

The Current State of Autism Spectrum Disorders in East Asia and Related Issues

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Introduction

In 2009 I had the opportunity to visit Beijing and Shanghai at the end of March and to conduct research at the Hanoi University of Education in Vietnam for six months from beginning in April. I also had the opportunity to participate in the Asia-Pacific Autism Conference 2009 (APAC '09) which was held in Sydney, Australia in August of that year. Based on these experiences, I would like to present the current state of, and issues related to, autism research, particularly in the East Asia region, as well as some of what I saw and heard during my overseas visits that is relevant to this topic.

The Current State of Autism Research in East Asia

In developed countries, it has been said that in the past the three major diseases among children with developmental disabilities were mental retardation, cerebral palsy, and epilepsy. The incidence of cerebral palsy has seen a significant reduction, however, due to remarkable developments in neonatal-perinatal medicine over the past thirty years, and impressive advances have been made in epilepsy treatments due to the development of antiepileptic drugs and advances in blood concentration measurement technology. However, in the area of developmental disabilities, the incidence of autism and similar disorders has been increasing in inverse proportion to that of these other disorders. In particular, the rise in the rate of increase in autism spectrum disorders from the late 1990s

onward (Figure 1) has become a notable worldwide trend.

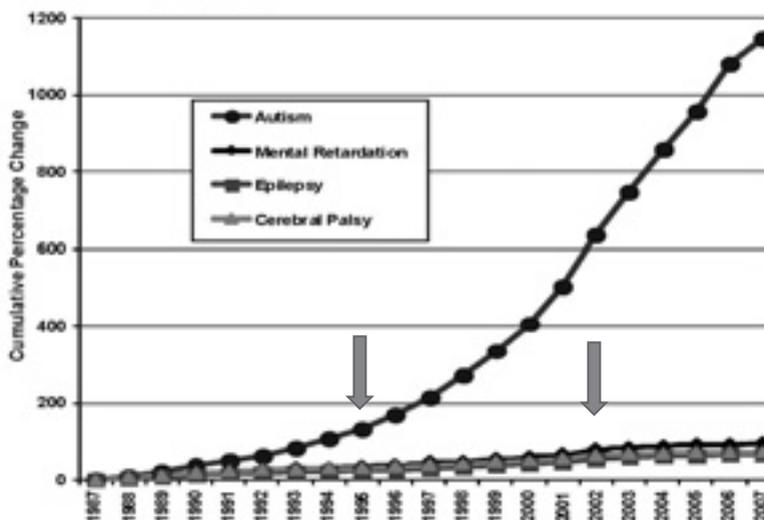


Figure 1: Changes in the Incidence Rate of Autism, Cerebral Palsy, and Epilepsy (California, USA)

The figure above shows the incidence rates of autism, cerebral palsy (CP), epilepsy, and mental retardation (MR) in California, USA from 1987 to 2007, and an ongoing surge in the incidence rate of autism can be seen from around 1995 onward. So what is the current situation concerning children with developmental disorders in developing countries such as Vietnam and China?

The figure below shows the results of children's medical examinations performed at the Department of Rehabilitation Medicine at the National Children's Hospital in Vietnam. At 10%, the incidence rate of autism is only one fifth that of cerebral palsy (50%). The relationship between rates of incidence is diametrically opposed to the previously discussed situation in California. For example, when a comparison is made for the year 2002, in California the rate of autism

is fifteen times that of cerebral palsy or mental retardation, whereas in Vietnam the rate of autism is lower than that of mental retardation and cerebral palsy, being only one-fifth that of cerebral palsy and two-fifths that of mental retardation (see Figure 2). It is clear that even when the variety and type of developmental disorder is the same, the incidence rate may differ in developed and developing countries.

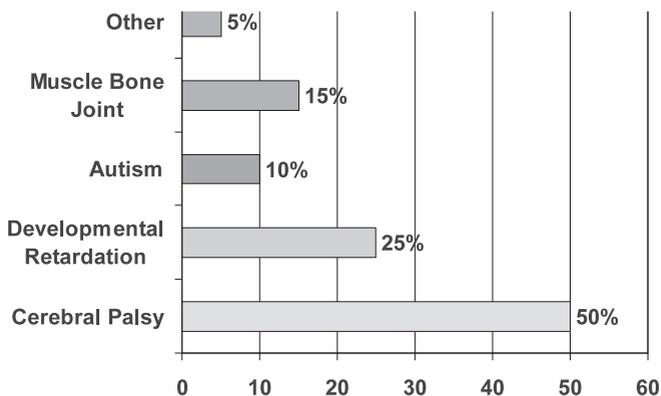


Figure 2: Incidence Rate of Autism, Cerebral Palsy and Mental Retardation (Hanoi, Vietnam)

Autism Research in China

I spent International Autism Day, at April 02, 2009, in Beijing. At a symposium sponsored by the Committee on Social Policy for Disabled Children, which was held in a hall at the Chinese Academy of Social Sciences, I had the opportunity to present a report entitled “The Current Situation and Challenges concerning Welfare Policy, Education and Medical Care for Children with Autism in Japan - Paradigm Shift and the Construction of a New Support System.” Other presenters included presenters from the United States, Taiwan, and China. Representatives of non-governmental organizations (NPOs) and non-profit organi-

zations (NPOs) concerned with education and welfare issues related to autism from all over the country gathered at this event (many of these organizations evolved from parent organizations). There were about 300 participants in total.

It is well known that the first case study in the world which used the name “autism” was conducted by the American child psychiatrist Leo Kanner in 1943, but in Japan the first such study was conducted by child psychiatrist Taeko Washimi (married name Nakazawa) in 1953, ten years after Kanner’s study and now over fifty years ago (Araki, 2011).

A report on the cases of four autistic children by Tao Guo Tai of the Chinese Children’s Mental Health Center published in 1982 was the beginning of research on autism in China. The history of autism treatment and education in this country began with the establishment of Beijing Stars and Rain. Beijing Stars and Rain was established as a private organization in 1993 by Tian Hui Ping, the parent of an autistic child, and was the first organization in China to provide educational services to autistic children and their families. The first purpose for which Beijing Stars and Rain was founded was to provide early, individualized education programs for children with autism. The second was to provide parents and other family members with knowledge about autistic children and to help these families acquire the knowledge and skills needed to facilitate the development of their children in their daily lives. The third purpose of the organization was to heighten social awareness and increase the understanding and acceptance of autism and autistic children and the recognition of the right of autistic children to exist and develop (Zhang and Araki, 2010).



Photo 1: At Beijing Stars and Rain
(With participants from Japan, China and Vietnam. Photograph by Araki.)

Beijing Stars and Rain is located in a suburban area about 40 minutes by taxi from the center of Beijing. Although this was my second visit, new facilities had been built for people in their adolescence and adulthood, and a new system to support children from their preschool years until adolescence and adulthood was being put in place.

In the last decade or so, the development of institutions for the education of children with disabilities has been making rapid progress in China, especially in urban areas. Although in the past there were classes for disabled children at elementary and junior high schools, the creation of schools for mentally retarded children (called “peizhi” schools, equivalent to “schools for physically or mentally handicapped children” or “schools for support special needs” in Japan) has been undertaken by both the public and private sectors. Housing facilities (dormitories) have also been built, making it possible for children to attend these schools even if their families live far away.

Autism Research in Vietnam

Autism research has been seriously conducted in Vietnam for about ten years. On two occasions during this ten-year period I had the experience of training educational specialists for children with disabilities in Hanoi. Beginning in August of 2008, I was involved in training educational specialists for children with disabilities through the JICA Grassroots Technical Cooperation project first in Ho Chi Minh City and then in Hanoi.

The “Thanh Mau” School for Disabled Children (now called the “Gia Dinh” School for Disabled Children) in Ho Chi Minh City, the principal of which was one of my students in the early days of engagement in this area, had been a school for mentally retarded children, but in around 1998 I visited this school to perform a developmental diagnosis as a result of an autistic child having enrolled. This was the first case of an autistic child having been accepted at this school.

It was from about this time that I began to hear the word “autism” in Vietnam, but it was only recently, around 2005, that the term “autism” began to appear in statistics in the medical and educational fields as agencies such as the Ministry of Health and the Ministry of Education and Training (equivalent to the Ministry of Education and Science in Japan) started to classify autism as a type of disorder in their documents.

Vietnam is a developing country that is making rapid advances in developing its electrical, telecommunication and transportation infrastructure with the assistance of developed countries. Being involved in infrastructure development, I have been able to observe some very unusual phenomena. In the agricultural regions and mountainous areas inhabited by ethnic minorities in Vietnam, there are many places where electricity has been recently installed, and as soon

as electrical lights came on in these areas television started to spread to every household. One can also see satellite antennas installed on houses even though they do not have electrical power lines yet (it appears that in many developing countries the spread of cellular phones is rapid but landlines are installed slowly). In urban areas, along with the spread of personal computers there are now many people who gather information from the Internet, and even in larger rural villages there is often an Internet cafe. Accessing information using the Internet is also possible in rural areas, and those who have acquired information literacy are being exposed to the latest cutting-edge information.



Photo 2: In front of the Hanoi University of Education, Faculty of Special Education (With the student participants in the JICA Disabled Children’s Educational Specialist Training Project. Photograph by Araki.)

The same is true of the acquisition of knowledge about autism. Although it has only been about ten years since the word “autism” started to be heard in Vietnam, recently, along with the word “autism,” other terms such as “learning disability,” “ADHD” (attention deficit hyperactivity disorder / hyperactivity), and “atypical pervasive developmental disorder” (PDD-NOS) have started to become topics of discussion among the relevant parties. There are still few specialist physicians in the field of child psychiatry and paediatric neurological medi-

cine in Vietnam, but children who have received one of the aforementioned diagnoses are starting to appear in kindergartens and elementary schools. In England and the United States, as well as in Japan, there are now over sixty years of case study reports on autism, but this process has been truncated in China and Vietnam, with changes occurring rapidly over the past ten to twenty years. The spread of electric lighting and television seems to be happening at the same time as these developments. For more information on the current situation and issues regarding the education of children with intellectual disabilities in Vietnam over the past 10 years I recommend Manabu Kuroda (2006).

The Necessity of Creating an Autism Network in the Asia-Pacific Region

I participated in the first session of the Asia-Pacific Autism Conference (APAC), which was held over three days beginning August 20, 2009 in Sydney, Australia. This was a regional conference where autism-related NGOs and central as well as governmental organizations, parents associations, and specialists gathered, and there were over 1,000 participants. Autism Europe has a long history as a regional conference. It is held every three to four years, and 2010 was its ninth conference. There is also the International Meeting for Autism Research (IM-FAR), a conference of researchers and specialists was held every year, and its ninth conference was also held in 2010.

As a result of the fact that the first Asia-Pacific Autism Conference was held in Australia, there were many participants from this country, but there were also more than a few participants from countries in the East Asia region, including China, Taiwan, South Korea, Japan, Vietnam and Singapore. There were not many reports from East Asia, however, and from the standpoint of accumulated research I was made keenly aware of the necessity of promoting regional research while building a network in the future.

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