

Report of the WHO Collaborating Centre Seminar

# Promotion of Employment of People with Autism Spectrum Disorders



March 2, 2008



National Rehabilitation Center for Persons with Disabilities

Japan

WHO Collaborating Centre for Disability Prevention and Rehabilitation

## Program

**Time & Date:** 13:00~16:30 March 2 (Sunday), 2008

**Place** : Auditorium of the College, National Rehabilitation Center for Persons with Disabilities (NRCD)

Facilitator: Dr. Yasoichi Nakajima, Director, College, NRCD

13:00-13:10 *Opening Address*

Dr. Tsutomu Iwaya, President, NRCD

13:15-14:00 *Keynote Lecture*

**“Promoting Success for People with Autism in Employment through Education and Matching of Strengths and Interests: An Inside View”**

Dr. Stephen Shore

President Emeritus and Board Member, Asperger’s Association of New England

Member, Board of Directors, Autism Society of America

14:10-16:10 *Panel Discussion*

Moderators : Dr. Reiko Fukatsu, Director, Dept. of Medical Social Work & Psychology, NRCD

Dr. Yayoi Kitamura, Researcher, Dept. of Social Rehabilitation, NRCD

14:10-15:22 *Presentation by Panelists*

① **“Act on Support for Persons with Developmental Disabilities”**

Mr. Masafumi Hizume, Developmental Disability Specialist, Mental Health and Welfare Division, Ministry of Health, Labour and Welfare (MHLW)

② **“Efforts of Employment Support of Persons with Developmental Disabilities”**

Mr. Hiroki Ichikawa, Specialist in Employment of Persons with Disabilities, Disabled Worker’s Affairs Division, MHLW

③ **“Establishing Consistent Support of Education and Treatment”**

Dr. Kunio Yoshino, Director of Nishitama Ryouiku Shien Center

④ **“Employment of People with Asperger Syndrome and High-functioning Autism”**

Ms. Hatsue Suda, Vice Chair, Autism Society Japan and  
Executive Director, Keyaki no Sato

⑤ **“Self-help Group”**

Mr. Morio Minta, Psychiatric Social Worker  
(he is with Asperger Syndrome)

⑥ **“Medical Diagnostic Treatment and Support of Autistic Spectrum Disorders”**

Dr. Makiko Kaga, Director General, National Institute of Mental  
Health, National Center of Neurology and Psychiatry

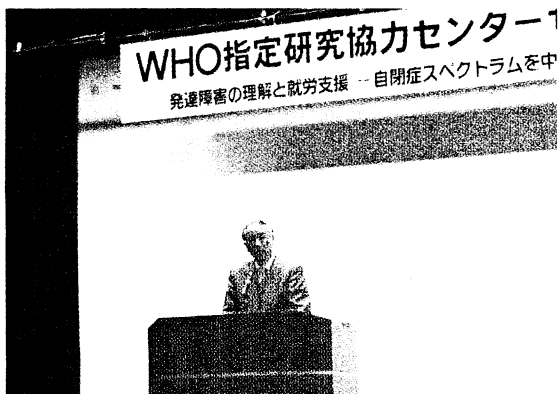
15:25-15:55 *Discussion*

by Dr. Stephen and above 6 panelists

15:55-16:10 *Question and answer with audience*

16:20-16:30 *Closing Address*

Dr. Fumio Eto, Director, Training Center, NRCD



Opening Address Dr. Tsutomu Iwaya



Closing Address Dr. Fumio Eto



Facilitator Dr. Yasoichi Nakajima



Keynote Lecture Dr. Stephen Shore



Panel Discussion

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## ***Opening Address***

**Tsutomu Iwaya**

**President, National Rehabilitation Center for Persons with Disabilities**

Thank you very much for coming and welcome to the WHO Collaborating Centre Seminar “Promotion of Employment of People with Autism Spectrum Disorders” held at the National Rehabilitation Center for Persons with Disabilities.

Today, we have Dr. Stephen Shore as a guest speaker from the United States.

From Japan we have guest speakers who are persons with developmental disabilities, people from medical establishment, education and treatment, job placement and government people. It is an extreme honor for us to have this opportunity to hold this seminar on employment of people with developmental disorders.

For the past few years we have been holding seminars on medical rehabilitation, independent lives and employment support for people with disabilities. Last year with the adoption of the Convention on the Rights of Persons with Disabilities at the General Assembly of the United Nations we held a seminar on the Convention on the Rights of Persons with Disabilities and the Creation of an Inclusive Society. This year we will be holding this seminar in relation to the research and establishment of employment assistance for adolescent people with developmental disabilities, which is research that we started last year in April. That was a response to the law to support persons with developmental disabilities being implemented in 2005.

The basic program for persons with disabilities was established in 2002. Japan sets as its target to build a cooperative society in which all persons with or without disabilities can mutually respect their personalities and individuality in the 21<sup>st</sup> century. “Symbiosis” in biology is living in close physical relationship. It means that people who have different characteristics live together to help their descendents for the future. Our society nowadays aims at multiculturalism where people live together as they acknowledge differences as differences.

The difference between people with disabilities and people without disabilities comes from unique psychosomatic functionalities. In other words, they are differences in how they perceive things and how they act. In the society, this is seen as leading to inconveniences being experienced by people with disabilities. In order to coexist with each other we will have to understand these differences. We have to expand our commonalities with each other. No matter how much we increase the commonalities, it would be very difficult to assimilate all unique psychosomatic functionalities. A

symbiotic society (in other words, a cooperative and inclusive society) does not simply mean assimilation and amalgamation. It means we have to pursue multiculturalism.

Looking back in history, people with disabilities were seen as losers in the survival race at one point in time. Following that, we saw an era where we tried to overcome the differences by improving or recovering their functionalities and assimilating and amalgamating these people with disabilities. We seek to aim at multiculturalism where people will live as equal components of the society. Multiculturalism means to admit the differences and, in addition to that, develop those differences as diversity and to create a diverse society.

In order to create a symbiotic society where we can overcome the differences, we will need to understand the differences and explain the commonalities but we should not stop at assimilation or amalgamation. In addition to expanding the commonalities, we should expand and build upon the uniqueness of each group and expand diversity.

Having said that, there are people who are still suffering from the differences. In today's seminar we have to come to grips with and face the difficult reality in society. However, with your participation in this seminar I hope the seminar will be an active seminar to promote the understanding of people with developmental disorders. I hope this seminar will be useful to establish a societal structure to assist the employment of people with disabilities.

Thank you very much for your attention.

## ***Keynote Lecture***



## ***Promoting Success for People with Autism in Employment through Education and Matching of Strengths and Interests: As Inside View***

**Stephen Shore**

**President Emeritus and Board Member, Asperger's Association of New England  
Member, Board of Directors, Autism Society of America**

Konnichi wa. It is my honor to speak in front of you today. I wish to thank everybody involved in bringing me in front of you to share my experiences regarding employment as a person on the autism spectrum.

Work is more than just going to a place to earn money. Work in its best sense is a way of adding meaning to life. We all hope to find employment in areas that interest us. If we're interested in something we're probably also good at it. Temple Grandin, who is probably the most well-known person with autism, reports that her life would not be worth living if she did not have intellectually satisfying work. One of Temple Grandin's strengths has to do with meat processing. As a matter of fact, if you go to the United States and you eat beef the likelihood is greater than 50% that you will have eaten beef that has been processed by one of the cattle processing plants that was designed by Temple Grandin.

While many of us are fortunate to find employment that matches our likes and our strengths, there is a difference with people on the autism spectrum. The reality is for those of us on the autism spectrum there is a combined unemployment and underemployment rate of at least 90%. This is according to a study done by the National Autistic Society in England. In other words, only 10% of us at most on the autism spectrum find employment that matches our strengths and matches our interests. However, if we can find a way to provide proper support we can find ways for people with autism to lead fulfilling and productive lives in employment.

It is our job to change this prognosis. We need to work towards preparing those of us with autism for the world of work. On the other side or one of the other facets is educating the world of work about people with autism at all levels. Then finally is thinking outside of the box. In other words, how creative can we be in regards to finding employment for people with autism and by extension people with other disabilities?

I think one way to look at it maybe is not to use the word "disability" but, as was mentioned before, "difference." Autism is a different way of being. It's not necessarily a disordered way of being. Certainly there may be a number of things about autism that are disordering. If you have someone with autism who has not developed a reliable

means of communication, that's quite disordering and there's something you need to do about that. You may have someone else with autism that has such digestive problems and they're in such pain that they just cannot concentrate in order to work or to learn.

Let us begin with a little bit about me. Things were pretty typical at first. After a 2 hour labor, my wife says that of 24 hours of age I looked like an egg. Things move along pretty well for those 18 months and then I was hit with the autism dragon. When the autism dragon blew his fire I lost functional communication, had tantrums, got involved in self-stimulatory activities, withdrew from the environment and had self-abusive behaviors. In other words, I was a pretty autistic little child. This was at 18 months.

In those days, my parents had no idea what to do. We're talking about the early to mid-'60s. No one had much of an idea of what to do. The incidence rate of autism was considered to be 1 in 10,000. However, for almost a generation now that incidence rate has been climbing to where the Center for Disease Control in the United States now accepts an incidence rate of 1 in 150. That's a lot of autism.

Where is this increase coming from? There are many questions. However, there are no conclusive answers. Some of it can be attributed to better diagnostics. We are better at categorizing people according to their characteristics. Some people are looking at vaccines. Other people are looking at diet. Some people are considering the environment as a possible cause. The best minds in this area consider autism to start out as a genetic predisposition which then gets triggered by one or more of those other categories that I mentioned. All we know is that if the increase in autism continues the way it has been probably within the next generation we'll be here talking about employment for people who are not on the autism spectrum because there will be more of us than there are of you.

Continuing on, there's a lot of autism. I know all through my public school days I was the only child I knew with autism. Now where I live in Boston there are 5 schools within about 15 miles of where I live exclusively for children with autism. The largest one is the Boston Higashi School, which is the sister school of the Musashino Higashi Gakuen. Boston has 189 students with autism there. There are other schools with 89 students with autism and still others in pleasant rooms in public schools devoted to children with pervasive developmental disorders.

It took a full year for my parents to find a place for me to get diagnosed, again due to lack of information. This was at a time when autism was blamed on poor parenting and in particular poor mothering, so the mother was blamed for psychologically damaging her child. The mother rejected the child. The child now in turn rejects the mother and

rejects the environment, as well. Fortunately, this myth has been debunked and we no longer believe that.

However, there is still a role for psychiatrists and other mental health professionals for people with autism because there are things about autism that may generate secondary psychological challenges. If you think about it, perhaps anyone who experiences the difficulty that many people with autism experience in successfully interacting in the world, developing relationships and finding successful employment, maybe that will cause depression or some other psychological challenges. If we find a way to work on those with this understanding, that can be very helpful.

At 2 and a half I did get diagnosed with strong autistic tendencies, psychosis and atypical development. My parents were recommended to send me to an institution because the professionals had never seen a child who was so sick. My parents, like so many parents here who advocate on your children's behalf, refused to listen. Instead, they took my situation into their own hands and provided what we would today call a home-based early intervention program emphasizing music, movement, sensory integration, narration and imitation. In today's terms, it would probably look like one of the more developmental approaches such as the Neuro method, Floor Time or RDI.

I was very lucky because my parents figured out what I needed. That's the basis of my doctoral research, matching the existing approaches to best fit the child's needs. I think that's an important thing to consider when helping children with autism lead fulfilling and productive lives.

By the time I reached age 4 my speech had started to come back. I got admitted to that special school, the school that had initially rejected me. My diagnosis got upgraded from psychotic to neurotic, so things were moving up in the world. By about age 5 my speech had pretty much normalized but many challenges remained. Public school kindergarten was very difficult. I didn't know how to interact with my classmates in a way that they could understand so there was a lot of teasing and bullying. Teachers didn't quite know how to reach me. I was usually about a grade behind in math and in reading.

I remember spending hours at my desk in elementary school reading books on my favorite subjects (various sciences like geology, geography, electricity and dinosaurs) and sometimes wondering if there was more to school than just reading my favorite books. I was very happy to do that but shouldn't I be reading in groups, for example? I think what that translates to is that teachers didn't know how to reach me but since I wasn't a challenge behaviorally they just left me alone to do my own thing, for better or for worse. I think in this particular situation it was probably for better. I remember in

about 3<sup>rd</sup> grade I had a stack of astronomy books on my desk. My teacher told me that I'd never learn how to do math but somehow I figured out just enough math to teach statistics at the college level—no more, just enough.

Fortunately, today a teacher would see a special interest in this nature. They would see the strength and power behind a focused interest or a passion in astronomy and find a way to link it to mathematics, reading and anything else that needed to be studied.

I consider my first employment delivering newspapers. This was in elementary school, starting at about age 9. That was my first business. It worked very well. You might say that it was a self-employed type of business. I'd get a stack of papers, put them in my bicycle basket, ride around on my bicycle and deliver newspapers. That worked out pretty well.

By the time middle school came around, I was old enough to work in a more formal type of setting. My first job was as a busboy in a restaurant. Initially that seemed good but soon I was overwhelmed by the sensory over-stimulation that is created by working in a busy restaurant. As a result, I'd go into a sort of shut-down mode and work very slowly. That wasn't helpful and as a matter of fact I lost that job.

My next job was more related to one of my special interests, one of my passions, and that's bicycles. As a matter of fact, I have 14 bicycles at home. That turned out to be much better because now I was working on something focused on my special interest. Additionally, it was lower stimulation as I worked in the shop room in the back of the bicycle store fixing bicycles. My interactions with other people were also based on my special interests.

I think it's important for us to learn what the special interests are of people on the autism spectrum. Again, this is the same as for everybody else but for those of us on the autism spectrum it's a matter of extremes. Whereas most of us are able to tolerate working in a job that we don't like and we wish we were doing something else, we see employment as way to fund doing fun things in life after we get out of work. Many people work this way. However, for people on the autism spectrum that doesn't quite seem to work, so it's imperative that we find a way to link a special interest to employment.

Another thing that we need to consider (and this is one of those "thinking outside the box" things) is how do we find employment for people on the autism spectrum? In finding employment for people on the autism spectrum I refer back to Dr. Temple Grandin, who I mentioned before, who recommends the use of a portfolio. A portfolio is a sample of a person's work.

As I was looking for bicycle repair jobs I didn't realize that I was using a portfolio

but that's exactly what it was. I'd get on my bicycle that I built by myself from the spokes and the hubs, the rims, putting it all together down to the last ball bearing. I would ride into a bicycle shop and strike up a conversation with the manager of the bicycle shop. We'd talk about my bicycle. The manager would be very interested. Then I would ask him for a job. By then, it was already clear to him that he knew what I was doing in so far as bicycle repair and they'd be eager to hire me.

That is in contrast to the typical way most people find a job, and that is through a job interview. The job interview is particularly challenging for those of us on the autism spectrum because it requires a lot of social interaction that is difficult for us with autism, one of them being eye contact. You're expected to make good eye contact with the interviewer and it has to be appropriate eye contact. What I mean by that is that we know that making eye contact is difficult for people on the autism spectrum. However, every now and then I meet with someone with autism who is told, "You have to make eye contact," and then that's all they do. They just stare at the other person's eyes and don't look away.

In reality, typical eye contact involves glancing back and forth between a person's eyes, their nose, their mouth, their forehead, objects in the room and then back again. It's a continuously moving thing. People with autism can learn this type of eye contact. We can approximate it but it requires direct instruction rather than just learning by observation. It's this type of behavior that's expected at an interview and if those of us with autism cannot successfully perform this behavior, we're not the ones to get a job.

In the United States studies have shown that the greatest predictor for success in employment has to do with social interaction. Of course, being able to do the job helps but you have to be able to get along with others in a way they understand and in a way they expect. If that's a challenge for us, we're not going to even get in the door from an interview.

Bicycle repair was very successful for me. I continued that all through grade school and continued it into college, where I repaired bicycles to fund my college tuition at the undergraduate level. Again, that worked out very well for me.

Speaking of college, college can be a wonderful place for people on the autism spectrum. It can be very liberating. I remember in college I had more friends. If I wanted to ride a bicycle at midnight I could find someone just as strange as I was to also ride at midnight. College is where I met my wife through a special interest in music, specifically. We've been married for almost 18 years. You can find out more about my autobiography plus read the contributions that my wife and my mother have made to my book in the Japanese translation of "Beyond the Wall," which is available from Gakken

Publishers.

I've also successfully finished my doctoral dissertation on matching best practice to the needs of children on the autism spectrum. That was another challenge that I saw facing people. People would get stuck in various approaches, such as applied behavioral analysis, to the exclusion of others and to the detriment of children on the autism spectrum. What I see is that autism is a widely diverse condition. Again, it's a condition, not necessarily a disorder. It's a difference. It's a different way of being and by definition there is so much diversity within the autism spectrum that's going to call for different approaches for people who have different needs.

Speaking of autism, autism is often considered as a spectrum. That's how most of us look at it these days. It's a good way to start. It's a spectrum ranging from severe autism. That's what most of society considers as autism, a small, non-verbal child rocking in the corner, having tantrums and difficulties with transitions.

One thing that we need to consider (and this has direct relationship to employment) is what happens to these children after about 15 to 17 years. The answer is they grow up to become adults with autism. The leading edge of this increased incidence rate is about 15 to 17 years of age. This bubble of 1 in 150 started almost a generation ago. We have all of these children who have now become very young adults who will leave grade school to go out into the community. The question is what kind of supports are we going to have in order for them to find fulfilling and productive employment, residences and in general lead a fulfilling and productive life?

Now we zoom all the way up to the right-hand side of the spectrum where we see high-functioning autism and Asperger syndrome. What becomes clear here, as it is with the entire spectrum, is the idea of twice exceptionality. What that means is that people with autism have extreme challenges. That's what people seem to notice. However, we also have extreme strengths because for each challenge there is going to be a corresponding strength.

We all have weaknesses. We all have strengths. If we take a look at a profile of a person it might go like this. Then you'll have a weak point over here, you'll have a strength over here and so on. For those of us on the autism spectrum, our challenges will go down into the basement and there will be corresponding strengths that will go through the roof. How do we use these strengths to help people with autism lead fulfilling and productive lives in employment and other areas?

One example of twice exceptionality is a friend and colleague of mine, Kassiane Ana Sibley, a 25 year old lady with autism. She contributed probably the best chapter to my second book, "Ask and Tell," available from Creates Kamogawa. She has a verbal IQ of

over 200. Those of you familiar with scoring IQ tests know that IQ tests don't go up to 200, so it's just a guess. She's an excellent writer and an excellent presenter. She has a lot to contribute to the world. However, on the other side she has extreme challenges in social interaction. She has extreme learning disabilities. She is on a 25 item food diet. If she goes off of this diet not only does she pay for it but so does everybody else around her.

This person, Cassie Ana, is considered to have high functioning autism. Some people would refer to her as having mild autism. The question is what is mild about her autism? Again, she's not going to be able to find employment the way most of us think about finding employment due to her challenges. What this signifies is that people all over the autism spectrum need support. People with Asperger syndrome may be brilliant at math or some other subjects. They may be brilliant at doing particular jobs. They are often still going to need support in the areas of social interaction and other areas. If we are able to get that support, it's incredible what we can contribute to the world of work.

That little circle represents where I landed on the autism spectrum, as I mentioned before, at 18 months when the autism dragon breathed its fire and I lost functional communication.

Getting back to employment, it's important to consider our characteristics. What are the strengths and what are the interests of people on the autism spectrum? This makes me think of a fellow who works in Paddington Station in England. He has high functioning autism. His job is to provide public transportation information to lost patrons. He uses his verbal interaction style to provide this information to questions that people have. What is the communication style of people on the autism spectrum who are verbal? He tends to be direct, factual, to the point and truthful. Is this the way that you want to receive your information when you're lost or do you want to be wading your way through idioms and jokes and trying to figure that out? His communication style is a real plus for him in this employment situation.

There is another part of this employment situation. That has to do with where he gets the information. His coworkers have to look up this information in a manual or in a computer. However, he has this information memorized. That's because the public transportation system of greater London is one of his passions or special interests. As a result, he can do his job much faster than anybody else.

This is also an example of what I often talk about regarding reframing the characteristics of autism. If we look at the characteristics of autism we see challenges in communication, social interaction, restricted interests and repetitive motions. However, if we look at the communication style and instead of calling it a deficit, which is what

so often happens to people who are diagnosed with autism or any other condition. When a person receives a diagnosis the first thing we hear are all of the challenges that they're going to face, all of the things that they won't be able to do, all of the challenges that they'll have in successful employment and all of the challenges that he'll have in making friends. If we look at these characteristics such as communication and instead of looking at it as a challenge or a weakness, we know that the communication style of people with autism tends to be direct, to the point and factual. If this is the case, let's use these characteristics as strengths.

If we take a look at what the DSM-IV refers to as "restricted interests," let's change that and call it "a passion," "a focused interest" or "a special interest." Many people think that Thomas Edison, for example, had Asperger syndrome. At the very least we can say that he had some Asperger tendencies. It might have been this focused passion that led him to try 50,000 times before he got the light bulb right. With situations like this there is a focused interest, intense interest, in an area that benefits him and as it turns out it benefits society. The light bulb is a very useful invention.

What is a special interest? If we look at the work of Tony Attwood, who is probably the most well-known expert on Asperger syndrome, he says a special interest is an interest of such great intensity that it interferes with daily functioning. That's exactly how he says it, too.

Here are some of my special interests. They come and they go. Sometimes there is more than one of them that occurs at a time. I find them very interesting. There's going to be a quiz on these at the end, so make sure you get them all.

Regarding gearing work towards interests, let's take a look at some examples. Back at home, during the times that I am home, one of my specialties is giving music lessons to children on the autism spectrum. One of the reasons why I do this is that in addition to the therapeutic benefits of interacting with music, music provides a real-life way in which to interact with other people, develop friends and get involved in the community (say by joining a community band).

These are one of the children that I worked with. He was really interested in subway maps. He focused on the entire transportation system of greater Boston. He also liked computers, so I often wonder that when he reaches an age where he can work what if he could design maps for the webpage of a public transit authority? I knew that the public transportation authority in Boston, Massachusetts was severely lacking in terms of a good webpage that was understandable and easy to navigate.

There was a young lady with autism who had a very difficult time verbally interacting with other people. She could talk just about as well as anyone else can talk but she was



extremely shy. She was extremely challenged to interact with other people. Like Temple Grandin and many other people with autism, she had a close affinity with animals. She understood animals like most other people couldn't. Her special interest was in being a horse doctor, an equestrian veterinarian. Here's an example where we can use an interest in an area to promote in her case her working in an area of challenge. She wanted to do nothing more than be a doctor helping horses.

We had a conversation with her. The conversation started with her interest in horses. Boy was she interested in helping horses with any medical problems they had! Then we got into a conversation about what is required in terms of being a good veterinarian. Part of the requirements is being able to communicate with the horse's owner, to be able to tell the horse's owner what is wrong with the horse and then what to do to take care of your horse. The only way that's going to happen is if she learns to talk to them. Once she became aware of this requirement in order for her to be successful as a veterinarian she started to work on her challenges with communication with other people. As a result, her communication skills improved. That helped, as well.

A similar thing happened with me. In undergraduate school I became aware that non-verbal communication was another mode of interaction. Studies show that 80% of the total communication package is non-verbal. In other words, what are peoples' bodies saying in addition to or sometimes even opposite to the words that they are speaking? I was totally fascinated with this. It became clear to me that if I wanted to improve my social interaction with other people I was going to have to study this. As a result, it became another special interest where I'd spend hours in bookstores reading body language books. What I was doing was building a lexicon of non-verbal communication. I found that to be very helpful.

Another curious example is of a fellow with a very good sense of smell. One of the characteristics of people with autism has to do with sensory variations, otherwise known as "sensory issues." Some of our senses are turned up too high so they're oversensitive. Too much information comes in. That's the reason why there was mention about not using a flash before we got started. Many of us with autism are hypersensitive to visual input. While a flash can be annoying to most people but they put up with it for many of us with autism a flash can be absolutely distracting and blinding. That's just one example.

Let's get back to this fellow with this hypersensitive sense of smell. His father is at home. He's an engineer. His father, by the way, also has autism. He's cooking up some food in a steel pot. The son from the other side of the house asks the father, "Why are you using a steel pot to cook food?" This made his father, who is an engineer, suddenly

realize that his son had a good enough sense of smell to know what type of metal was being heated up to cook food.

Somehow he managed to move that along to the point where his son goes into aircraft hangers and smells the engines of an airplane. He doesn't go up to the engine like a dog and sniff it. He just catches the ambient smell and from this smell he's able to say, "This engine over here needs an oil change. The one over there needs" something else. This fellow is pretty strongly affected and he has autistic behaviors, behaviors which would not be tolerated in a typical workplace. However, he is able to do something that nobody else is able to do so the workplace puts up with him.

Let's take a look at some other areas. You have someone who has difficulty with verbal communication. Might there be a type of employment that we can engage the person in that doesn't require much verbal interaction? You may have someone else who is challenged with socialization. Is there something that they can do?

Sensory stimulation brings up the example of a parent here in Japan. I was giving a workshop and she mentioned something about her son. I think he was 13 years old. He would enjoy putting his finger under a running water faucet and spray it all around. He got really good at it. His mother realized the importance of promoting special interests but by the fifth time there was a big flood in the house, she had some other ideas. She asked, "What can my son do? He's pretty severely affected. He has limited verbal ability. What kind of employment can he engage in?"

If we think about it, why is he spraying water like that from under the faucet? One reason he might be doing that is because he craves the sensory input of the water pressure on his thumb and he uses that to spray a high pressure stream of water. That then can get you thinking, what kind of employment opportunities involve spraying water at high pressure? One thing that may immediately come to mind is the idea of a firefighter. Sometimes it takes 4 or 5 strong men to hold a hose so that it doesn't flip away from the backpressure and to spray it into a house that's on fire.

Then you think a little more deeply about being a firefighter. What are the requirements? One of the requirements is good verbal interaction skills. You need to be able to listen to the fire chief issue a command to do something. At the same time, you need to be able to issue a command to your fellow firefighters if, for example, the house you're in is about to collapse, so this job wouldn't work for him. However, there are other jobs that involve spraying water at high pressure. One of them might be working in a carwash. Another one might be washing buildings or sidewalks with a high pressure stream of water. What about being a gardener? We need to be careful with that. If he can enjoy spraying water at low pressure to water plants, that's great. However, if it's got to

be this high pressure thing then he'll probably kill the flowers. We need to be careful about that, as well.

Later on in the conversation his mother said, "My son really likes schedules." That brings up another idea. What about working as an assistant on a water delivery truck? He helps to make sure that every business and every customer gets their water when they're supposed to. If he's also craving the deep pressure on his thumb from spraying the water it might be that he would crave other deep pressure experiences. He might enjoy lifting heavy bottles of water and carrying them to other people's houses. This is an example of using a characteristic of autism, in this case sensory-seeking behavior, and finding a way to work that into a successful employment situation.

Transitions are difficult for many people with autism. Can we find a workplace for this person that has little change, a stable work environment? Sometimes a nice, small family business is a good way to do that. An assembly line, for example, is perhaps another way to do that.

Many of us have strong visual-motor skills. As a result, we may be very good at putting together little pieces of things such as printed circuit boards for a computer, computer assembly. That might be good for someone with strong visual skills. If someone has challenges with behavior we need to find situations where this person won't encounter triggers to those behaviors.

If we look at savant skills, extreme strengths, I have a friend with autism who is so good at math that one of his favorite things is to ask you when you were born. Then he'll say, "Oh, yeah! That was a Sunday." Then he'll say, "You know, that makes you 947 million and so on 200 seconds old." He's done all of this in his head and he does it about as fast as I just spoke that sentence. He's a tax preparer. That works very well.

I have another friend with autism who loves to stim on bright, shiny objects. He'll take an object and he'll look at it from all angles like this. If you are familiar with people with autism, that's probably pretty familiar to you. It turns out that this fellow, who is about 55 years old, is a very successful coin dealer. He buys and sells old coins and he makes a lot of money doing it, as well.

It's very important to be flexible in the types of job structures. Most of us focus on the first two. We think about employment as needing to be competitive, full-time employment. However, there are many other variations. Self-employment works well. Referring back to Temple Grandin, she's self-employed with her meat processing design business. She says being self-employed allows her to go in, do a job, be successful at it and then leave before office politics take their toll. Office politics present a major challenge for many of us (I'd say most of us) on the autism spectrum. That's true for

people who are not on the autism spectrum, as well, but for us it's even more so.

As for myself, I guess I consider myself as self-employed, as well. My mission is to help people with autism lead fulfilling and productive lives. A part of that is traveling around the world consulting and talking about autism and giving presentations. Writing books is another. Giving music lessons to children with autism is yet another.

Next I'll talk about accommodations. If you can teach the skill, find a way to teach it. There may be times when we're challenged to teach a skill. Let's see if there's a way that we can adapt it or work around it. For whatever task we're asking a person with autism to do, can we figure out a way around it? If we can't do any of the above, teach the neurotypicals to deal with it. There are many things that those of us with autism can contribute to the world of work. It's just a matter of finding a way to provide needed support for those of us with autism so that we can lead fulfilling and productive employment lives.

If you want to take a look at it strictly from the financial end, if we don't support somebody with autism in employment this may be a person who will be living say in an institution, spending most of their time doing nothing and not working. That's a very expensive thing to do. Let us suppose that we find a way to support someone with autism to find successful employment to the best of their ability. Now we have someone who's living with some independence. We have someone who is going out and contributing to society. We have someone who is happy and fulfilled because they have the pleasure of being able to do a good job because they're being supported in doing so.

In closing, I want to say again it's a pleasure to see all of you who are sitting here, all of you who are devoted to helping people with autism lead fulfilling and productive lives through employment. Doomo arigatou gozaimasu.

***Panel Discussion***

***Presentation***

## ***Act on Support for Persons with Developmental Disabilities***

**Masafumi Hizume**

**Developmental Disability Specialist, Mental Health and Welfare Division,  
Ministry of Health, Labour and Welfare**

Thank you, ladies and gentlemen. Dr. Shore, welcome to Japan and all of you, welcome. Dr. Shore was very good at sticking to the time. I'll try my best to do the same, so let's get started.

About the Act on Support for Persons with Developmental Disabilities, the purpose of the Act on Support for Persons with Developmental Disabilities is ① to identify developmental disabilities at early stages, identify the responsibilities of the central and local governments for providing developmental support and ② to provide support for overall life in order to contribute to independence and social participation of persons with developmental disabilities so that those people who were not able to enjoy such services can now enjoy the services.

The Act defines developmental disabilities which have not been covered by the system and for which necessary support has not been reached such as autism, Asperger and other pervasive developmental disorders, learning disorders, attention deficient hyperactive disorder and other similar disabilities. It also includes those with intellectual disabilities, as well. Other similar disabilities of brain functions, this includes for instances Turret's syndrome, et cetera. When you go home and try to explain to others about developmental disabilities please remember that such disabilities are also included.

As for the measures we are taking at the Ministry, they are based on this Act. Number 1 is to form an effective network of the relevant areas in local governments, given that persons with developmental disabilities need a broad range of support to establish community-level support systems.

The age at which family members and others first notice developmental disabilities could vary because the spectrum, as Dr. Shore mentioned, is very wide. Sometimes early detection is possible. Other times, only after becoming an adult does one notice developmental disabilities. If just one office within the government knows about such a condition, such a person is not enough because it could also involve older people, as well. Our aim is that all of those involved at the offices concerned knows about developmental disabilities. That's the purpose of establishing support system in the community.

Number 2 is to identify effective support methods through projects and studies, promoting them through various meetings and promoting provision of support, given that standard support methods are not adequately established or spread out in terms of support for persons with developmental disabilities.

About establishing a standard support method, at the moment each organization in each area and region is improvising about how to provide support to those with developmental disabilities. I don't deny this situation but because there are so many differences and variations sometimes it's not convenient for those to be supported. Also, because of the related confusion sometimes support cannot be started. Therefore, the idea or objective is to establish a more standard way of providing support.

To provide information through different means, currently some information is provided through websites but there are people who do not have access to websites such as older people, et cetera. Not just through websites but through symposia like today, brochures and other media we want to provide information. That's our plan.

Number 3 is to cultivate human resources who will provide support as the core of the community and take measures to extensively adopt human resources, given that there are an inadequate number of experts who are capable of responding to persons with developmental disabilities and their parents and guardians. About human resources, there are a number of issues and challenges here, as we see it.

First, what is good and effective support? That means people who know about what they are, who can actually implement such support and can communicate about that to others. This is the kind of human resources we are after. Also, one does not have to be a professional. There are many people in this world who are working very effectively together with those with disabilities. We want to encourage such people by coordinating on how they're doing in their job well and what is particularly good about it. We want to encourage and to motivate such people.

Thank you.

## ***Efforts of Employment Support for Persons with Developmental Disabilities***

**Hiroki Ichikawa**

**Specialist in Employment of Persons with Disabilities, Disabled Worker's Affairs Division, Ministry of Health, Labour and Welfare**

My name is Ichikawa from the Employment Measures for the Elderly and Persons with Disabilities department of the Employment Security Bureau. The measures and services that those with developmental disorders can use, including help with work, will be the topic of my presentation.

Hello Work is a facility that will assist people in being placed in jobs, so this is a facility that is related to employment. These are the measures to promote support for people with developmental disabilities. As was mentioned by Mr. Hizume, support for persons with developmental disabilities has been implemented. Hello Work, as the local assistance facilities, had been providing support in this area.

Within this role, there are people who have difficulty in maintaining employment. The target of this is to assist these people. Even those people who do not have passes for disabled persons can be covered by these measures.

There are counters at Hello Work that can provide assistance to people with disorders. Expertise and assistance can be provided at least for understanding the disorders. There is also a trial employment system where they can be employed on a trial basis for 3 months. Yesterday we had the budget passed in the Diet and we can tell you that we can promote this measure. We will be targeting over 8,000 people.

The third point that is listed on the right-hand side is about assistance. Fourth, we are looking to expand assistance after employment for persons with disabilities. On the left-hand side, you can see that there is assistance very specifically targeted to people with developmental disorders. The first part is an employment program and communication skills for young people requiring support.

We have issued evaluation reports and when it comes to welfare for disabled people there are some people who are not covered by any of the measures. For example, if you take the example from questionnaires for parents with children with learning disabilities, almost 20% of them go to special schools. The remaining children go to general schools. Once they graduate, they will hope to gain employment. In many cases, they might have been doing fine at school but they have difficulty finding jobs in the first place. Once they are at the workplace they cannot adapt and they will change jobs or leave their jobs.



Some may withdraw from society or they may fall into depression.

We do have assistance measures for young people who are not able to adapt to their workplaces. Among them would be people with developmental disabilities. This measure started this year. This is not specifically related to the specialist counter at Hello Work. We will have people with expertise at the general counter of Hello Work so that we can identify people who have not recognized their problems themselves. There will be a referral to specialist facilities. In some cases, people do not want to be supported through a specialist. In that case, there will be measures provided that are suitable for that person within the general framework of assistance.

There used to be people who were not covered by the traditional measures for people with disabilities. In order to cover these people, we established this employment program for the young requiring support in communication. For those people who have disabilities and have difficulty finding employment, we will be providing special support to the people who are working at the Hello Work job placement counters.

For employment assistance for adolescent people, we are at the stage where we have just collected the know-how and some case studies. We want to expand what is being done now. We only have 6 nationwide yet. However, we have our counters. We have insurance people, medical people and people in education. All learn through seminars what assistance can be found for employment of people with developmental disabilities.

We also have seminars for people who run businesses. We teach them what kind of support can be provided to people with disabilities. As is written on the bottom of the page, persons with developmental disabilities may have the opportunity to report on the difficulties that they have faced. By listening to those stories, the people who provide assistance will learn about what kind of support can be provided.

I have mentioned that there are 6 centers nationwide. The Labor Bureau in those locales will work with the Hello Work counter. Business owners will also cooperate with the people at the Labor Bureau and Hello Work.

We do have assistance provided through the Japan Organization for Employment of the Elderly and Persons with Disabilities. How can we develop careers that are suitable for the particular persons involved? That is being researched now.

That was a brief look at the measures that we have to promote in employment assistance. Thank you very much.

## ***Establishing Consistent Support of Education and Treatment***

**Kunio Yoshino**

**Director, Medical Care and Educational Support Center for Children with Developmental Disabilities (Nishitama Ryouiku Shien Center)**

I have included a summary of my presentation. After having prepared this, Dr. Kaga's presentation turned out to be exactly the same as what I prepared so I'll leave other complicated matters to her. I will just talk about our experiences from the field.

I want to emphasize today how difficult it is to prepare people so that they can become employable. Those people with a high functioning condition have been hurt and beaten up throughout their life before reaching the stage of being employable. That being the case, it is rather difficult to cope. If we want to talk about and think about successful employment, we need to start very early in childhood to prepare those young people for the labor market. I'll try to be brief. The most important part of my presentation is to show you a video showing you the children that I work with.

First about diagnosis and detection, I'm sure this will be discussed again later. Most of the children with low functioning ASD are diagnosed before they start primary school. In some areas, they are regarded as intellectual disorders or disabilities but mostly through periodic official medical examination by the time they start school they are already diagnosed.

However, in the case of high functioning people detection comes later. Sometimes it is detected at a year and a half but sometimes because of attention deficit they are detected at school or because they cannot cooperate. They can be even older before they are detected. For many people, it's difficult to identify where the problem comes from. With a clearer understanding of the features of these high functioning people, I believe earlier detection can be hoped for from now on.

What is the educational training that should be provided to these people? I've always been thinking about this. This changes with time, also. I believe the most adequate way for now is what the SPELL that the British Autism Society is advocating, be it high functioning or low functioning.

In the case of low functioning, first I'll talk about introductory family guidance. That used to be my dream in the past. In the community, during the infant stage screening medical examination they are detected but that's not good enough. The mothers need to be guided. They need guidance. Without being fully prepared for that the training starts, especially in Tokyo. Without having enough understanding of what autism spectrum is

parents have to start training. They try to get information from the internet. They become very concerned, over-worried and confused. It should be the municipality taking responsibility to give introductory guidance to the family members. That should be done.

About the medical and educational model, there are a number of different models applicable for how to develop capacities and capabilities. Americans and Europeans talk about how to organize things, to enable independent living and also to foster capacity for interpersonal relationships. Also, it's necessary to continuously monitor development. Monitoring is very important.

For this, there are a number of support systems for high functioning people. Basically it's the same but in terms of cognition and learning a lot of support is necessary. It's also necessary to try to foster the children's pride because during young adulthood I think Japanese children get very hurt mentally. I was in Delaware recently. I was talking with Andy Bondy in Delaware. School refusal is not a problem at grade schools and middle schools there but in Japan 1 out of 10 children refuse to go to school. Truancy is a problem.

We need to introduce a support model to encourage development so that children especially will respect rules and also logic. Depending on whether a child is influenced more by emotion, logic or rules (depending on the child's personality and characteristics) the support must be designed. Also, the family's mental health is of utmost importance. How can the mental health of the family members be achieved? That is another important aspect of the necessary support.

Now I will show you the children I work with.

This is about scheduling or structuring. At this point, he was a low functioning child. Structuring is done a number of different ways. He is about 4 or 5 years old.

This is how we work. Support for structuring now is done in the form of homework, at home. He is helping prepare breakfast. That's one of his chores. He did this every day. He is now 18 years old.

If we turn to the next chapter, we see a handicraft or do-it-yourself session. Such skills are developed. Such activities will help parents to identify and understand the characteristics of their child. Also, they can have fun together. This is a very severe case but the father is working together with the child. This is a small group playing.

This person is high school aged with very severe disability but he can use a washing machine. He is quite capable. He does his own laundry.

He cannot speak at all so special methods (PECS) have been used for communication.

He is currently selecting a snack. This is a vegetable garden. He loves to work.

Although he has a very low IQ, he is already working. His IQ is below 50 but he is working in Chinese restaurant.

These are children with high functioning Asperger doing a small group activity. For Asperger we also need a high structural approach. They are very good at manipulating machines like this so we set a very ambitious goal so that they can develop themselves to the highest standard and try to do everything as much as they can.

In the last case, this was the child you saw at the beginning visiting some facility and putting on a concert.

For high functioning cases starting at a very young age we ask the parents or the teachers to develop picture books like this for developmental use. This is another picture storybook that we use for support. This is a 5 steps method that the mother produced. Whenever this child gets a cold he tries to skip school. She's trying to explain with this material that there are different conditions of sickness. Therefore, you don't have to skip school all of the time.

There are a number of challenges. We have to come up with individual planning, et cetera. An educational program is necessary. Hopefully we can overcome all of these issues and challenges so that we can fully prepare children to be successfully employed.

Thank you.

## ***Employment of People with Asperger Syndrome and High-functioning Autism***

**Hatsue Suda**

**Vice Chair, Autism Society of Japan**

**Executive Director, Keyaki-no-Sato**

Good afternoon, ladies and gentlemen. We heard specialists talk about a variety of things. Today I am the only person to speak from the viewpoint of a parent. How should we interact with our children as parents?

Actually, for over 3 years we funded research of people with high functioning autism and Asperger syndrome. We picked 40 people over 20 years of age and 33 responded. We found various difficulties through that research. What kind of education or what kind of environment will the children be reared in? That will have to be considered since the children are small to have the children lead a fulfilling life.

In order to assist employment of these children, there is this socially abnormal behavior, interruption behavior, and these will have to be dealt with. Children themselves will have to be able to recognize those states. The parents might have to assist the children in being able to do that.

The basics of relationships with the children are to establish a relationship based on trust with the parent. That trust-based relationship will have to be established. From the Autism Society of Japan a book called “Kagayaki” will be published soon. In it there are examples of parents with children 15 to 43 years of age. According to the questionnaires given to these parents, washing dishes with the children, cleaning the house with the children and having activities with the children related to the establishment of a relationship based on trust is important.

My son was a trouble maker. When we go out and ride on trains. Sometimes passengers are confused, like having their glasses taken away. However, from personal experience there is a lot for the children to learn about social interactions. A trust-based relationship will be established with a parent as the basis of the relationship. If the children do not trust their own parents, autistic children will not open up.

We also have to identify the difference in development compared to non-autistic children. Sometimes it is very difficult to understand the inner feelings of a child with autism. Why does this child think like this? What is the cause of this behavior? That will have to be understood. Once you understand that, the child will get involved with the parent may also be able to overcome difficulties.

In the case of autistic people, they do have emotions such as anger, sorrow and friendship. However, when it comes to anger or sorrow they do have that feeling but they have difficulty expressing that feeling. Once they go out into the society there should be many cases when they feel anger or sorrow, so we need to create an environment where they experience anger and sorrow and help them understand that feeling.

In having interpersonal relationships, we have to understand how the other person feels. In order to do that, the children themselves will have to understand the feelings of anger or sorrow. Of the respondents, many of them have been employed once but they were not able to have successful interpersonal relationships with their colleagues or with their bosses. Especially high functioning people blame it on others and build up a rationale saying that they are not in the wrong. From when the children are small, we have to teach them about emotions and how to understand others' needs and others' feelings.

Autistic children can use words but they only use words in a selfish manner. They do not listen to others, especially among the high functioning people. By training them, they will be able to more smoothly communicate with others. From when people are children, we should teach them to look others in the eye and understand the feelings of others. They should also be taught to explain to others how they feel and if the other is not convinced they should learn to give way to others.

As Dr. Shore and Dr. Yoshino mentioned, these people have strengths but even if the children are very severe they can have dexterity with their hands. In the longer-term, if we let them work on things we may be able to identify their dexterity, for example. We should try to link that strength to the types of jobs they can get.

However, as I mentioned before, we have to teach them not only to think about themselves but what the friends or colleagues feel or need, as well. That kind of communication will have to be taught.

This is not included in the summary but at the Keyaki-no-Sato we receive subsidies to run our workplaces. There are severe persons who have almost no IQ. There are 2 persons with mild autism. These persons work in a group to produce pallets used for transporting things with forklifts. As was mentioned by Dr. Shore, they can be taught to have eye contact. Their instructor, through work and daily learning, can teach the children how to produce the pallets. The children are able to do that no matter how mild or severe they are. They have some characteristics of autism but those difficulties may be overcome and by doing so they can go out into society and get jobs.

The Developmental Disorder Assistance Center and facilities like these can provide

help for these autistic people. That will be the basis of people with autism getting stable jobs. I may be repeating myself, but they need to acquire skills necessary for social life and they need to build resistance or strength to overcome difficulties when they face them.

When we established our facility there were a lot of objections. It took us 7 years to build our facility. It may be difficult to get these people access to employment. We have to change society and at the same time we have to teach the children to have pride and overcome difficulties. I believe getting employment would be one of the ways to achieve those skills.

In the summary, there is some reference material on the research that we did on employment of high functioning autistic people. We will be able to understand how difficult it is to have high functioning autistic people get jobs. Please read more.

Thank you very much.

## ***Self-help Group***

**Morio Minta**

**Psychiatric Social Worker**

**He is with Asperger Syndrome**

Sometimes I come across a website where people are asking, "What is the most suitable work for people with developmental disabilities?" I don't think there is any. It's just the same as asking, "What is the most suitable job for neurotypicals?" In other words, there are many varieties amongst those with developmental disabilities. Some people have communication problems. Others have execution function issues. Others don't. Some have hypersensitivity. Some do not have that. However, there is some inconvenience and that seems to be the commonality. I am here as a person with Asperger but even with the same diagnosis there are many other people who are totally different from me. Please understand what I'll be discussing is just my experience.

I represent a self-support group of adults with a developmental disorder in Kyushu. Four years ago we started holding meetings in this group. Every year we have a different representative. I am the current representative. My main job is to organize the meetings and prepare materials. As an officer, I am in charge of public relations, publicity, accounting and also some of the administrative work such as securing meeting sites and post office boxes. Currently 4 of us take care of that. We have meetings in Fukuoka city about once a month but starting this year we will be holding meetings at the Kumamoto chapter, as well. Aside from holding meetings we sometimes go out on the town together drinking but all of the participants are volunteers so we do not hold seminars or come up with publications because that would force people to do more work.

We had rules really before starting the group. We have this meeting handbook that talks about all of the rules for the meetings. We selected the topics of meetings and developed a website. These were started by people who are experienced in this area with other support groups. That's why its going well now and our activities are effective.

The purpose of our meeting is to provide a place to be and share wisdom with each other. In the case of other support groups, they sometimes aim for recovery but that's not our case. We meet to be assured that we're not alone, to sympathize with each other, to complain to each other, to be comforted and to share wisdom as to what should be done so that things will go better so that we can solve, even a little bit, the



inconveniences. Also, we manage to be able to improve our self-esteem and accept ourselves as is. It seems that the people participating in meetings become more and more positive so I think it was a good thing to start this group.

Now let me cover all of the developmental disabilities in general among the membership. The recent trend is that there are an increasing number of people members who are diagnosed with Asperger. This is probably because while they have interpersonal relationships at work, et cetera, they start suffering from depression, for instance. As a result, during treatment they end up being diagnosed with Asperger. We do not have anyone with ADHD. Those people can manage without such group participation because they can go out together with friends or colleagues from the workplace. There are people with learning disabilities and they are often unemployed or having difficulties at their jobs. Several people in our group have a disability pass, amongst them some with Asperger. For many disabilities on the autism spectrum I believe some form of public support is necessary.

People with Asperger, they often have a lot of problems even with work. They are often just barely hanging on to their job, just being given manual or side jobs. As for myself, I am not very good at understanding others' situation or understanding what people are thinking or how they feel by just looking at them and their facial expression. Sometimes I say things so casually which are insulting and so became unemployed.

My biggest problem was that I did not understand why we get paid when we do a job. More specifically, I did not understand in the past that companies are there to pursue profits. For that, work should be done efficiently and there are several sections in a company. By allocating appropriate people to a section, work can be done effectively. Work is ordered by a client from the company based on contracts. Responsibility lies not with each individual but with the company. If you have a problem with your day-to-day work and if your work seems to be overflowing you have to discuss it with your superior and make sure that the necessary measures are taken so that the contract can be fulfilled. If you are doing something unsure then that could be a problem for the clients. You have to make sure to discuss this with your boss and other people and get help. It's all natural and taken for granted but I failed to understand this in the past. In other words, I did understand how money flowed. I did not understand that and I only thought that by going to work I was able to be paid.

Having now understood that, I have made efforts to take initiative as a member of society and observe society's rules. I tried to convey using words what I am feeling and what I was thinking about and things got better.

I don't know if this will apply to other people. When I got my job was 19 years ago.

Compared to that time, with the collapse of the bubble economy now it seems that there is a lot of stress at work sites even for neurotypicals. In the past I recall people laughing very happily and loudly at job sites but nowadays we hardly see that. Even the neurotypicals are having a lot of difficulties at work so it will be very difficult for someone with a developmental disability to maintain their job.

Recently a number of measures have been introduced such as job coaching, indirect support and also to give support to the employers based on disability passes. Sometimes in the big cities companies are competing for people with disabilities but in the local areas more recently the grants under grant system for employing persons with disabilities is limited. However, I believe now a bill is submitted to the Diet to expand the scope so maybe it will get better soon.

We need to try to do everything we can on our own but sometimes it's difficult to try to accomplish something by oneself, so we do need a system where we can get support anywhere it is necessary. My dream is to establish a system which can insure more than 5 million yen for an annual budget. If each one of us can capitalize on our abilities, I don't think that this is too difficult a dream to fulfill.

Thank you.

## ***Medical Diagnostic Treatment and Support of Autistic Spectrum Disorders***

**Makiko Kaga**

**Director General**

**National Institute of Mental Health, National Center of Neurology and Psychiatry**

Thank you for the introduction. As a pediatrician, I have seen patients with developmental disorders. The first patient that I saw is already over 30 years old. I am a pediatrician but I still have the opportunity to see people who are over 30 years old.

Recently with regards to autistic spectrum disorders, when we make a medical diagnosis, the DSM-IV by American Psychiatric Association I or the International Classification of the Disease 10, ICD-10 by the WHO is used. Based on the current criteria listed in these, the particular individual is diagnosed depending on how many criteria are met.

The autistic spectrum disorder looks at individuals as a continuum. There are various ways to consider. Pervasive developmental disorders as listed in the ICD are almost synonymous with autistic spectrum disorder, I believe. Characteristic features in social interaction, communication, behavior, interests and activity patterns should be seen in autistics before 3 years of age. If they cannot be explained by any other disease, they will be diagnosed as autistic. However, because these items are qualitative, diagnosis depends on the physician's experience and capabilities.

I am belong to a hospital, so I call them "patients" in many cases but I know there is some controversy about the word "patients." We see them as out-patients and look at their condition, their history of development and their interaction with their families. All of these findings will be considered at in making the diagnosis. We look at interpersonal relationships with their parents and unfamiliar people to them, how they can look the other persons in the eye and the expressions that they show. When I ask questions on an out-patient basis I check whether there are new, unexpected and surprising responses.

At our out-patient clinic, we have a carpeted room that is about 30 square meters. We have some toys in the room. This is the case of a 3 year old child. This boy has connected 3 meters of these blocks all placed in the same direction. We also ask the children to draw pictures. They are very good at pictures but they give some strange impression. Because on the left, you see a 9 year old child's drawing of 4 children with no eyes. On the right side is a 12 year old boy's drawing. His IQ is about 130. This drawing is also strange. It seems that the perception of the body image or the sense of

people is different. It's not that all children draw the same pictures. We look at their behavior in the out-patient clinic to make the diagnosis.

There are many ways to look at it, whether this is a disease or not. There are cases where autistic symptoms are manifested along with other diseases. I check whether they have any of these diseases listed here, for example tuberous sclerosis, fragile X syndrome and whether there is a history of infantile spasms. All of this will be asked about to the parents or guardians.

Sometimes people show symptoms very similar to those of autism as a sequel of encephalitis. Looking at the child and taking precise developmental history may be sufficient to diagnose autistic disorders. However in many cases we do tests to evaluate children. For example, we do standard intelligence tests and other cognitive function tests. Often an autistic child is not able to recognize something properly and because of that, they may have difficulty in their social lives. We do a variety of neuropsychological and physiological tests to evaluate their cognitive functions.

We also have checklists to look at their mindset. Of course, we do not do all of these tests for all patients. It depends on the requests of the parents and on the state of the children and we will determine which tests are to be run to each child. About half of all autistic people have abnormal EEGs. Depending on the status of the patient, we will do brain imaging tests. We may look at functional brain imaging to see how the brain is functioning while they are doing something.

These tests give us some hints about what kind of responses or measures can be taken for helping these patients. This is called a social story test. We ask patients to respond whether these particular behaviors written in a certain story are appropriate or inappropriate in a particular context.

This is an example story of a 19 year old lady. She slept late and therefore she skipped breakfast and ran to the airport to take an airplane. Is this appropriate or not? I think this is appropriate for her. However, because she did not take breakfast she was very hungry. On the plane when the cabin attendant came to serve lunch, she ate up everything that was for her. She found a child sitting across the aisle from her who was not able to eat all that she was served. This 19 year old lady leaned across the aisle to ask her father if she could have the leftovers from that young child. In the case of this lady, this may be inappropriate.

These kinds of tests are done for checking on the condition of the patients but we can also use them as a work-book for the autistic people. Mothers are persuaded to create stories like this kind and to make their children read and practice how to behave in their daily life.

We also look for epileptic symptoms in them. Autistics seem to be difficult to differentiate familiar or unfamiliar faces. We ask autistic children to look at their own faces, their mother's face, a stranger's faces and objects to examine this impression and recorded EEG during those sessions. In the case of normal adults they respond most to their own face. In typically developed children response to their mother's face are most prominent. However, in autistic children with high IQ their response to any kinds of faces was the same amplitude, though they can actually differentiate faces themselves. This part of the brain may not be functioning appropriately.

From outside, their hurdles are difficult to be understood. We would like to apply those results for helping autistics in their daily lives. Medical treatment and educational training are the cooperative way to help autistics. Currently we cannot cure autism by pure medical treatment. However, we do have ways for their best possible lives.

Earlier diagnosis and treatment is the principle for any kind of diseases. However for autism and developmental disorders, the earlier the better method may not always the best. "Timely" diagnosis and treatment may be more appropriate. Their symptoms and their environment is differ from patient to patient. The diagnosis should be accompanied with the opportunity to take the appropriate action for the child.

In many cases, autistic people have the complication of epilepsy and in that case we can treat them with medicine. There are various drugs for behavioral problems. We have to be careful of the side effects but when you give these drugs in a timely manner they can be very effective. Antipsychotics or antidepressants can be used depend on their symptoms and their problems. Many autistic patients have sleep disorders and the ordinary drugs may not work. Melatonin seems to be effective in many patients with autism. In the United States you can buy melatonin in drug stores but in Japan it is not approved as medicine by Ministry of Health, Labour and Welfare..

Of course, education, training or appropriate intervention is very important. I will not mention about these details because other panelists have already stated upon that. We can take measures to respond to the behavioral issues and also we can try to characterize and utilize upon their good points. We have to consider how to improve their daily and future lives.

In many cases, autistic people have very good at visual concept, so we may be able to use that strong points. Dr. Oya of Asahi Central Hospital taught me about this list of treatments of autism. Some of these are appropriate measures and many of them may be inappropriate. No chemical substances and no diets have proven to be the cause of autism. The cause of autism is unsolved. There have been so many "therapies" because there has been no proof for the only and the best treatment for autism. I have to say that

some of these raise a lot of concern and suspicion.

For the families, these people are ready to grab at any opportunity or any possibility of treatment. We want media people not to throw unfounded therapies and to confuse parents.

For autistics with high intellectual ability, social skill training is necessary. They may need to practice how they should behave under certain conditions. Appropriate diagnosis should be made in a timely manner. They should be surely educated. Health management is always important. In order to be able to work and to study, they need to be healthy. In many cases, autistic people experience weight gain, especially immediately after graduation from school. We need to take measures against that. Including that, we will have to manage their overall health and self confidence so that we can assist them more in getting their job. We need to increase the number of people who understand their characteristic way of thinking and behavior.

Thank you very much for your attention.

## ***Panel Discussion***

## ***Discussion***

**Moderator Fukatsu:** We are now joined also by Dr. Shore. We will have a discussion on the topic of employment. After that, we will take questions from the floor. Today in regards to persons with developmental disabilities education and employment was discussed throughout their lifespan. As Dr. Yoshino pointed out, we have health examinations, educational training and then moving on to employment in the process. Especially after graduating high school or higher education, even for neurotypicals trying to find a job will be one of the most difficult changes in life. How to cope with that and deal with that I believe is an important subject of today's discussion.

Today we heard from the government's side about welfare support and employment support. We heard from two specialists from the government. Then we heard from physicians and about educational training and support. Then we heard from actual persons with this condition and their families. We heard their experiences. Dr. Shore in his presentation touched on having Asperger himself. Also, he is involved in research in this area, taking a special interest in this area. We had reports from many different viewpoints. Therefore, I believe that our discussion will also be very valid.

Before we start the discussion, Director Takaki from Chichibu Gakuen Institution is also participating. Her school is in Tokorozawa, in this prefecture. Today she is a physician at a developmental disability clinic. She is the director there. Perhaps we can hear a little bit from her point of view being a director and a physician. Do you have any impressions from today's discussion or anything else to say?

**Takaki:** Good afternoon. I am Takaki. As was introduced, where I am at National Chichibu Gakuen Institution there is a specialized outpatient clinic for developmental disabilities. Dr. Kunio Yoshino started this clinic in 2000 at the Chichibu Institution. This is a facility that accepts people with intellectual disabilities. Capitalizing on that experience, there has been an emphasis on the educational development of those with developmental disabilities. Now I have taken over his position and I'm involved in the actual practice or treating these people. What I feel most in my experience is the tremendous burden on the part of the families.

At our Institution currently there is educational training for preschool children. Also, this year we are starting a program where we dispatch our staff members to schools to create good environments for such children. However, even with such help extended by us, perhaps this will make the family's burden just a little bit lighter.

The question is who will actually be doing this? It's the family members, so I keenly feel that what we do is only the tip of the iceberg of what's necessary, actually. Every day it is a big headache to understand what we can do to lessen this burden for the



families. We feel at our Institution that various institutions involved in the community will have to collaborate together to solve this problem. For this collaboration and networking that is necessary, the family members are also working in this area to get the most information. Hopefully such burden can be shared by different institutions and centers.

We have early detection during preschool age and at the infant medical examination. We should also consider what should be done at nursery schools, kindergartens and daycares and link that to school age children. So far all that was necessary has been taken care of by the family members, which is a tremendous burden. We keenly feel that this is a big problem and difficulty for the families.

As the director of the Institution in this area, in the Tokorozawa community it is necessary to be working together and networking. We are determined to do our utmost and will make my personal contributions to the utmost, as well. I will continue to ask for your help and support so that we can make this a very effective network. Thank you.

**Moderator Fukatsu:** Thank you very much, Dr. Takaki. Now we would like to have some discussion among the panelists. You probably have questions for each other. Is anyone willing to break the ice? Does anyone wish to add something that you were not able to mention in your presentation?

**Hizume:** I have a question for Dr. Shore and Mr. Minta. Before I joined the Ministry of Health, Labour and Welfare, I was in Nagano Prefecture at the Mental Health Center in charge of an adult group comprised of adults with mental disabilities. In the group some of the members said because their colleagues were working hard and making efforts, they should do the same. Today you were talking about becoming an adult and starting work. Dr. Shore talked about in his book a guide for self-advocacy and also Mr. Minta talked about his self-help group. In either case, I believe it is very important to get help from your colleagues, from your peers.

My question is how can you find your friends and how should you associate with such friends and peers? We always think in terms of extending support from authority or whatever but I think support amongst people in a similar situation is very important. How can you find such people to help each other and how can you associate in an effective manner so that it can be maintained?

**Shore:** There are two parts to my answer for this question. One is that finding friends is pretty much the same as for everybody else. You find friends through getting involved in favorite activities, in activities you like to do. People who are interested in computers can join a computer club. Those who are interested in various sports may join a team or a volunteer group of people who are involved in these sports. People with various interests tend to congregate together.

For those of us on the autism spectrum, the same holds true. The difference is for us it's a little bit more of an extreme. People with autism tend to be much more successful when gatherings are activity-based rather than gatherings that are socially based. Again, it may be a computer club if that's an interest or a group of people who get together to swim. That may be another interest. By gathering together and by going to activities such as this you increase the probability of finding people who are of like mind. If they

The other way, which should be done in addition, is to get involved in organizations relating to your condition or situation. It's not necessarily a disability. That means making contacts in our case with other people having Asperger syndrome or autism. These days with the availability of the internet our network can easily be worldwide. It's just as easy to e-mail somebody in Pakistan as it is the person next door. Getting involved in local groups, if there is one, is a great idea as well so that you can have physical face-to-face contact and do things.

I guess one other thing I would add is that it's also important to make friends who are not on the autism spectrum, to make friends with people who can be allies, who can advocate on your behalf if needed, who can help you understand when challenges present themselves in the workplace and other social situations. Getting involved in these three areas I think will go a great way towards building a support network for people with autism.

**Moderator Fukatsu:** Mr. Minta?

**Minta:** I have participated in hobby groups. I talked about self-help. There is a limit to what they can do. There are some people who will be able to assimilate into that group and those who will not be able to assimilate into that group. If you are not able to assimilate into that group it would be stressful, so you should not be there. However, in our case the situation is that there is no other group. If there are multiple groups we will have a choice but if there is only one group there is no way that everybody can be accommodated. Therefore, we have to create more self-help groups.

As I mentioned, we have made preparations. We have to study how the group can be

operated or managed. In my case, I worked with another person and with that person I participated in another group. We did understand how a group should be operated. Even if we faced problems, we were able to observe that and face that. We had the experience that allowed us to do that. Without that experience, it would have been difficult.

I heard that 70% of alcohol and gambling-dependent people have a tendency for developmental disorders. Before they reach the age of adulthood there needs to be some education to prevent them from becoming dependent. Among those with developmental disorders, there are people who carry out inappropriate activities. We need a curriculum to assist these people and we need assistance in managing or operating our groups. It doesn't have to be public assistance. It can be assistance given by volunteer groups or other groups. There are some measures that do create a support system for that.

**Moderator Fukatsu:** Thank you very much. Was your question answered?

**Hizume:** Thank you very much. I have an additional question for Ms. Suda. I think you talked about working with others to assist people.

**Suda:** I talked about Keyaki-no-Soto where 90% of the people are autistic. I have been running this facility for 23 years. In the beginning, there were many, many difficulties. We took the people out into the outside companies.

We visited companies. The autistic people by seeing this facility or seeing the companies at least have been able to understand what it is like to work.

After 5 years we decided to establish a workplace within our premises. We established a workplace or factory where people can work. This work-making pallets seemed to be dangerous so it must have been very difficult for the people teaching them. When they see others working they would feel like they should work themselves.

Assessing the severe people, they are progressing well and they are looking at others who are doing well. They have made improvements and they are also good at enjoying their leisure time. They are very good at entertaining themselves. In the beginning when they went to karaoke they had to learn from the teachers but nowadays the children enjoy karaoke a lot. When they go back to their homes they tell their parents how much they enjoyed themselves even when they are severe. They even start dancing with each other.

As people working together, we came to have a similar mindset. These are people who didn't know what it is like to receive a salary but now they are receiving salaries. They understand the meaning of working and they now have pride in themselves.

It happens that our workshop for autistic people is the only one in the world. It accommodates 20 people. Last year the sales were 120 million yen. They received salaries and they do not have to receive assistance from their parents. They can accumulate pensions for handicapped people. It is for me like a dream come true. When people go and visit their factory or their workplace, all of these autistic people will come out and say, "Welcome to our facility!" As necessary they will use English. If among the visitors there is a Korean person or Chinese person they can at least say "welcome" in these languages.

They have pride in working and they take pictures. The visitors will take pictures of the facility. There are some people who did not get their pictures taken because they are just transporting wood but they insist that their picture should be taken, as well. I believe that Dr. Shore has been to our facility, correct? Yes, he has seen our facility. We should not give up on autistic people regardless of the severity.

Autistic people themselves can find friends among themselves. For high functioning people, if you do a questionnaire they really want to have friends. For the first 1 or 2 years they may have good friends but afterwards their relationships do not seem to last in many cases. It seems like making the relationship last may be difficult but overcoming various difficulties of autism from when they are young is very important. That is what I think.

**Moderator Fukatsu:** Ms. Suda, I think you said you had a question for Dr. Shore.

**Suda:** You mentioned that you have to identify the strength of that person and find a job that is suitable to that strength. What should we do for people for whom we cannot identify any strength, if we cannot find any advantages or capabilities that they have?

**Shore:** That's a good question. I find that if I observe and study a person long enough I will find some strength. I will find something that if it's not a strength that is directly attributable to a particular job there will be something that can be molded into an activity that will fit into some particular job.

Let's just say for example you have a child or an adult who loves to line things up. What they'll do is they'll take a bunch of blocks and they'll line them up on the floor. They'll just keep going and going and going and going. If they hit the wall, then they'll turn 90 degrees and keep on going. Just looking at that particular behavior, it doesn't seem that there is much there. One thing I would start to wonder is might there be a way to take that affinity for lining things up (and of course perfectly in the way people with

autism will line things up) and could that be translated into, for example, laying a set of bricks or stones that could be the boarder of a garden? This is how I would think about looking at something that a person with autism is doing and very likely doing it over and over and achieving some sort of pleasure. That's how I would go about it. Arigatou gozaimasu.

**Moderator Fukatsu:** Is that OK? Dr. Shore talked about a child who loved to splash water from the faucet and enjoyed the sensation of water pressure. Abe from Keiai, do you have a question related to that?

**Abe:** I am Abe from the Keyaki-no Sato, the facility with autism. As a parent, I would like to share some comments or experiences with you. My child is 45 years old now. As Ms. Suda said, he is the severest case. He is one of the champions in that regard. In the days when he was young there was no mandatory education for people with disabilities so hardly any public education was given. However, we worked hard with advice from seniors and we learned from our child and gained educational training. In a way, I was experiencing something quite like your parents, Dr. Shore.

My child used to love playing with water. I was fully aware that he was enjoying the sensation of water pressure from the hose but we were living on the second floor of a building and if we flooded the floor, that would be a big problem for our neighbors. I had a big headache trying to figure out what to do and how to stop that. Also, he was very hyperactive. He was always moving around. Just in one second he would be gone.

I was looking for a way to solve these two problems. I could not prepare dinner or lunch because I had to keep an eye on him all of the time. In those days even the term "autism" was not so well-recognized, even among some of the specialists. I thought because he loves water why not work in the kitchen together? That was how I started.

First he would wash vegetables, potatoes, Chinese cabbage or whatever. Then he moved on to do the dishes but he didn't know how to wash the dishes. He could do one thing but not in a continuous way as a process. So I broke down each action necessary and taught him each step that was necessary. For instance, I taught him to turn on the faucet and get the water and then stop the water and then the next step is to take the sponge, et cetera. I taught him holding his hands. It took about 2 years of working to be able to do this continuously. by himself He started at 5 years old and as Ms. Suda said earlier this helped to foster a relationship of trust between myself and my son, as an afterthought anyway. Although that wasn't the main purpose of it, it helped us to trust each other.

What does it mean specifically? “Well, if it’s mother saying it maybe I can wait to do something. I really want to go over there but maybe I can wait. I really want to go, but why not wait a little bit because it’s mother telling me that, not somebody else.” I think he started to feel that way and think that way.

Then one thing would lead to another. We started with dishwashing and then doing the laundry. Then he would clean the rooms. I had to teach all of the actions one by one but he became capable of doing those chores. In this process, the child learned that he could do all of these things, which led to self-esteem. He was very proud. Then the characteristics and features of autism would be very helpful and effective because it helped him to lead a much more comfortable life.

However, another problem came up. It worked with me but not with other people. Dr. Yoshino was talking about starting at a young age. We had to work together with other families, sharing information from very early days. If that were available that would have been nice but in those days there was no such system at all. There was no networking, no nothing, so that was a big headache for me.

Finally, when the Keyaki-no-Soto group was set up, I found hope. They were operating earlier on without official approval. Then we introduced a system where each support staff held responsibility in each people We introduced daily chores. Also, we would visit different places. We visited this pallet factory and my child became employed there as a trainee in a crew. There they taught him how to remove nails. Over 3 months he learned that. Now he can do that.

What happened was after that interpersonal relationships between my child and the staff expanded immensely. He would trust staff members there. All of a sudden, very rapidly, with all of the other staff members and his peers working in the same facility this trusting relationship expanded and spread.

When we talk about employment it makes one think of officially visiting companies and being interviewed, et cetera. My experience is that being able to work also leads to being able to enjoy yourself in your leisure, as well. That’s what’s really necessary when you’re a grown-up. I think my child is really enjoying that. He is very severe still but he is carrying lumber in the factory and he is very proud of himself.

That is also reflected in how he lives in terms of rehabilitation. It has had an immensely positive effect. When he was small when I would scold him he would scream his head off crying. He would become panicky and bite people, et cetera. He lost that when he was about 10 years old. Now he would buy his favorite music CD and play with toys. With the support of his support peers, he developed that far.

To establish an initial relationship of trust is important. If you can do that there will

be other people to support you and peers to support you. Although my child is a very severe example and although this is not a regular kind of employment, he is working from 8:30 to 5:30 in the afternoon and he can do that.

I have a request to the government about a job coaching program. As Ms. Suda said, the group starting in 1985 was prior to job coaching starting in the United States. This was introduced not just for regular employment but even for groups. Hopefully this program can be expanded so that people with severe autism could work and contribute to society and also in turn enjoy life and gain satisfaction. That is my request to the government. I was stimulated by Dr. Shore's comments and therefore I gave my comments.

Thank you.

**Moderator Fukatsu:** Thank you very much. There are people who love being under high pressure. Maybe one of the possible jobs could be washing dishes. Mr. Ichikawa, do you have anything to add?

**Ichikawa:** From my experience as a job counselor, there is something that came to my mind. "Working" may involve having a job contract but that it may be that "a job. It is an extension of your daily life. Nowadays, washing dishes is regular practical job training of special support school. At least in Tokyo, usually there will be at least one intellectually disabled person working in restaurants washing the dishes.

For the job coaching system, we are responsible for the employment area. Of course, we will be providing job coaching assistance so that they can get employment. One of the major missions is to move from welfare to employment. Qualified people will be job coaches. These job coaches, who understand the individual, will be providing advice.

Under the Act on Support for Persons with Developmental Disabilities there are some training sessions for administrator of rehabilitation services. Employment assistance is a very important part of that seminar. Job coaching is a methodology so we have people at the facilities that have learned that technique. The people will be able to get jobs that will give them higher income.

You talked about group employment. What we are thinking of now is for people with schizophrenia. They can go to the workplace, assist each other, maintain their health and do well on the job. There are already some systems or structures but we are doing some research and studies to make the system easier to use.

**Moderator Fukatsu:** Thank you very much. As time is running out on us, it is now time

to take questions from the floor. Please wait for the microphone and ask your questions. We have panelists from various areas of expertise. The person sitting at the very front?

***Murakami:*** Thank you for the very meaningful seminar. I am Murakami from the Tokorozawa-shi Teetsunagu Oyanokai and also I am involved in the soccer team of persons with intellectual disability. Let me speak about my own experience. A special subsidiary system for employment has now been introduced.

I did visit a factory the other day and there are over 30 people with disabilities working there. There is a person at the reception. There is a shop there and there is a lady there. This person will ask the name and birthday of each visitor. When you go there the second time that person remembers you and will say, "Hello." If your birthday is close she will say, "Happy Birthday." I heard that this person was not able to speak that much before but now she is able to speak smoothly. She asks for your name and birthday. Dr. Shore, are there any cases in the United States where there are people at a reception desk who will ask your name and birthday and they remember those names and birthdates?

***Shore:*** There must be someone in the United States who does that but I haven't encountered them. I think that's a good link towards social interaction in a job situation. One thing I might think about is whether there is something else that you could link to you might say the vast memory bank of this person that they could comment on in addition to birth date. Maybe it could be something related to the clothing that they wore last time. "Last time I remember you wore this beautiful blue coat," something like that, for example, but I think that's a good start.

***Moderator Kitamura:*** Thank you very much. Are there any other questions? The person at the very front?

***Kuroiwa:*** I am a person with ADHD. My name is Kuroiwa from Saitama Prefecture. I think Ms. Suda mentioned that a high functioning autistic person in many cases have not been identified when they were young. When they grow up and get employment they may not be able to adjust to that environment and they may be fired. That is something that ADHD people experience. Because they were not careful when they were children or they were not trained when they were children, when these ADHD people become adults how can they adjust to their environment? What can they do themselves and what kind of assistance can others provide?



**Moderator Kitamura:** I'm not sure who to ask but perhaps we can start with Ms. Suda and if anybody wants to answer then please speak afterwards.

**Suda:** Actually, Dr. Kaga talked about the diagnosis According to the questionnaires, the parents do not care to go and get a diagnosis. Especially when their IQ is high, when they grow up to be junior high school students they become pretty violent inside their room. At that time, the parents acknowledge at last that there is something wrong with their children and they bring them to the doctor at that stage. However, when they are in junior high school that means that the child has grown up already to the extent that they have formed their features to a certain extent.

When they are abnormal since they are young and in the case where IQ is high but if there is a speech problem in the early stages they would do better. However, if the parents do not recognize the abnormality, if they are not accepting of the abnormality, there will be a problem. What is important is to accept the fact. That will have the largest impact on employment.

The parents seem to want to only accept the fact that they are good at something. They accept the fact that they are good, for example, in math but if they are not good in language or Japanese language they make the child work hard on their shortcomings. They push the children too far and the daily lifestyle forced onto children by parents may confuse the children. My advice is to see an expert or specialist as soon as possible.

When a person with Asperger goes into kindergarten they may be speaking normally. However, high functioning people may be speaking but they are only using a limited number of words. High functioning people and Asperger people seem to be different according to the results of the questionnaire.

The fact that the parents are not accepting of the fact is a problem. That may arise from the fact that the high functioning people they seem to be able to achieve a certain level of functionality. If they are intellectually handicapped from the beginning the parents are more accepting. However, when they find out after the children grow up to a certain age the parents are very shocked and the children will have problems after that, so it's very good to detect early.

**Shore:** In getting to know Mrs. Suda and Mrs. Abe it becomes clear that one of the largest factors to success for children with autism (or with other conditions, disabilities or whatever you want to call the difference) is that both of these parents and mine as well accepted us for the whole persons that we were. At the same time, they recognized that there were in many cases significant challenges that needed to be overcome in order

for us to lead fulfilling and productive lives. I think if we focus on the characteristics of autism, ADHD or whatever the condition might be without putting a value on it (not saying that it's bad or terrible or even that it's good but this is just what it is) then we find a way to use the strengths of people with autism to accommodate these challenges and lead a fulfilling and productive life.

**Moderator Fukatsu:** Mr. Minta ?

**Minta:** I would like to make a comment. Someone talked about ADHD. As you can see from my profile, in the past I was diagnosed as ADHD but now I am diagnosed as Asperger. I knew about Asperger all the time but because of the system I just let go. You need a physician who is capable of diagnosing Asperger. Then someone with any other diagnosis, if one has some verbal difficulties that would be Asperger most of the time. Although this is limited in adults, I think to have this diagnosis is important.

Also, many people are hypersensitive. Because of such a possibility, there are also sensory tests available. Society is providing that. I was tested last year. Increasing the number of people who can provide such tests I think is related to better employment. Thank you.

**Moderator Fukatsu:** Dr. Yoshino?

**Yoshino:** If I may add just one point, there is no specialist in education. Maybe we have missed that because I have a lot of questions and criticisms about education. With Asperger and high functioning cases I think diagnosis is necessary to protect their rights. For a better life, you need to understand the characteristics of these people much better. If you can do that perhaps they will realize that there's a big chance that the person can lead a life that is different from other conditions.

Another problem is even if you're diagnosed with Asperger in Japan, training for social skills and problem-solving skills are not taught at school. It's not done. There is no such program at schools. Reading, writing, arithmetic and simple greetings are all that's taught. How to interact with others, how to carry out a conversation and when to change the topic in a conversation should be taught from primary school all the way to graduation. A consistent program should be provided but what's done is just a one-time session here and there. Then the teacher in charge of the class gets changed.

Someone who loses their job would come to us for the first time. Due to lack of communication capacity, they got fired, and also because of lacking common sense.

Another thing that's necessary is to distinguish between medical diagnosis and educational diagnosis. Medical diagnosis is necessary when it's necessary, but for educational purposes we need to plan at which point this person needs a certain kind of education. For that, we need diagnosis. If the parent is afraid of their child being diagnosed as such then the child will lose all of the opportunities for being educated or being trained or they may be misdiagnosed and the disease name would never change. We should recognize that there are such needs and hopefully there will be better support.

**Moderator Fukatsu:** Thank you. Dr. Kaga, you are involved in early diagnosis and you have very long experience. Do you have any comments, please?

**Kaga:** Early diagnosis itself is not always necessary. However to make sure their guardians to know their children's autistic character and the way of thinking to child-rearing is essential at the earliest stage. Basically, the sooner, the better, if diagnosis is along with treatments. The question is how can we tell them whose child is autistic? At first we discuss with the parents that your child has this kind of tendency and characters. That process would make the parents prepare to be able to accept the medical diagnosis, as well.

Just an early medical diagnosis, giving a disease name at very early infancy, is rather harmful. To facilitate the child by seeking the necessary support at his/her home, nursery, kindergarten, school and his/her profession is always necessary. Medical diagnosis should always be associated with their parents' understanding of their children's characteristics disposition or behavioral tendency as necessary information. We do try that all the time. I would like everyone to consider in any way what they can do for the child.

**Moderator Fukatsu:** Thank you. We still have a lot of questions and comments, I'm sure, but unfortunately we have run out of time so with this we'll close the panel discussion.

## ***Closing Address***

**Fumio Eto**

**Director, Training Center**

**National Rehabilitation Center for Persons with Disabilities**

Good afternoon. I am Eto in charge of the training center at the National Rehabilitation Center for Persons with Disabilities. As a part of activities as a WHO Collaborating Centre, we have held this seminar to increase awareness of developmental disabilities and to increase employment support. We had a large audience. We are very happy.

In the keynote, Dr. Stephen Shore told about his own experience. He also presented to us what's important for achieving success in employment and also how important it is to continue having passion for one's interests. It was very impressive and informative. Thank you very much, Dr. Shore.

Also in the panel discussion that followed in the very much limited time available I'm sure a lot of you wanted to ask more questions from the floor. The panel members were very good at keeping to the time. Thank you to the panel members for sticking to the time. Also, we give our thanks to all of the audience. Despite the fact that this is a Sunday afternoon, thank you for your active participation in the discussion. I am sorry that we did not have enough time. Hopefully we can have another opportunity in the future for a meeting of this nature.

Developmental disabilities have to do with the whole process of becoming an adult to continue being trained and educated to acquire necessary skills for being employed. In this process there are difficulties. That is a characteristic or feature of people with such disabilities. There are a number of difficulties involved in learning disabilities and mental disabilities. Especially in the case of mental disabilities, it's not so apparent from outside. Therefore, quantitatively and qualitatively support is lagging behind.

Today we listened from government representatives for autism and PDD, as well. A new law has been enacted to support those with PDD. We have been involved in rehabilitation of the people with cognitive disorders very actively. Under another new act, physical, mental and intellectual disabilities are now identified, clearly as the same category subjects to be supported for their independent living. By the second half of this year, the name of our facility will be changed to adopt to treat the persons with any three types of disabilities. We are determined to be very active to extend support.

When it comes to rehabilitation, what is important is to provide support service that is

matched to the individual needs of those with disabilities, so we need to understand clearly and accurately what their needs are. We also need to hear directly from them. In that regard, the symposium today has been most helpful and informative. With this, we will be able to do a better job in supporting social activities and employment. To that end, we want to continue developing necessary techniques and technologies and also do work in other areas, as well.

Thank you again for coming this afternoon. Thank you.