメンタルヘルスに関する国民の共通認識と合意の形成は、大規模な臨床研究の発展の前提であり、すべての国民との開かれた議論を踏まえて、国主導の取り組みが望まれる。

### 3. 子どものメンタルヘルスの診療体制の整備

子どものメンタルヘルスを考える際の大きな課題は、この領域の専門家も診療機関も圧倒

的に不足し、地域格差が大きいことである。にもかかわらず、不登校、ひきこもり、少年犯罪など、この数十年間で専門家への社会的ニーズは高まっている。2004年6月に閣議決定された「少子化社会対策大綱」や同年成立の発達障害者支援法では専門家養成と医療機関の確保が謳われ、それを受けて厚生労働省は「子どもの心の診療拠点病院」作りとそのネットワーク化に乗り出した。このモデル事業は地域の一般小児科医あるいは一般精神科医による1次診療から、入院機能も持つ中核的医療機関での専門医による2次あるいは3次診療までの体制整備を目指すものである。日本の子どもたちにとって最良かつ安全な治療法は、このような日本の拠点病院を中心とした多施設共同の大規模臨床研究によって、倫理的な方法で検証されたエビデンスに基づくものである<sup>3)</sup>。たとえば、既に成人で有効性と安全性が確認された薬物治療や認知行動療法などの非薬物治療についても、それらを用いた子どもでの有効性と安全性や標準的治療法のエビデンスが早急に検証される必要があるが、ここで述べたバリアが克服されないと大規模臨床研究の実施は困難である。

### 4. 児童精神医学の高度専門教育の確立

この領域を志す医学生が常に一定数いるにもかかわらず、人材不足が解消されないのは、現在もなお国内の大学病院や臨床研修病院に

おける児童精神医学に関する後期研修の選択肢がきわめて限られていることもその要因の一つである<sup>4)</sup>。さらに今後期待される能力として、エビデンスを生み出す臨床研究を主体的に遂行できる研究能力が重要であり、その習得も今後、整備すべき高度専門教育の目標に含めるべきである。樋口<sup>5)</sup>が指摘するように、臨床研究軽視の傾向は精神医学領域の特性と相俟ってその発展にきわめて大きなバリアとなっている。臨床研究の入り口にあたる精神医学的診断の段階で、データの信頼性確保に必要な構造化面接などの診断手続きがわが国ではまだ標準化や訓練すら保証されていないことも、国内外の多施設間でのデータ共有と共同研究のバリアとなっている。そうした現状への反省を踏まえ、今後、児童精神医学領域の高度専門教育を確立するには、海外の例（英国モーズレー病院/ロンドン大学キングスカレッジの児童青年期精神医学卒業ディプロマ・コースなど）も参考にしながら、大学やナショナルセンターなどを拠点とし、従来の専門性を超えた柔軟性に富むシステム設計をもって、そうした教育研修、実効性のある臨床基盤の拡充と研究の発展という三位一体改革を毅然として遂行していかなければならない。

## 5. 基礎研究と臨床研究の 双方向的な連携

精神医学研究一般において、今後ますます「発



### PROFILE

神尾陽子  
(かみお ようこ)  
日本学術会議連携会員、独立行政法人国立精神・神経医療研究センター・精神保健研究所 児童・思春期精神保健研究部部長、医学博士  
専門：児童精神医学

達」の視点が重要となってくる背景には、今日、分子レベルで解明が進んでいるエピジェネティクス機序により、人の発達期にみられる精神現象や行動、パーソナリティの多様性や個人差が説明されうるのではないかと、という期待がある。エピジェネティクスとは、DNA配列の変化を伴うことなくDNA修飾により遺伝子発現制御の変化が生じるメカニズムを指す。実際に、人において特定のDNA配列多型と児童虐待など特定の環境、そして精神症状との間の関連を検証することで、精神症状の発現に関する遺伝と環境の相互作用(G×E)が確認されている。ここに、精神疾患の発症におけるエピジェネティクス機序の関与が示唆されているのである。今後は、分子レベルから動物モデルに至る(広義の脳科学研究も含む)基礎研究と、人を対象とした治療研究を主とする臨床研究とを双方向的に検証させながら推進する段階に来ているのではないかと、と思われる。目指す方向が同じと言っても、基礎研究と臨床研究の間には大きなギャップがあるのは事実で、それを埋めるために不十分なままの仮説検証から臨床応用を急ぐと、児童精神医学が過去に冒し

た同じ過ち（自閉症の母原説など）を繰り返すおそれがないとは言えない。もちろん、研究のスピードアップは常に求められるのではあるが、異なる学問的背景を持つ多領域が、人の発達していく脳機能の破綻と回復に関する結論を出すためには、生態学的にみて徹底した妥当性検証の議論をし尽くすだけの成熟した学際的研究土壌を育てることが先である。そうした土壌の中ではじめて基礎研究と臨床研究とが健全なバランスを保ち、社会への真の貢献が可能になるものと思われる。

## 6. 長期間に及ぶ 大規模コホート研究の実現<sup>6)</sup>

ニュージーランドのダニューデイン研究（Dunedin Multidisciplinary Health and Development Study）などの長期間のコホート研究では、精神疾患の発症を予測する因子が多数特定され、G×E相互作用の観点からライフステージを通じた精神機能破綻のメカニズムだけでなく、過酷な環境の影響からの回復過程（レジリエンス）のメカニズムについても解明されようとしている。今年から、わが国でも全国10万人の子どもを対象とする出生コホート調査（エコチル調査）が立ち上がった。その目的は、子どもの健康に影響をもたらす環境要因を明らかにすることで、主要なアウトカムの一つに自閉症が位置づけられ、その他のメンタルヘルスも調査項目に含まれている。ただ残念な

ことに13歳時点で追跡は終了予定となっている。このような大規模コホートの実施はまさに国家的事業で非常に貴重な財産である。今後、ぜひ多方面からの協力を得て追跡期間を延長し、老年期までの長期経過を明らかにすると同時に、自然史をたどる観察研究群に加えて、介入を行うハイリスク群を追加するなどすれば、臨床的意義がさらに高まるものと考えられる。

## 7. おわりに

本稿では、日本の児童精神医学研究の現状と克服すべき課題を整理し、将来の発展のために研究やそれを支える体制が目指す方向性を中心にいくつか提案を行った。子どものメンタルヘルスが長らく精神医学の対象とならなかった背景には、アリエスが「子どもは近世になって発見された」と考察したような社会学的事情が無関係ではないであろう。今日私たちは、子どもの脳は遺伝的な制約のなかにあっても、社会学的な文脈だけでなく、あらゆる意味において環境からの影響を受けて多様な発達の道すじを辿る、ということを知っている。精神疾患の予後の向上や予防に役立つ介入は、いつ、どのようになされるべきなのかという問いに対する答は、児童精神医学の枠組みを超えて精神医学にとってもまた重要である。児童精神医学の研究基盤整備が診療体制や高度専門教育の整備と同時並行で早急に進められることを期待する。

.....

## 参考文献

1. Kessler RC, Berglund P, Demler O et al. Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry* 62: 593-602 (2005)
2. National Institute of Mental Health. Strategic Plan. <http://www.nimh.nih.gov/about/strategic-planning-reports/index.shtml>
3. 日本学術会議臨床医学委員会臨床研究分科会 提言「エビデンス創出を目指す検証的治療研究の推進・強化に向けて」(準備中)
4. 山内俊雄. 子どもの心の診療の現状と問題点: 全国大学医学部・医科大学における教育・心療の実態調査から. 第104回日本精神神経学会総会シンポジウム児童精神科医の育成、現状と課題. *精神神経学雑誌* 111:174-187(2009)
5. 樋口輝彦. なぜ、今、臨床研究が大切なのか. *学術の動向* 11:10-14 (2009)
6. 神尾陽子. 発達障害の子どものさまざまな育ちを支える. *学術の動向* 4: 58-63 (2010)