

WHO Collaborating Centre Seminar
Academic and Living support for Students with
Disabilities in Higher Education

February 7, 2009
National Rehabilitation Center for Persons with Disabilities
Japan
WHO Collaborating Centre for Disability Prevention and Rehabilitation

Program

Time & Date : 13:00~17:00

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

”United States Students with Disabilities in Higher Education: Blending Equal Access, Vocational Rehabilitation, and Independent”

Mr. Jim Marks

Director of Disability Services, University of Montana

President Elect of the Association on Higher Education And Disability (AHEAD)

14:10~16:45 Panel Discussion

Moderators: Dr. Reiko Fukatsu, Director, Information Center for Persons with Developmental Disabilities, NRCD

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

Presentation by Panelists

“Report on Results of FY2007 Actual Survey of Conditions on Academic Support Technology”

Mr. Atsushi Tanikawa, Director, Special Assistance Division, Japan student Services Organization

“Activities of DO-IT Japan and Higher Education Support to Students with Developmental Disorder or Higher Brain Dysfunction”

Dr. Takeo Kondo

Project Assistant Professor, Research Center for Advanced Science and Technology, University of Tokyo

“University and Graduate School Admission Support and Academic Support for K as Person with High-Functioning Autism Spectrum Disorder”

Dr. Kazuko Takahashi, Assistant Professor, Research Center for Child Mental Development , Kanazawa University

“Daily Living Support Essential for Academic Support for Students with Severe Disabilities”

Mr. Akira Terashima, Dean and Professor, Urawa University

“The Path from School Admission / Readmission to Employment for Students with Spinal Cord Injury”

Mr. Makoto Ohama, Chairman of Japan Spinal Cord Foundation

Discussion

by Mr. Jim Marks and 5 Japanese panelists

Question and Answer

with audience

16:45～16:50 Closing Address

Dr. Fumio Eto, Director, Training Center, NRCD



Facilitator Dr. Yasoichi Nakajima



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Opening Address

Tsutomu Iwaya

President, National Rehabilitation Center for Persons with Disabilities

Good afternoon, ladies and gentlemen. Once again, thank you very much for coming to the WHO Collaborating Centre seminar. In Japan, there are people who cannot attend higher education due to disabilities and people unable to continue studying in a higher education environment because there is no device or method to replace or assist with their disabilities. Even those people who graduate from the higher education system still cannot find employment and are therefore isolated from society. Recently, the mindset regarding disabilities has shifted from the medical model to bio-psycho-social model and, at the same time, various functional impairments are being understood in many dimensions. And also, we started preparing support services to cope with some of the disabilities which were not included in the former or traditional social welfare services, such as higher brain dysfunctions and developmental dysfunctions and difficulties. In Japan, taking the first 10 years of the new century, we set a target to make a society. To realize a cooperative society, we need to think of empowering each individual. Through education, we can develop each individual to develop their abilities and also gain the capabilities so that they can fully participate in social activities. Every day, we are engaged in medical services and social welfare services. From our perspective, we have been thinking of contributing our knowledge to the educational system so that we can provide more services, systems and also shed some light from the perspective of the medical services on the educational system so that they can be equipped with better facilities for students with disabilities.

Now, we have invited Mr. Jim Marks, who will be sharing his experience and the current situation in the United States, as a specialist in this area. Within Japanese universities and the higher education system, only 0.16% are students with disabilities. However, in the United States, among all the students in higher education, 11.4% are students with disabilities. Therefore, we are very much looking forward to learn from Mr. Jim Marks so that we can import some experience of the United States to Japan. We have been holding this type of international seminar over the last several years and through these seminars, we hope that we can revisit our systems and legal frameworks and also, in comparison to international legal frameworks and regulations, how we can modify our current legal system. We hope to shed light on those issues. And I don't think that we can achieve results from this seminar immediately. However, I hope that we can contribute to the discussion so that we can plant some seeds to stimulate the

sociological actions in the future. Thank you.

United States Student with Disabilities in Higher Education: Blending Equal Access, Vocational Rehabilitation, and Independent Living

Jim Marks

Director of Disability Services, University of Montana

President Elect, Association on Higher Education And Disability(AHEAD)

Thank you very much. Konnichi wa! I'll get myself settled in here a little bit. I am very honored and happy to be invited to speak at this seminar. This is my first trip to Japan and I am learning a great deal and will be able to go back home and talk about the things that I've learned, so this is an experience for me, very much so. One of the students that I serve in the University of Montana in Missoula, he is a wheelchair user. I met him one time in the hallway. He was looking at an automatic door opener. It was of a style or design that had a large plate instead of a small button so that a person with a disability could push the button with an elbow, a shoulder, a head or whatever. He was looking at that device on the automatic door and I asked him what he was doing and he said, "I am from a small Montana town and when I was at home, I had to struggle for everything I wanted and every place I wanted to go but here, when I look at things like this automatic door opener that's designed so well, I can tell that others have been here before me." And I took from that conversation the importance of learning from one another and growing from one another and developing relationships that can make the world better for each of us. On my way here, I studied a couple of things about Japan and Montana. Montana is a state, like a prefecture, and it is about the same size as the nation of Japan geographically. One big difference, though, is that in Montana there are only 900,000 people, so less than one million people. However, we might, instead of having 127 million people as Japan does, have 127 million cattle in the state of Montana. Another thing I was looking at was yesterday my wife was reading from the English version of the Japanese Times. She read a haiku that said 'income tax, forms filled out, hope and savings gone,' and I thought that's just like Montana, so we have many

similarities. What I wanted to do is talk about two things. One is about the office that I administer at the University of Montana and the other is the professional association of people who have jobs like mine, called the Association of Higher Education and Disabilities. So my lecture will consist of two main emphases on those two topics. The University of Montana is a college – a university – that offers everything from trade programs, like learning how to operate heavy equipment, to some small medical programs through graduate degrees and pretty much anything you'd like to name. Essentially, we are a liberal arts institution. We do not have a school of medicine. We have a school of law and about 14,000 students attend the University of Montana, so it is a medium-sized university in the United States. My office is part of what's called the "student affairs division," so my boss is the Vice President of the University for Student Affairs and her boss is the President of the University. In my office, we have approximately 15 staff members. Their positions vary, but the core – or main – positions in the office are what we call "coordinators" or "disability service coordinators." Each student with a disability is assigned a coordinator with whom they work to build a plan or strategy for how that student can participate in the University of Montana programs. We assign students to coordinators in a unique way – even for the United States – in that our coordinators do not work with specific disability groups. Traditionally what would happen is that you would have a learning disability specialist or a deaf/hard of hearing specialist. For us, each coordinator serves people with many different disabilities. We do that for a specific reason and that's because we want to emphasize environmental accessibility or accessibility of the environment. And we like the idea that when a student comes to us, the first question we ask them is not, "What is your disability?" We ask them, "What is your major? What is your academic study?" And we believe that that emphasizes the more important thing, which is the reason why the student is at the University of Montana. In support of these four coordinators are other people, including myself, an administrator. We have a receptionist, an office manager and we have an assistive technology coordinator. I am sure in Japan, like in the United States, higher education is relying more and more and more on instructional technology for its infrastructure. We need an assistive technology coordinator to ensure that those

instructional technologies are accessible to and usable by students with disabilities, so it's a very important position for us. We also have about five sign language interpreters who also serve as real-time captionists for students who are deaf or hard of hearing, and then we have a person who converts print technology to e-text. In addition, we have about 20 to 30 student employees that come from a variety of different majors all throughout campus. Most of them work for us through a financial aid program called "Work-Study" and they serve as test proctors, readers, scribes and assistants to the students as well as to many of the staff in my office. As you noticed, I am blind and many of my staff members also have disabilities and so we tend to be able to model the kind of first-class citizenship that we expect for people with disabilities – for the students that we serve - and so our student employees will also provide support directly for the staff members. Then the other, last group of employees of people who assist – actually, we call them "volunteers" – are students who assist other students with disabilities in classroom lectures by taking notes. They are note-takers. And so that is a kind of outline of the office and how we're structured. It's rather small. The number of students with disabilities is relatively large. We've identified 1,000 students out of 14,000. That's a little over 7% of the student body. You heard the statistic earlier that over 11% of students in higher education in the United States are people with disabilities and I believe that's probably true but the 7% that we've identified are those that have asked for and received some kind of service. Not all people with disabilities use services. We know that there are others out there that do not use my office but they're out there. I've been in the job for 20 years. I often like to tell a story about the first student that I met. I remember this distinctly because it was an important day for me. I had just taken the job in 1988 and I remember walking into the office. There wasn't much at the University of Montana for disability services 20 years ago. I had a room that was small. There was no computer. There was a filing cabinet with some files in it but not much and a closet that was essentially full of poster paints. And I remember looking at the office and thinking, "Oh my, I've got a lot of work to do. There is much to be done." And there was a knock at the door and I opened the door. It was a young man – a student – who was very upset. He said to me, "You know, I know you're brand

new to the job but your predecessor told me that I could get talking books and I'm not getting my talking books. I have a learning disability and so I listen to the talking books and read the print at the same time and so that way I can keep up with my reading. But without it, I'm not going to be able to access the University of Montana." So we sat down and talked and I said, "You know, I can't fix this problem right away. It's going to take some time." And we figured out a path for the student to follow. We used programs outside the University of Montana, such as Recording for the Blind and Dyslexic, a provider of talking books. We used scan and read technology, which at that time was fairly new and also quite expensive. One of the nice things about technology is that it gets better, cheaper and smaller as time goes by and so what's available today is amazing compared to what was available 20 years ago. So we put together a toolbox with several tools for this student to use to access his reading load and he was able, with these services, to do well. He ended up graduating and then I lost touch with him and about 10 years went by. And then he came to my door later on. This time he was wearing a suit and tie and looked very handsome, very professional. I asked him, you know, "What brings you to campus today?" And he said, "Well, I am here to attend the education fair that the University holds." It's a fair where potential teachers come and find out about jobs and can get jobs as educators and in many places in the United States in Montana, the North West and beyond. It's an important event for our school of education. And I said to him, "Great! Are you looking for a job?" because I figured that he, you know, was still looking for work. And he said to me, "No, I am now a superintendent of schools. I am here to hire teachers." And when he said that to me, I felt immense pride and happiness for his success which he earned himself, which he did himself, but I was glad to have played a role to making it possible for that young man to get an equal footing so that he could study and achieve the things that he wanted to do with his life. The reason why disability service programs exist in the United States – well, there are several reasons – but really, it's a legalistic thing and I want to talk a little bit about the laws, if I may. The first law was passed in 1973 and it's called Section 504 of the Rehabilitation Act. It's a very simple law, only one or two sentences. It says that if you are an entity that accepts federal funding then you must promise not to

discriminate solely on the basis of disability. The interesting thing about it is that when that law was passed, no regulations were written for it for five years. And so in 1978, activists with disabilities were tired of waiting for the United States government to write the regulations that would make changes that would allow people with disabilities to participate in programs like higher education. And so they took over in a protest several federal buildings throughout the United States. One of the more famous ones was in San Francisco. They demanded that those regulations be written and so they were. The President at the time was President Jimmy Carter, who directed the Health, Education and Welfare Department to draft the first regulations. And it was at that time, in 1978, when disability service programs became commonplace in higher education throughout the United States. Before then, there had been a few. For example, at the University of California Berkeley there was a program that provided extensive support to people with spinal cord injuries. It was the birthplace of the independent living movement in the United States, as well. There were other programs, such as the one at Southern Illinois University in Carbondale, Illinois, and it was designed for returning veterans of foreign wars who had disabilities – disabled veterans. And it had been going for a long time but after 1978, that's when offices were formed. An interesting thing happened later on. President Ronald Reagan was famous for his desire to trim government and make it smaller, so he assembled a commission of people with disabilities, leaders with disabilities, that shared his political viewpoints and he asked them to look at Section 504 of the Rehabilitation Act for dismantling it. And among that group of people was a man named Justin Dart. Justin Dart actually has a strong Japanese connection. His wife is Japanese and he was the owner of the Tupperware fortune. Tupperware became so popular in Japan in the 1960s and 70s and it was a place where Japanese women could get work, so he had strong ties with Japan. What happened with this commission, which was led, to a large extent, by Mr. Justin Dart, was that they took a look at Section 504 and they said this is such a good idea that we should extend it to the private sector. And so what happened is that this commission, which was designed to dismantle disability rights, actually reinforced them and the Americans with Disabilities Act was born, the idea for it. It took a few more years for it to be passed but the Americans with

Disabilities Act was passed in 1990 and, at that time, disability access became very much a part of the American psyche and understanding. We look at disability differently than we used to. We still struggle with many concepts but, essentially, what we look at now or we try to move towards is what we call “a social justice model of disability.” What is more common is a social welfare model of disability, which is an important model but it essentially says that people with disabilities are the objects of the good works of the providers and the support systems, that we make sure the people’s welfare is taken care of well and we provide services but it really does not put people with disabilities in control of their own lives and the services offered to them. So now we’re using more and more in the United States a social justice model. The social justice model says that a disability is essentially a characteristic. It’s a characteristic like having, in my case, gray hair and large feet. My blindness is very much part of me but it’s not all of me and I think it definitely shapes me in many ways but I am so much more than merely blind. And so a social justice model shifts the emphasis to rights, to the right to participate on an equal footing with others. And what we look at is discrimination and how to remove discrimination. A concept in the civil rights laws for people with disabilities is a concept of reasonable accommodation, also called “reasonable modification.” And what it says is many times discrimination is based on plain discrimination that says, “I do not like blind people. I’m not going to hire them.” That’s not usually how it works. What usually happens is, “I don’t know about blindness. I don’t know how to make my program or my job accessible to this blind person or this disabled person.” And so reasonable accommodation involves changes in the way things are done so that people can do the important stuff but stuff that can be changed may be changed so that a person can participate. And many people ask, well what does “reasonable” mean? The truth of the matter is, we really don’t know what “reasonable” means. We look at it instead on what is unreasonable and in higher education the main thing in unreasonableness involves a fundamental alteration of academic standards. It could involve an undue financial or administrative burden, although there has never been a university or college in the United States that has successfully said that people with disabilities cost too much. It’s just not done. And then the third thing is a personal

service. The fundamental alteration is an interesting one. An office like mine is sometimes mistakenly thought to be an advocate just for people with disabilities. In fact, we are not. What we're an advocate for is justice and sometimes justice involves accountability. It means people with disabilities do not get everything they want and that the expectation is high that people with disabilities will be held to the same standards and performance expectations as would be any citizen. And so a professor could say in the United States that a modification request could go too far. For example, say a course of study requires four examinations. A person with a disability might say, "That's too many examinations. I would like to take just two." What would likely occur is that the professor would say, "No, you must take four examinations. I will give you extra time to take each of those examinations but you must take all four." And reducing the number of examinations would be dropping the bar or expecting less or a fundamental alteration of the program. But extra time to take the exam may be allowed the person the extra time it takes to write if they write more slowly, to read more slowly, to process the information in a more timely way. The extra time for an exam doesn't matter. It doesn't hurt the academic standard. I'm going to really skip the undue financial burden part of it because I think that's pretty self-explanatory. If something costs too much, it's unreasonable. But I would like to move to personal services. A disability service office in the United States does not exist in a vacuum or on an island. It is part of a much larger infrastructure of social services such as medical rehabilitation, vocational rehabilitation and social welfare programs in the United States under what we call Medicaid or Medicare, which pays for many of the services that people with disabilities use. And a disability service office has a fairly narrow mission or purpose. It's there to make sure that the learning environment is accessible so that we're not discriminating against people with disabilities in the use of the program. So the personal services or the office does a great deal of collaboration in working with other outside agencies. I am happy to hear today that that's one of the focal points we are looking at because I think it's really essential. We need to build networks and we need to have more communication and interaction – just like we're having now – to build the best possible set of options for people with disabilities, people without disabilities and society in

general. I'd like to shift now, if I may, to who it is that the University of Montana Disability Services Office serves. Like I said, there are approximately 1,000 students with disabilities. The largest group by far consists of students with learning disabilities - things like reading comprehension difficulties, dyslexia, sometimes symbolic language deficits or other kinds of processing deficits that involve the core part of the academic work. They're by far the largest group. Then next comes attention deficit disorders or attention deficit and hyperactivity disorders. Of course, like many of you probably know, it's common for learning disabilities and ADD to co-exist and that's well over half of the 1,000 people, those two together. Probably the next largest group and one that is growing in the United States are students with psychiatric impairments. Probably the most common diagnosis there is bipolar disabilities. It's something that is growing. Then the rest of the students with disabilities consists of more traditional disabilities. We have at the University of Montana probably around 30 people who use wheelchairs and probably about 6 or 7 deaf students and we have probably 15 students who are hard of hearing. We have students with heart impairments or respiratory impairments, head injuries, all different kinds of the 7 conditions. The majority of the people that we serve have disabilities that are invisible. When one looks at them, you can't tell that they have a disability. In fact, interestingly enough, many of the students that my office serves are star athletes. Due to confidentiality reasons I can't tell people what I know sometimes about those students who are playing American football or basketball or track who are well-known in the community for their athletic abilities but many times they are also students served in my office, so it is quite a mixture. That pretty much gives you a picture of the University of Montana disability services. I know that in the United States, we tend to be - one of the speakers at a conference earlier this week made a comment that sort of illustrated the fact that Americans tend to be pretty litigious. We tend to like to sue one another and fight quite a bit. Dr. George Kersher from the DAISY Consortium in his speech talked about how the United States has 5% of the world's population but we have 50% of the world's lawyers. So much of what happens becomes legal issues in and around higher education involving discrimination. So I'd like to switch to the final part of my lecture. That's on my role within the Association of

Higher Education And Disability – AHEAD. AHEAD is an organization of people who have jobs like mine or my staff. It is an international group, although we've not done as much as we would have liked to and we wish to do more. I know that some of you have been to conferences in the past and I'm hoping that more will come later. I am the President-Elect of AHEAD. The way it works is that you're elected for two years as President-Elect and you are groomed and trained to run the organization for about two years. Then you become its President for two years. I've actually served on the AHEAD board of directors for quite a while now. Before I became its President-Elect, I was its treasurer. AHEAD is an organization that I really like because it's a place where we come together to learn from one another. We hold an annual conference each summer. The one coming up this year is in Louisville, Kentucky. During that conference, we will have speakers on many, many different issues. One of the hot topics for the United States right now is the fact that we are engaged in two wars and we have many soldiers coming home with disabilities. It's having quite an impact on services in the United States in many, many different ways and higher education especially because our military is a voluntary military and people sign up in order to get higher education once they've done their tour of duty. And so our young men and women are experiencing disabilities in numbers that we've never seen before. In Iraq, the most common injury results from explosive devices and you don't have to be near an explosive device to have its impact. You can be quite a way away and still receive a head injury as a result of it. You can also because of explosions become visually impaired or hard of hearing and, of course, as with all wars orthopedic disabilities are very common. But the most common effect is what's called Post-Traumatic Stress Disorder, a psychiatric disability that actually can be cured, but the stress that our soldiers are under is horrific and when they return home, the transition and the adjustment is extremely difficult. So higher education is looking more and more at how to serve veterans with disabilities. Interestingly enough, it also changes some of the attitudes that we find because people who are resistant to serving people with disabilities oftentimes are open to serving veterans with disabilities just because of patriotism and the culture in the United States. So we're doing things like that. We also hold symposiums like this one. We hold

training sessions at several different places across the United States. AHEAD does more professional development than most. We have a website. The website is a simple one. It's ahead.org and you can go there and look at some of the things that AHEAD is doing. I'd like to give you another example of an AHEAD activity. Recently, we were discussing certification of people who hold jobs like ours. We were thinking that it would be important to assess the abilities of the people working in disability services in higher education but we decided not to do that, mostly because we felt that certification of vocational rehabilitation counselors was not very effective and we didn't want to repeat the mistakes made by vocational rehabilitation in the United States, so we decided instead to look at program assessment and evaluation. So now we're building surveys so that we can look at and compare disability service programs and try to build some consistency and similarity of practice throughout universities and colleges that like to follow the AHEAD models and guidelines. Internationally speaking, AHEAD does not do as much as we would like it to. It is a membership-driven organization and it tends to be very centric to the United States. There is a great deal of talk about laws in the United States but we also realize that the United States is only a small part of the picture and that there's much, much more out there. AHEAD would very much like to have much stronger international ties. I'm very lucky. In my office one of the coordinators is Mika Watanabe-Taylor. Mika is Japanese and she has been working with some of you in the audience and with others in Japan to try and build bridges between AHEAD and Japan. I know, speaking for the board of directors, we would very, very much appreciate more networking and more collaboration so that we can learn from one another. And with that, I would like to thank you. I understand there will be time for questions later. I appreciate very much being here. Doomo arigatoo.

Report on Results of FY2007 Actual Survey of Conditions on Academic Support for Students with Disabilities at Universities, Junior Colleges and College of Technology

Atsushi Tanikawa

Director, Special Assistance Division, Student Services Department

Independent Administrative Institution

Japan Student Services Organization

Good afternoon ladies and gentlemen. Thank you very much for your introduction. My name is Tanikawa. I am from the Special Assistance Division, Student Services Department, of the Japan Student Services Organizations. I am very happy to be here and I am very happy to be able to speak to you in front of all these people. But, at the same time, I have to say that I am under tremendous pressure. Dr. Masukawa received the Nobel Prize and there is one thing in common between me and Dr. Masukawa, we do not speak English, so we are under tremendous pressure. The most important thing for me is that I studied English and I don't speak English, so that is a sharp contrast between myself and Dr. Masukawa but still, I'd like to speak in Japanese for the next 15 minutes.

I would like to speak about the 2007 survey result on the survey about the support for students with disabilities at universities, junior colleges and technical colleges. First, allow me to introduce the organization called "JASSO." It was established back in 2004. We see a merger of 5 organizations and when they were merged into one, one additional work was included on top of the areas covered by the 5 organizations – namely, special assistance for students with disabilities. Already several years have passed since it was established. We have been working towards the realization of this goal. We have been working on the provision of the scholarship. This is a major pillar. Also, we do have work related to support for students' lives. Let me speak about the result of the survey. The targeted schools were the schools shown here. And we looked at universities and junior colleges and also technical colleges and also we have included the correspondence courses. Then there is the definition of "students with disabilities." These are people with physical disability certificates and also for those people proved to be disabled based on a physical checkup. However, in the case of the developmental disorders and health impairments, we limited them to the students with a doctor's diagnosis. We have 1,230 schools and we were able to receive all the answers from all

the schools, so this is 100%. Normally, we tend not to receive the answers from about 100 schools but I visited each and every one of them and that's the reason why we were able to cover 100% of schools. We are now conducting the research and survey for the year 2008 and we are now asking for support for the rest of the group, which is 63 schools. Then, as I said, for students who are disabled, they have the disability booklet. Let's take a look at the situation in Japan. In what way are the people able to receive the certificate or the booklet, as we call it? This is just for your reference. This is a very busy slide, so I'd like to share the last page with you. This is the 6th grade of visual impairment. I think this is the lowest degree of impairment. If one eye has visual acuity of 0.02 or lower and the contralateral eye has less than 0.6 in acuity and the bilateral acuity is over 0.2, this is the sixth grade. Now we have universities, including junior colleges and technical colleges, we have 3.23 million people. This is the total number of students, 5,404 of whom have disabilities. The percentage is 0.17%. As compared to the situation in the United States, which was introduced by Mr. Marks, it is much smaller. One thing that is quite noteworthy is that in Japan we have many people who have hearing impairment and physical/health impairment and also visual impairment, which comprises about 75%, and we only have 3.3% for developmental disorders.

Then let's take a look at the involvement of students with disabilities. The number of schools with more than one disabled student is shown here in the green part. We can say about 60% of schools have more than one student with disabilities and on the right hand side, it says 0. This means they do not have any student with disabilities at this moment. It is 40%, but still 88 of them said that they had previously had students with disabilities. So last year there was one but this year they are not studying at our school. That's the answer. 88 of them answered in this way. So even if we say we have 520 schools without students with disabilities, it does not mean they have never experienced such students. Then also we looked at the requests made for the accommodation for the students. As I said, the total number is about 5,400 and about 3,000 people asked for and received assistance. For visual and hearing impairments, the percentage of students receiving support is higher but in the case of physical and mental disabilities, they do have a high level of numbers but still the number of students receiving assistance is low. This shows the situation at the schools. In total, we have 1,230 and 711 schools said that there were no such students. I said earlier that 519 schools are providing support out of these 711 schools.

Let's take a look at the situation in the entire nation. So we compiled this page. The total population is 127.7 million and the number of people from age 0 to 19 is about 24 million. According to the cabinet office white paper on the disabled, we have these numbers for the physically and intellectually or mentally disabled. This yellow shaded

area is from 0 to 18. In the case of the physical handicap or physical disability, we have 980,000 people. Then, if you can look at the percentage, it is 0.41% against the total population. This is below 18. We have 370,000 and the percentage here in total is 1.63%. Maybe my calculation might not be correct but according to the public data, I was able to make this calculation to say that the total number of people with disabilities is 1.63% in the age from 18 to 20 years of age.

Let's take a look at the special accommodations made based on requests. For the entrance exams, we have the admission office entrance exam or the recommendation entrance exams. We have 252 people who received special favors for admission and then we have the ordinary entrance exams with 246 people, so we have a total of 500 people who received these exams. And the total number of people with disabilities is 1,200 and 700 people received no special assistance and 500 received special assistance. One thing that I realize is that at the time of entrance, they request some assistance but after they pass the examination they do not want to disclose their disability so they do not make any applications for assistance. This may be quite unique in Japanese universities. Then, after they enter the university, what kind of assistance is given by the university? This is a chart given by the disabilities, the textbooks created with enlarged letters and also translated into Braille or block letters and note-taking. These are the areas for visual impairments. Also, note-taking and others are shown here for the hearing impaired. But, depending on the extent of the disability, we have to provide them with a different level of support and also with the same level of disability, one university may be able to provide support but another might not, so there could be some variation here.

This is a chart to summarize the overall picture. How many of these schools are establishing a council or committee to support students with disabilities? This is the result of the survey we conducted. All in all, we covered only 29 schools. About 88% of them have a council and 59% of them do not. Actually, we are having these criteria depending on the number of students studying at university. If the number of students is higher, they have a greater tendency to have the councils or committees. With regards to a dedicated position or department for the provision of support for the disabled students, 44 schools had dedicated departments. As for the liaison person or key person, this is about whether the school has established a key position or key persons. We can say that only 1.8% of the schools or 22 schools have the key persons, dedicated persons, but 138 schools already have people – although they are not dedicated – they do still have the capability to support students with disabilities. 84.9% of the schools have a person who is partially responsible for the provision of services for the disabled students.

Then, what are their courses after graduation? I'm talking about the final year of

university. On the left hand side is the final year. We had 1,217 people in the year 2000 and then in the following year we looked at the number and it was 1,005 of them graduating from that and 700 of them took up jobs or moved into even higher education. The percentage might be slightly lower than the able-bodied students, so I think there is a need to go further into this area. So that's all from me, thank you very much. This was the survey result for the year 2007. We would like to have further effort to provide support for the students with disabilities and we have been working hard, but still we do believe that there is room for improvement. We are ready to listen more to the students themselves and try to have further services for them. Thank you very much.

Activities of DO-IT Japan and Higher Education Support to Students with Developmental Disabilities or Higher Brain Dysfunction

Takeo Kondo

Project Assistant Professor, Research Center for Advanced Science and Technology, University of Tokyo

Good afternoon, ladies and gentlemen. I am from the University of Tokyo. Now, DO-IT Japan activities done at the University of Tokyo, I'd like to share with you one of the activities that we are conducting right now. Thank you very much for giving me this opportunity to speak to you. I am sure that some of you in the audience are already involved in DO-IT Japan activities but this DO-IT originated from the US. This is sort of a transitional program for the high schoolers for higher education. This originated from Washington University and we tried to emulate this in Japan. We do not implement this as it is but we also try to localize the content. The Research Center for Advanced Science and Technology of the University of Tokyo and also governments and other private organizations have rendered their support to implement this.

The high schoolers with disabilities – in the United States, every year they select about 20 students and those selected students go to Washington University. They spend about 2 weeks to experience what it's like to be in the University. The Japanese version of DO-IT involves us selecting about 10 or so disabled students and spend about one week at Tokyo University experiencing what it is like to be a university student. So what do we do? This is the flow of applications. The process starts in April. We will start opening this program in April again this year, so please come to our website if you are interested. High schoolers all over Japan can experience many types of activities in the universities. We do not limit disability to a certain area, such as physical disabilities, spinal cord injuries, the deaf or blind or higher brain dysfunctions. We do not make any differentiation by the type of disability.

They are there to experience the university. This is not just about classes. The most important thing is the type of support that the disabled students can receive at the university and how they can use and how they ask for different assisted services at the universities – for example how they can utilize the assisted technology or how you convey the messages that they need some services. Since they have to live away from their parents and spend one week, they actually stay at a hotel, but disabled high schoolers usually don't get to experience independent lifestyles, so usually it is the first time for them to live

independently of parents. This experience itself is very important for them.

There are three points here. The first is about telling what type of disability they have – so what type of services, assistive services they need. Secondly, they also visit a corporation so that those collaborating corporations welcome them. Usually, their predecessors, disabled students, are already working there so students can also exchange information there. Thirdly, we also have assistance from the councilors. Based upon their consultations, high schoolers learn how to supplement and also replace their disability with personal computers and other assisted technologies.

DO-IT Japan itself is only 5 days but that is only the starting point of these activities because after this DO-IT Japan week, we will continue to have online mentoring through the Internet. We use Windows LIVE for SNS but we communicate with each high schooler to support them mentally. So far, we have done two years of DO-IT Japan activities, so this is the third year. We have the scholars and also the people who got involved in this program have been connected through this SNS method.

The programs provided by DO-IT Japan can be categorized as these. The first one is about experiencing the university, so the high schooler can talk to volunteers and also other students. Since they have to live independently, they need to have good accommodations. Sometimes they have to communicate with the surrounding people and so forth. We try not to help them too much because the students must be independent. Rather than intervening in their activities too much, they need to discover what type of needs and demands they have to have and they must also convey those messages to the surrounding people.

One interesting point about DO-IT is that we do not limit the type of disabilities. In the latter half of my presentation, I will talk about higher brain dysfunction and also other disabilities but since we do not make any separation or limitation on the type of disability, sometimes they discover different needs. Some people have difficulty in note-taking or reading something or trying to summarize what they think or sometimes they can't really concentrate on their work. There are so many different difficulties and needs, so rather than categorizing them as a type of disability, there are so many things that disabled students can share, some of the problems and difficulties they have. They can think of how they can overcome these difficulties or how they can replace their disabilities with supportive technologies.

After this, now I would like to talk a little about high schoolers with higher brain dysfunction. We have had two years of experience already. There are already 23 scholars out of this program. This year, we will be selecting about 10 high schoolers, developmentally disabled students. There are two Asperger syndrome students and one with developmental dyslexic and three with higher brain dysfunction, so altogether

there are six high schoolers who have developmental and higher brain dysfunctional disabilities.

What type of support can we give them? In the case of these high schoolers, we need to provide transitional support. In other words, they are changing their living environment, so they must be independent and they must live on campus. So transportation and help for schooling and day-to-day lives; all this overall life support is very important for those students.

Then, what about the assistive technology for those students? There are many types – for example, reading or writing. In the case of higher brain dysfunction students, sometimes they can't concentrate on their work or they have some disabilities in terms of visual capabilities, so some of them can't really read. It doesn't mean that they cannot see. They can see but they cannot recognize the characters. So we need to support them from that side. With PC software, it can read textbooks for them and also the software must show the students where the software is reading.

Another disability concerns short-term memory – for example, even though the student is reading a text, he or she can't really remember what they are reading. In that case, we use this mind map. The content of the text by just reading this wording is insufficient for them, so we make this map as a structural map so that it can help the student to remember the contents of the textbook. We also use IC recorders, some memory tools and digital cameras. We provide these tools for the students to remember.

For the Asperger syndrome type of hypersensitive high schoolers, we provide earplugs or noise cancellation headphones and such devices to limit the incoming stimuli from the outside world. And sometimes it is difficult to have face-to-face communication. In those cases, we use SNS. Everyone has their own blog site so they can express themselves by typing rather than face-to-face communication. Without being physically together, those people can easily express themselves. So these are the main supports that we provide as technological supports.

Lastly, I would like to talk about some of the challenges that we face. We are supporting high schoolers. We really feel a lack of support for high schoolers, especially for the entrance exam. Visually impaired high schoolers should use Braille or magnified text and these types of support are done in many entrance exams. However, in the case of higher brain dysfunctions where they can see but they don't actually understand the characters of the text, with these types of brain-related disabilities magnifying the text or Braille doesn't serve much purpose for those high schoolers. So someone has to read the text so that they can aurally understand rather than reading them. Also, some device must be able to enhance some of the wording. However, there are very few cases where the universities allow this type of support for high schoolers.

And another one concerns the communication among universities and high schools, because there are some universities which provide special support for disabled students but on the high school side, the administration or teachers do not really know which universities are providing what type of services. This is the big transition point of the entrance examination. Therefore, the high school teachers and administrators must be able to learn about what type of support they have. So we really think that we need to have continuous support from high school to universities, not just at the universities. And also, there should be one continuous support from high schools, universities and employment.

And another problem concerns the learning disability. There are not enough textbooks. Last year, we enacted the Barrier-Free Act for textbooks. This means that textbooks must be usable by disabled students. However, when it comes to entrance exams for the universities, not just the textbooks but also supplementary books and special journals and other books must be also accessed by disabled students. We need to make an environment so that all these textbooks must be accessible by the disabled students. Reading done by someone else, that type of special assistance, must be allowed for entrance exams for disabled students but there are not many universities providing this type of special assistance. I think it is time for me to wrap up, so thank you.

University and Graduate School Admission Support and Academic Support for K as Person with High-Functioning Autism Spectrum Disorder

Kazuko Takahashi

**Assistant Professor, Research Center for Child Mental Development,
Kanazawa University**

Thank you for your introduction. My name is Kazuko Takahashi. I am an Assistant Professor at the Research Center for Child Mental Development at Kanazawa University and I am also the director for the Osaka Asperger Disorder Association and the Alclub. Thank you very much for giving me this opportunity to speak about one high functional autism person. He is my own son. He is now studying at the engineering department of Kyoto University. I'd like to speak about the support he received for the university admission and academic support. So I'd like to share with you some results of the survey conducted on the students studying at university by Alclub.

First is the theme. We are talking about the support for people who are studying at university but in the case of high functional autistic people, is it ever possible to say that it is better for them to get into higher education? In some cases, they are not able to go into employment because of the fact that they are studying at university, so in many cases they hesitate to go into higher education or universities because of that.

One reason behind that is that there are institutional problems or legal problems. For one thing, even if they are diagnosed as High-Functioning Autism Disorder(HFASD) they are not considered to be disabled. They are not considered to be persons who are subject to intellectual disability certificate booklet because they do not have any intellectual disorder. In some cases, they are given a mental disability certificate but, as was mentioned earlier, it varies depending on the locality and the prerequisite for the issuance of that mental disability certificate is that they go into the stage of remission, so it is only meant for a very short duration. In the case of autism or other high functional ASD, we are not able to expect remission so in many cases they are refused. Also, employer can't understand developmental disability only by a mental disability certificate booklet. That's the reason why it is very difficult, if not impossible, to receive assistance.

The second is actually a problem of the medicine and the person himself. In many cases, they have difficulty having the diagnosis at an early stage, so generally speaking they go through adolescence or adulthood when they are first diagnosed as high

functioning autism. In many cases, they have difficulty in understanding their real self and they are too proud to accept this fact and accept the support. Also, parents have difficulty understanding and accepting the disability. In many cases, there are very complicated co-morbidities or other complications present at the same time. In junior high or college, they are in many cases in the stage of maladjustment or maladaptation to the society.

The third is that the universities do not have the transitional support concept, so they do not have any support with employment in the future as the goal. The faculty and staff members are sometimes unaware of this disorder HFASD. Even if we explain to them, they have difficulty understanding what it really is. In the case of high functioning autism, they do not know what kind of support and assistance are needed in order to put them into the real world. So in the case of Japan, almost no university is providing any support whatsoever for the transition and placement for the high functioning autistic students.

These are the prerequisites for the high functional autistic students to get into universities, so there are some conditions for that. For one thing, they should be able to live in the university by themselves, so they have to have a certain level of communication and social skills. Also, they have to select the best schools or courses which are comparable to their interests and the profile of the disability. They have to select their future goals and it is very important to have a very key person who is good at understanding the situation.

This slide is what I made social skill support for my own son. Starting from age 0, you can see the figures 0 to 18 shows the age. I tried to make sure that he would be able to live outside of the house, starting from 0. In the middle is the mobility and the lower part is managing objects and money. Then the lowest part is about the support for labor and housework and then on the upper part is the skill management and skill support for leisure. So until the age of 18, he was able to –actually, the goal was to make sure he would be able to attend and gain the capability to live alone. In the elementary, junior high and high schools, they should have received support but in the case of Japan it is very difficult, so they just get into university without any help and it is very difficult for them to fit in.

Now, starting from here, I'd like to speak about my son K. I'd like to share with you my experience with K. There was no problem with the entrance exams, so there were no special accommodations made for him. He took the test with the able-bodied students. He studied one year longer. So after the graduation he studied one year and then after that, he passed his exam and the second part of his examination, because he was very good at writing. Only two days after the report, we had to have the procedures ready for

entrance. So we looked into the situation regarding visual impairment or hearing impairment and also physical impairment. I tried to go through the formal procedures based on that. So I reported the fact my son had a disability and tried to ask for support and consulting for the kind of procedures we can take.

We had only two days as the window of opportunity to do so. I asked for support from Dr. Takashi Okada, child psychiatrist of the medical department of Kyoto University. I knew him from academic conferences and I talked about the kind of organizations we had to talk to for securing the resources. Also, one more thing is that we had had been making a teacher's manual to understand and support K from junior high onwards, so we created a university version of that. And also we were not able to get ahold of the diagnostic certificate of the attending physician in time, so I submitted my own paper. They accepted that and I am really thankful for this. We had meetings with the person in charge and we talked to the individuals to hold a meeting.

Based on my strategies, I started out with the instruction section of the university and then I talked to the Institute for the Promotion of Excellence in Higher Education. Kyoto University has an Institute for the Promotion of Excellence in Higher Education for the general education part for the first two years. Then, after that, I talked to the student office or the counseling room or the Department for Physical and Psychological Counseling. We also discussed with the person responsible and who is able to provide counseling in the area of developmental psychology.

My son had problems with interpersonal relationships. He doesn't like or he's not comfortable with intimidating people and people who tend to yell at people. So even though he has some social skills, when he does not know the solutions for certain problems, he is at a loss. So he needs to have some kind of key persons or key locations he can refer to. And also, he is easily taken in by, for example, deviousness or people who have intentions, so he is an easy target for devious groups such as extracurricular clubs. The University made a plan to establish a support team for K as well as support for the physically impaired students or students with visual and hearing impairments.

So on the 31st of March we established a meeting. We had a support team, which was also joined by the parents. Let's take a look at the members of the support team. 6 professors and the assistant professors of chemical engineering of the Department of Engineering and 3 staffs of the student affairs of the engineering department. We also had three people from IPEHE and we also had one person from the student counseling room, so we had more than ten people. And also, depending on the needs, we were allowed to contact the persons from the education department and the medical department.

I provided some explanation concerning the support and understanding of K, based

on the manual. I made a specific presentation about the specific support. One is to establish a safe haven for him to go to when he is in a state of panic. And also, we asked them to protect him from various inducement such as invitations from club activities and circles. And then there was a question from the university side – actually from a professor. He asked whether the student would annoy the faculty members by following them around and incessantly asking questions. I said that is not the case. And then the counselor intervened and said that we must establish rules to try to ensure that K understands the office hours and the time when faculty members are available for him.

And also we established a key person. The vice president of IPEHE took up this job of key person. He is always in the same room, so that is the place for a safe haven. Whenever there is a problem, he can go to that person. So that person can be termed the key person not only for K but also for other students. Starting from April this year, my son is going to graduate school and the vice president of the IPEHE will continue to serve as the key person. So whenever there is a problem, my son is able to talk to that person. Whenever it is necessary, he serves as a coordinator to invite the involvement of other people. So he is the coordinator or organizer for the support. And also, he came up with scenarios in which K might have difficulties – for example, at a physical checkup. It is possible that many clubs could contact him. So they gave my son tips for avoiding these invitations.

This is the support from the support team. I received the syllabus, so I was able to be involved with the process for enrollment and I was also allowed to participate in the orientation. To be more specific, the professors and assistant professors visited the high school that K graduated from and asked for the support from K's counselor and K's classroom teacher. At the same time, they were interested in the relevance of the support, so they conducted interviews with K to understand whether the reports are made duly. They also established a web page and a bulletin board in the class. This is an example of their daily support. My son is responsible in charge of test preparation and so he has responsibility for the provision of information of the test to classmate. The first question is, "Could you give me the site of the information?" Then my son says, "The information was shown during classes. The former test examples are sold for 1,000 yen and I was surprised to see this." Then the other student C says, "If you are responsible for providing information, then why don't you just give us the test free of charges?" And then C says that we should not accept these tests. Then my son also raised some other questions about the accuracy of the information. Then he reduced the price to 250 yen. Also, he made further investigations and decided that there is some other information in some other areas. So this means that also some other things were covered, but he was not able to cover everything. And in some cases, he said that he would not

like to continue serving as the person in charge of providing the test information.

Then, after that, the student B said, "Is this the only thing that you're doing?" Then my son actually said that, "I'm not able to give you the answers to the test. That is meant for privileged ears." And then there was another input. "It seems better to collect former tests so that we are able to ask some questions to the person in charge of the provision of information." Then my son said, "Yes, thank you very much." Then after that there are many other involvements. Whenever this kind of information is given through the internet, many people seem to have difficulty determining who is who. So this kind of homepage, or web page, is a very good tool. Also, the kind of support provided to K and helpful as a sophomore or junior student first is about the reports for the chemical experiments. In the case of K, he has some problems. His papers are quite accurate and he does much verification but, still, he has too many observation failures. So the volume is too much. And take much time to prepare report.. So in order to avoid cheating, the students are only able to use ballpoint pens. They are not allowed to use whiteout correction fluid. So for students who are as clumsy as K it is very difficult because it takes too much time. Also in the case of K, he is a perfectionist, no matter what it takes. So what the teacher said is that it is possible. Because of the fact that they have to use the ballpoint pens, they have to write down the report in paragraphs. In this way, they are able to have some corrections.

Also, the volume was too large and it is very important for K to eliminate unnecessary parts of communication and also minimal retention level should be understood. Also, as to the deadline of the submission of a report K was not happy because he is a perfectionist and he wants to perfect the report as much as possible. He communicated with the teachers, and so they established a rule. The due date is set. K has to submit the report on the due date although it is not complete. The evaluation is made on the due date but after that, the report is given back to K and he can fulfill the report to his satisfaction.

And then K has hypertension, which is auditory hypersensitivity. Whenever the female students are whispering, he has difficulty concentrating, so the group formation is made such that there are no female members. In the fourth year, there are 240 people and 60 courses. And there are 40 specialized courses for him. It was very difficult for Kei to understand the necessary level of advice about the way that the research is done. This is of my own making. I looked into the research styles and divided them into three parts, into three styles. One is the body type. The second is the built up type and the third is the scrolled document type. The body type is like a gamble. They try to do many things at the same time and try to come with some interesting data. The built up type likes to accumulate things from the bottom. The third is to do certain things for a long time and

then establishes certain things after for a while. The second and the third are suitable for autistic students but number one is difficult. Kyoto University has very good professors who are able to be considerate of these differences. But in some cases they are not good at getting along with PDD or pervasive development disorders. Some professors are better at getting along equally with PDD students. They have good communication and they have flexible values. It is better for autistic students to have teachers who have real emphasis on the students' guidance and who are also able to think about the career path of the student. This way they will be able to incorporate the skill manners and skill training from the very first year.

Finally, I would like to summarize. When students with developmental disorders get into higher education such as universities, the PWD himself or herself and their family should be the initiator of the movement. And also we have to have the involvement of persons with expertise – the medical personnel, the psychologists and also the educators. Also, there are established rules. Based on the established rules, it is possible to deal with this and request needs. And also it is important to see the hand-out with information, especially in all level of the staffs. The sense of the awareness, the understanding, is different between different individuals. And also it is important to have the support for the selection of the seminars and the courses. It is better to have good teachers rather than good items. Understanding the support for career options is much needed. That's all from me. Thank you very much.

Daily Living Support Essential for Academic Support for Students with Severe Disabilities

Akira Terashima

Dean and Professor, Faculty of Social Welfare, Urawa University

Thank you for your introduction. I am Terashima of Urawa University. At the beginning, the speaker mentioned that there are a growing number of universities which provide special assistance for students with disabilities, which is a very good thing. However, there are so many issues we still have to solve and overcome. At Urawa University, we started accepting students with very severe disabilities because we are providing assistance for the toilets. When I ask questions to the students with disabilities around the Kanto area, Urawa University is the only university which provides special assistance for toilet use. So the students with disabilities usually visit the university before they do the entrance exam and usually the administrator says, “We are welcoming students with disabilities. However, when it comes to the toilet, there is no assistance and you must be able to take care of yourself.” So sometimes they need to hire home helpers, special helpers to help, or mothers must come to school every day to help them use the toilet. Therefore, even though they say they can accept students with disabilities, those universities do not become candidates for them. That’s why Urawa University is accepting many severely students with disabilities. We also have a college which has a special care nursing department, so those students help the students with disabilities to use the toilets. It for a charged of 330 yen per help but other than that, they also help with note-taking, reading books for them and other things.

What other services do we have? To speak a little bit about what we do, this is my personal experience. Urawa University is a university for social welfare. Therefore, we do not reject students for their disabilities. I am a dean, so this is a very strict rule, but I am retiring from this position this year, so I am not sure about the future. But at any rate, for the visually impaired students we need to provide services to supplement their visual ability. For example, when the student has to write a report, another student must also make it into MS Words so that the computer software can read the text for the visually impaired student. This is a must for all other students. And I also produce all the text in text file so that the software can read all the papers. And students also read journals of social welfare. The journals are all translated into MS Word so that the PC software can read them out. It takes one day for me to do that. At First, I have to scan the words and then transform it into text file by OCR, but there are charts and tables. I always hope,

“Please do not make a complicated paper or large chart.” But at any rate, I take almost one day to translate everything. I always wish that someone else could work on this. At any rate, I am doing this so far.

Examinations – we, of course, allow the student with disability to extend the time and also I use a USB memory to give all the questions and themes for the students with disabilities. In case of auditory impaired students, I can do some sign language and also the manual alphabet, so I can use them. Also, I can do note-taking while giving lectures in case some deaf students are present. So while I am speaking, I type the same thing into my computer so that on the screen the students can read what I am saying. Not all the professors do this. I am the only one who is doing that. I also put captions on various videos. For note-taking, we ask volunteer students to take notes. It is for pay at 2,400 yen per hour. It is a type of paid service which is done by volunteer students. For students with physical disability, in the case of severely impaired students, they usually have visual difficulty, too, so we allow them to sit in the front row of the classroom and also extend the test-taking time. We also loan students special PCs in which software is installed to read out all the text and also we have assistant services for the use of the toilet. We had so much difficulty in coming to this situation. At the beginning, we accepted blind people but we had many difficulties. The technology professors said that blind people cannot use PCs. There is software called “Screen reader” and when the Screen reader software is installed on the PC and when the PC is attached to the campus LAN, sometimes it makes the whole network unstable and some engineers complained about it, so we had to overcome many things.

However, luckily, I have a colleague who used to work at the rehabilitation center. Myself and the colleague already know that it is a right for the students with disabilities to receive education but other than that, regular professors and teachers do not really know what they have to do to help students. So we really have to convince other professors to use Screen reader or other software to help students with disabilities. So we conducted many demonstrations to convince other colleagues. My colleague ever worked at the Tokyo Metropolitan Rehabilitation Center. Thanks to my colleague’s support, now we have created special support programs for students with disabilities. We also had student support committees so that we can pay volunteer students. So, based on these experiences, I came to think of what we need to do to help students with disabilities. It is the same as covering some lack, but people must understand the philosophy of helping students with disabilities. Supporting students with disabilities is an obligation for teachers. Many teachers understand they are obliged to help students with disabilities but unless they can act on it, it doesn’t mean anything. For example, in the Japanese constitution, article 25 stipulates “All people shall have the right to

maintain minimum standards of wholesome and cultured living.” And the specialists in social welfare are all aware of this. This is usually given in the qualification examinations of social workers. And such specialists are trained their behavior to practice on this idea. However, when you look to Article 26, “All people shall have the right to receive an equal education correspondent to their ability,” do the educators all know about this? Do they actually receive education to learn about this? The answer is “no.” I don’t think all the educators actually know about it. Last May, the Convention for Persons with Disabilities became effected and Article 24, section 5 says, “The State parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination,” meaning people with disabilities have rights to receive education but the educators do not know about it.

Social welfare specialists and rehabilitation specialists know well that when the student with disability wants to have tertiary education, the education system cannot reject the student. That’s our strong belief. However, under the reasonable accommodation, do educators really understand this or not? The reality is that all people are not aware of this. Furthermore, even in social welfare areas, some people are not really aware of this. In the case of social welfare universities, they receive students with severe disabilities and sometimes they have to ask private companies to accept those students. Even if they are with disabilities, they should be welcomed by outside institutions. However, when we started talking to those outside institutions, sometimes it’s very difficult for them to accept students with severe disabilities. So even in the social welfare services or rehabilitation areas, sometimes we see some people who lack these human rights aspects. Practical information is necessary, like what type of services they need to have and what kind of assistance with technology there is, including sign language, manual alphabet. Of course, it is better for people working in these areas to be equipped with this knowledge. Lastly, when you think of all these, the liaisons between social welfare and education is very important. The first one is not just understanding the principle but acting on it. Also, the educator must have practical knowledge on how to help them. Thirdly, the education arena, rehabilitation and also social welfare must have linkages. For example, when we hold a workshop it’s not just giving a workshop to the social welfare specialists but also maybe we should propose joint research between social welfare study and regular universities or ask the outside institutions to accept more students with disabilities. So for the future, I really would like to say we need to think of how to receive students with severe disabilities. I am thinking of maybe changing the system of the toilet itself so that we can accept disabled people without having a helper and also accepting developmental dysfunction or higher brain

dysfunction students. How to combine higher education and rehabilitation programs is one challenge for us, so I do want to say that the linkage and collaboration between social welfare services and educational services are necessary. Thank you.

The Path from School Admission/ Readmission to Employment for Students with Spinal Cord Injury

Makoto Ohama
Chairman, Japan Spinal Cord Foundation

Good afternoon. I am Ohama. I'm from JSCF. May I start? I'd like to speak about the path from school admission to readmission to employment for students with spinal cord injuries. I'd like to express my sincere appreciation to the organizer for giving me this opportunity. Because of time, I'll not speak about the organization JSCF. Because of the difference in the order, you might not be able to see the page in your materials. Because of time, I omitted some of the pages about the organization.

The first thing I would like to speak about is the difficulties people with spinal cord injuries have at the time of employment and schools. When they have sports, they tend to have injuries. Because of the fact that they are young, in many cases there is major pressure applied to the spinal cord so we have to say they tend to sustain very serious spinal cord injuries. So when they sustain profound cervical cord injury, they have to receive lifelong medical assistance for excretion or activities. In higher education, we do not have the regulations or the institutions for the spinal cord injury students. Especially important is the toilet issue and have not been solved yet at most of the universities. So these individuals with the spinal cord injuries will have to pay attention to excretion management or toileting management. It is impossible for them to deal with it by themselves, so that is the major block or barrier. With this, they are able to have the opportunity to go into employment or into schools. I'd like to speak about all these things. In many cases, persons with cervical cord injuries or spinal cord injuries do not have access to helper services, those who need 24hours care have difficulty in money and political limitation. I'd like to discuss several cases.

This is case A. This is a case in which the person with a cervical cord injury became a lawyer. During the fourth year of university, he sustained a cervical cord injury when he was doing judo, C5. Mine is C4, so his severity is slightly lighter or better than myself. He uses a powered wheelchair. He has finger paralysis, so he writes with an assisting device. Although he has a disability, he wanted to become a lawyer because it is possible for a lawyer to have a disability and remain active. So he completed law school for three years and after that, he completed training at the Supreme Court Institute. I heard he received a bar exam. in 1.3 times longer than other people. He has been quite active as a lawyer. He is starting to serve as a lawyer from this spring. I was involved

with him after his injury. Before going back to university, he had difficulty in dealing with rehabilitation. I was involved there. I think he received rehabilitation here in this NRCD and then he went to the United States to receive further rehabilitation. He came back to Japan and came back to the university. And after that, he joined law school. When he joined law school, he moved closer to the law school and lived alone, and last year he passed the bar exam. He completed training at the Supreme Court Institute and he will start working as a lawyer this spring. He needs 24-hour help or support for taking a bath and toileting and the helper was always with him whenever he went to graduate school or training. This is a 24-hour system, so the helper is accompanying him every day and everywhere. So he had to go to the lawyer's office or the court and he was always accompanied by helpers. There are many places where helpers are not allowed in but whenever possible, he went in by himself and asked for the support of the receiving party to contact the helper whenever something happens. He has a very profound disability but was able to write with an assisting device.

I'd like to speak about the problems here. This is a very complicated issue because I have to speak about the Japanese system. One is involving commuting. For commuting, it is impossible to receive assistance from the caregiver. In the Japanese system, according to Japanese law, the law to support the independence of disabled persons, commuting is not covered so it is very difficult to find a helper to do that. And also, when he graduates we have to go through the changes of status. After graduating from law school, he has to go to the next step or next stage, so we have differences in the systems and the transition of this is difficult. He has to go through all these cumbersome processes. I was involved in this process and it was very difficult. There were very difficult issues relating to the change of status. Then, after that, he became a student at the Legal Training and Research Institute. This institute is sponsored by the Supreme Court, so the Supreme Court is involved in this area. The MHLW and the Supreme Court had very good discussions about this, so that was a very good situation for that. All of the costs were borne by the Supreme Court. So before becoming a full member of society, people with disabilities have to work tremendously with the administrative processes. So even if someone is very talented, because of the difficulty due to the disability, it is very difficult for them to fit into society. Before and after university education, policy for PWDs are unreasonable. It's a real situation. As is shown here, when he was at the university he was covered by the welfare system of the place of his parents. Then, after he graduated up until when he took the bar exam, then after a while, he had to register himself for a new area. Each locality had different systems and it was very difficult to overcome these difficulties or differences.

This is Case 2. He has not actually entered higher education yet but is trying hard at

high school. He sustained a cervical cord injury participating in judo and initially was C5 or 6 and then, after that, it aggravated and now is C1 and C2. This is much closer to the medulla oblongata, so he is totally paralyzed and he has difficulty moving the diaphragm, so he always has to use a respirator. So 24-hour support is needed and he also suffers from dysfunction of diaphragm. But during the time when he was receiving rehabilitation at Spinal Cord Injury Center in Fukuoka, he took the joint first stage achievement test. I'm not quite sure of the background but maybe because of the fact that a personal computer was not allowed in, he was not able to pass. He was not able to write and calculation is difficult. Certainly, people would have to calculate using their pencils but because of the fact that he was not able to use a computer or calculator, he was not able to answer the questions. He was easily a genius at math but he couldn't pass the exam and so he is now studying even harder to pass the exam for the national university. But this not easy, as I just said, If you read Asahi newspaper the Yomiuri newspaper, you might be able to understand the situation. In the case of his locality, he was only covered for 5 or 6 hours of helper time for a day and also there were many problems, we have to say that he is a refugee of the welfare system in his locality. That's the reason why the family decided to come to Tokyo. There, the welfare system is better. So initially he had to live with the helper and his parents. Then, at this moment, he is now able to live alone with the helper. In the Tokai area, he was only covered by 6 hours of helper time but now he is given 17 hours of helper time per day in Tokyo. He experienced the campus experience Do-IT at University of Tokyo as a PWD, which is held by the advanced research. Now he is making his best effort to again challenge the joint first stage achievement test.

And also we have some other cases. This one is N. He has tripelegia. I'd like to briefly touch upon his case. He is 30 years of age. He is a male. When he was 22 years of age, he had a motorcycle accident, C7 total destruction and the C5 to C6 in the ADL based on the worker's compensation hospital's classification. His nerves on the left hand side have been already pulled out because of the accident, so he is not able to use the left arm. So he is only using his right hand to manipulate the wheelchair. He had a rehabilitation period of 2 years and after that, he went back to university. For the university, he was allowed to use the stand up wheelchair. He is an assistant teacher of the university in Tokyo now.

These are the cases that are introduced in the manual. If you are interested, please pick one up. I think they have to have self control capability of the body in order to get into higher education, so self-management is the key. Also, it is very important to secure helpers full time for independent living. This is the kind of shift we have to have and also networking in a community-based network is very important. We have to establish

that by ourselves in the seminars and circles and volunteer groups to be utilized and we have to cooperate with the other organizations. So advocacy should be established as an institution or custom. Inter-site access in the institution, inter-site access, note taker and assistive technology for communication may be needed. Then the administration needs to guarantee the rights of the patient in public higher education from the administrative standpoint. Guide helper, note taker, assistive technology for communication, barrier free at this stage may be needed. This is the minimum level. These are things that they have to have when they come to the universities.

Finally, one of the members who has a spinal cord injury who applied at my office is studying outside of Japan. She is attending the Edmond hostel and school. This is a long-term boarding school. One third of the students are using respirators and everybody seems compensated for their assistance for PWDs. This is very unique to Denmark. They are providing university courses for the Japanese PWDs. That's all. Thank you very much.

Discussion

Moderator Fukatsu: Are you ready? Thank you very much for waiting while the desks were prepared. Now Mr. Jim Marks is here on the stage plus five other panelists are here for discussion. So, first of all, I would like to ask Mr. Jim Marks a question. You have been listening to all the panelists' presentations. Did you have any comments, questions or suggestions? Please share that with us.

Marks: Thank you very much. I'm really struck by the similarities of what happens in the United States and what goes on in Japan. With each of the panelist members I saw a great deal of zeal for advocacy to make the world better for people with disabilities and for society, as well. On the issue of statistics or data collection, the United States is not doing nearly as good a job as we should. Just this fall, the American government passed a new law called the Higher Education Opportunity Act and part of it includes a requirement to count students with disabilities in higher education. It's the first time any such formal requirement has occurred. So the statistics and data that we have come from many different sources and have not been consistent. Now we hope to have some consistency. In terms of project DO-IT and technology, I am a technology guy. I love technology. In front of my desk right here I have a Brailnote, which is a small device for the blind that has Braille that I could read with my fingertips and it also has speech output. Technology is a major part of our lives and I like the notion that technology brings to us, which is to look at the impact of a disability, its functional limitations, and then try to find solutions to either mitigate the impact of the disability or take it away entirely so people can compete or participate on equal footing. On parents of children with disabilities there are a couple of things. One is that higher education affects not just the students with disabilities but also entire families. Disability is a family issue. The second observation is that with new emerging disabilities or with the different kinds of effects, we have to rethink. We have to stretch our imagination and vision for what we could do to make sure that every person gets a chance. We don't know that the next person with autism may be the person that can cure cancer or can make things happen that we all will benefit from. There's a strong benefit in society to making sure we open up those doors.

With the rights issues, a big chunk of my talk was about rights and inclusion of people with disabilities in higher education. The United States, unlike Japan, doesn't have an educational clause in our constitution. It comes from laws that come after the constitution. The whole notion of support for people with disabilities, the independent living support and things, all that stuff is really critical. We can't just look at one part of

the picture. We have to look at the entire lives of people with disabilities. We also have to look at the lives of the professors and administrators and the things that happen in college. We need to not only give people with disabilities the tools, we need to make sure that the faculty and the administration have the tools to be able to respond adequately. With groups of individuals such as those with spinal cord injuries, we in the US again come back to advocacy. We really believe people who have a special interest to do something should be able to exercise that right and that we can join together to make things happen. At my university we have a group called ADSUM. It stands for "The Alliance for Disability and Students of the University of Montana" and it was started by a man with a spinal cord injury who later on became an attorney. It has been in existence now for over twenty years. It has provided a way for students with disabilities to have not only a voice but a chance to learn about what is possible, to think about the realms of possibility so that people can expand who they are. ADSUM means in Latin "I am here." The group does incredibly good work in terms of providing support to one another and making sure that my university is accessible. So it's really, really critical to think about working together to make things happen. Those are my observations at this point. Thank you.

Moderator Kitamura: Ok, let me summarize what he said because some of the receivers did not work well. He pointed out seven points. First, he felt great enthusiasm about all the speakers. Second, the data and statistics are very good in Japan, but Jim expects that Higher Education Opportunity Act will contribute to the data collection in the U.S. The third, Jim likes technology and is a technologically aware person. Forth, parents and families are all involved with the disabled students. Fifth, we need to stretch our vision that autistic students may be able to come up with a great invention in the future. The sixth, ADA and rehabilitation act is there. However, the constitution itself does not stipulate the rights of disabled people as Japan, so the faculty and administrators must understand the rights and obligation. Lastly he touched upon the activities of persons with spinal cord injuries and ADSUM, which is the students group and has a twenty year history. That is what he said. Thank you. So let's start the discussion among the panelists. Do you have any question or comments for each other? Anyone? The first discussion is among the panelists. Anyone?

Marks: Thank you very much. I have one question for my fellow panelists. It seemed to me that advocacy was a theme that each of you talked about coming from different perspectives. If there was something you could change for people with disabilities that would promote access to higher education, what would be that thing you would ask for to be improved?

Moderator Fukatsu: Well, any panelists had the same issue, so why don't you start

from the left-hand side. Ohama-san, maybe you can start? Could you hand Ohama-san the microphone?

Ohama: Well, it is so difficult to select one thing because I have so many requests. Does it have to be one? I have so many. Many things come to mind. We spinally injured people have great potential, so we need to make use of that potential. We want to have an environment so that our hidden potential can flourish. In other words, accessibility is one, and also help for the toilets. We want to have a good environment so that our hidden potential can flourish.

Moderator Fukatsu: Mr. Terashima?

Terashima: Allow me to repeat myself. The human rights philosophy is important. For all the faculty members, we have to make sure they understand fully the concept of human rights preservation and also we have to have substantive measures in which we are able to fulfill the philosophy of human rights. That's the first and foremost thing that we'd like to request. That's all.

Moderator Fukatsu: And Mr. Ohama, you talked about the administrative issues. We have to have some kind of framework which would have a better implication for the education. Mr. Ohama and Mr. Terashima, could you make further comments?

Ohama: Alright. We have the Ministry of Health, Labour and Welfare(MHLW). we have the Ministry of Education. We are under the auspices of Ministry of Education but the Ministry of Education should not be the only ministry. We have to have involvement of the MHLW. We have to have the involvement of the relevant ministries so that it will be possible to cover everything that is related to the persons with disabilities. So we have to integrate all of the stove-piped systems which are in the hands of each individual ministry. So integrating is of the essence so that we are able to have a clear-cut system which is easy for us to use. So this is the kind of request we can make to the national government. For example, in the case of regenerative medicine, I am involved here. Regenerative medicine has that kind of problem. We have research for the Ministry of Education and then the application area should be covered by the MHLW. Then, because of the stem cells, the cabinet office is involved. Again, we have to have the integration of the systems. We have to have an umbrella organization to deal with these sorts of things. Thank you very much.

Moderator Fukatsu: Thank you very much. Mr. Terashima?

Terashima: I would like to say the same thing, basically. In ratifying the Convention on the Rights of PWDs, I'm sure that Japan will ratify the convention in a short while. In ratifying this, Japan government will pay more attention to this issue.

Moderator Fukatsu: Mr. Tanikawa, would you like to make a comment?

Tanikawa: I do not pay too much attention to the rights but, further, the faculty

development is very important. Maybe this is outside of what you meant in your question but in our scope of activities, I think faculty development to enhance understanding among faculty members, including the administrative staff, is very important because the kinds of activities exercised at this moment are not sufficient, even in the advanced universities. It is led by a handful of teachers and leaders and the students. So this is the status quo that we have to look at. The kind of support that we have to aim at should be the involvement of the entire university and entire faculty. We do have the school education law, which covers kindergarten to high school, but higher education is not covered. So it is important to establish a program with which we are able to work on the faculty department in the areas of support for the persons with disabilities or students with disabilities. So, again, allow me to repeat myself. We have to start with education and also skilled involvement of the faculty and administration staff.

Moderator Fukatsu: Also, you have a webpage for the provision of support for the students with disabilities, this is very good. It is marvelous. Many people here are in the interviews for assistance, so if you wish to make announcements, please do so.

Tanikawa: At the exhibit we have copies of the paper to explain our activities and also an explanation of the webpage is shown. We try to introduce the activities and the involvement of the universities. Also, whenever they have seminars and lecture meetings that, we hold that and share the results with you. So we are trying to fulfill the content of the webpage, so we would like each and every one of you to understand the existence of the webpage. Maybe this is very helpful to the university students as well as the high school students so that we are able to make sure that you understand the status of students with disabilities, so we'd like to take a look at the webpage whenever possible. Thank you.

Moderator Fukatsu: Dr. Takahashi, could you make a comment about the rights?

Takahashi: In the spectrum of the disease of autism, it is very important to fulfill their full potential. They have the potential to make a contribution to society. They have to understand that. The most important is employment. Certainly, they are rejected at the school entrance and they are further rejected from entering employment. NASA and FBI are aggressive in employing people with autism who have vocational aptitude. So making sure that they understand it, it is possible to enlarge entrance into higher education for these people.

Moderator Fukatsu: Mr. Kondo, could you make a comment on the topic of rights?

Kondo: I'm not sure whether I'd like to speak about rights, but I talked about the DO-IT program. The largest difficulty that they might encounter is the entrance exam. At the time of the entrance exam, they tend to receive measures to extend the time for the

exam. These are some measures, but in the case of high functional brain diseases, whether it is possible for them to bring in computers or calculators. They are not allowed to do so. On top of the extension of time, they could provide some more support. They have more problems. In the case of people with hearing impairment, they are able to provide some kind of solution for the hearing exam. On top of that, they have people with a brain dysfunction that have difficulty understanding the meaning of the question. So it is alright to have a testing arrangement which is an extension of time, but for people with health impairment it means they have difficulty taking the test because they get tired, so you might think of dividing the test into two and taking it in two days. Then, the secrecy obligation is at stake so it is difficult in case of the unified first stage admission test. Actually, they have the SAT, which is very similar to the achievement test that we have. They have different menus, for example, the introduction of readers, the use of personal computers. Also, they can use alternative formats and also many other things. So these are the menus provided to those that take the SAT test. They have support from the high schools. They can receive support from the universities in Japan but they are not able to receive any support at the time of the entrance exam. We are receiving these voices of concern from the DO- IT members, so we have to deal with that situation. Thank you very much.

Moderator Fukatsu: Ok, thank you for all the input. Are there any questions or comments? This is going to be the discussion among the panelists. Mr. Terashima?

Terashima: One thing is about the textbook. We have a limitation of copyrights. So let's say I want to use a video for deaf students and I want to put captions on the video for deaf students. Of course it is necessary but if I receive some video produced at a different university or institution, that violates copyright. So we have to produce the same thing again in our university so as not to violate copyrights. What about in the United States? Do you have this issue of copyright if you want to use something for deaf people?

Marks: Yes, absolutely. Copyright is a major issue and it has a great deal of impact. For captioning for deaf students, we do have the Telecommunications Act that requires captioning for videos. We've run into trouble because oftentimes the supply of videos that are captioned is small. The demand exceeds the supply and we end up trying to figure out how to provide that accommodation ourselves. It can be quite expensive. That's one problem. We see copyrights interfering with the issues around textbooks a lot. AHEAD is working with the publishers to try to find a solution to the problem of access to textbooks that assures copyright compliance at the same time. We want both access and copyrights to be protected at the same time. So the American Association of Publishers, which is the largest publishing association for college textbooks, has started

a program called "Access Text." That's the name. Access Text is going to be a network where colleges and universities can call one place to get permission from publishers to convert material to an accessible format or to get the textbook in an electronic format directly from a publisher. So this place will not be a library or a repository but it will be a distribution center for permissions and tell us where we can go get actually get the file from the publisher, should it exist. We're constantly working to find a balance between accessibility rights and copyrights.

Moderator Fukatsu: Thank you. Ms. Kitamura, I think that you have been working with DAISY. I think you know something about copyrights, too. What is the situation in Japan right now?

Moderator Kitamura: Well, maybe Mr. Terashima is knowledgeable about this, so please correct me if I make a mistake. Last year, the Barrier-Free Act for Textbooks was enacted. When it comes to textbooks, you can change the format without getting permission from the publisher to use at elementary school for children with any kinds of disabilities. In January 2010, a new copyright act will allow the textbook to be transformed into an electronic format or any other format without having permission from the publisher. So this is going to be a groundbreaking type of act. I participated in the AHEAD conference last summer and they debated heatedly about copyrights. AHEAD has been working on the publisher of textbooks as a group rather than individuals, so the group has some kind of impact. Five years ago I think they had a bad relationship between the two but now AHEAD is awarding publishers so they are making much more amicable type of relation between the two rather than being hostile. I think we have to do the same thing in Japan. I am a newcomer for this. I think Mr. Tanikawa and JASSO can take the initiative in having a good relationship between the textbook publishers and the Disabled Students Association. Are there any networks you are creating right now, Mr. Tanikawa?

Tanikawa: What we are promoting right now are as follows. We need to enhance the services for students with disabilities nation-wide, especially for the tertiary education support system. Just in the last few years we started working on them and drawing attention. I started the network services among students with disabilities and we designated some universities which are rather advanced in supporting students with disabilities and held a conference among them and published a paper to stimulate other universities. That's what we are doing right now. We've just begun these activities. Miyagi Educational College, Tsukuba University, Nihon Hukushi University, Kansei Gakuin University, Doshisha University, Hiroshima University, Fukuoka Education University and Toyama University are the members of this network of advanced universities. We have just started publishing the papers among ourselves.

Takahashi: This is not only for students with disabilities but in our center became a federated graduate school with Osaka University and also Hamamatsu Medical College in this April. We call them the “liaison universities.” They are far apart geographically, so we are planning on using e-learning and remote learning systems. In the case of e-learning, the teacher gives lectures and uses Power Point and that can be opened to everybody. If we use this type of measure, then students with disabilities can learn on the internet. I think it is, again, related to copyrights for the lecturers, so we need to clarify these issues. If we can make this type of common assets, we can share these assets with everybody in Japan.

Kondo: Well, copyrights issues are going to be modified. There is a growing trend that the copyright act is going to be modified soon, but in reality when we try to support students with disabilities, let’s say text information, do we make it open? But this text must be transformed into a different format for fair use. However, it costs. We have blind researchers and they must work on massive amounts of papers and journals to make them into Braille. They have to work morning into night to transform the formats. Publishers must have their text information but can we get access to that data? We can’t do that. We have to transform the format to begin with. The publisher is rather reluctant to do it. Who will share the costs? I talked to the publishers but they are reluctant because of the cost. Let’s say someone wants to make a magnified text. The government can share that cost. When the copyright is modified, that is great, but after that who will share the cost of transforming the format of the paper text? Who will provide the funds? That is going to be important.

Moderator Kitamura: We’d like Jim to make further comments later on. We participated in a meeting of AHEAD last year and yesterday there was a meeting held in Kyoto. The electronics introduction is a major issue at this moment. In the Baltic states or maybe in the Nordic states they do have a very good system but in the United States volunteers are very active. Here in Japan, volunteers are the ones who are expected to work, so we don’t have funding capabilities here even if we tried to introduce the electronic form. In the United States two or three years ago, in the case of textbooks for K to 12 all the materials should be put into electronic format. This is called the NIMAS (National Instrumental Materials Accessibility Standard) format. It’s exactly the same as the DAISY format. Government would have to establish their textbooks into the electronic format. They wanted to use the term NIMAS for the format. For compulsory education, they use NIMAS but in order to put that into this format, they had difficulty dealing with maps and charts and mathematical issue so they don’t have a standard for that yet. In the case of textbooks, you might want to take a closer look. For first English textbooks, it is very difficult to change them into the electronic format and because of

vested rights it is difficult to have a good distribution system. In the US they have NIMAC(National Instrumental Materials Accessibility Center). This is an organization for distribution but, although two years have passed, they still have difficulty dealing with the situation. The same could hold true in Japan. Integrating all of these issues will be very difficult but still is very important. That is the situation. About e-learning, in the United States they are very active. They have satellite offices and satellite schools. Jim, could you make a comment about e-learning and copyright issues?

Marks: More and more instruction is occurring in what we call “on-line environments” where a student takes computer using instructional software such as Blackboard or Web CD. There are several others that are out there, too. The accessibility to that is an issue. Instruction is changing daily and technology is changing it a lot. Many instructors post scanned images from magazines or parts of books and post them in our libraries in electronic reserves and those documents are many times not accessible. I don’t think there will ever be one single solution to this problem. There will be many solutions. One such solution might be a universal format that publishers might use that could be rendered accessible. At the DAISY consortium meetings in Kyoto earlier this week a lot of talk occurred around a file format called “e-pub,” which is right now not accessible, but it could be. Publishing companies are wanting to create a universal standard. If they can do that and find a way to make that universal standard accessible then a lot of the problems might go away. We may see a day in which a person could buy a book in a print format, an electronic format or any flavor or way that they would wish and pay the same price. The publisher makes the money, and the student gets the book.

Another issue that is happening is the issue right now of online books. There's a company called “Horsemart” which is providing books electronically. They deliberately make the electronic books inaccessible so that the intellectual information contained in the book cannot be taken. It’s ironic. One would think that something that is electronic would be easier to make accessible than print but in the case of these online books like those of Horsemart, due to the security that's involved the books are actually more difficult to render accessible than print would be. In fact, a lot of times the solution is to print the book and then convert the print to something that one can use. There are lots and lots of issues. I agree very much that cost will be an ongoing issue. We're going to have to find ways of paying for the support as we go, as well. Thank you.

Moderator Kitamura: Thank you. It’s time, so we’re going to close the panel discussion and we’d like to take some questions from the floor. We’d like to listen to the input and your comments. In order for the simultaneous interpreter to be able to translate, please raise your hand if you have any comments or questions. We have many hands. From the supporter side, Professor Ito of the Toyama University, please.

Ito: Thank you. My name is Ito. I am from the disability services for students in Toyama. One question is to Mr. Tanikawa and the other question is for Jim. For Mr. Tanikawa, I'd like to ask you a question in Japanese and to Jim Marks, I would like to ask a question in English. Going back to Mr. Tanikawa, I look at the slides and I'm sure all of you have copies. Please refer to page 11. You talked about the number of people with disabilities. It is categorized in physical, intellectual and mental disabilities. Actually, you use the term "people with intellectual disabilities." Intellectual disabilities can be included in developmental disorders using different criteria. Developmental disorders outside of the intellectual disabilities are not included here, so the Cabinet Office had a very weird understanding of this situation. I'd like to make this a case in the future. In the case of mental disorders, for example, we had depression and schizophrenia in this case. The problem here is depression in the 30's, so many people are paying attention to mental diseases in middle age but in the case of university students with depression which is relating with withdrawn into homes so people are not paying too much attention. Within your organization, Mr. Tanikawa, in JASSO, you talked about the definition in conducting this survey for the physical disorders and developmental disorders. I'd like to pay more attention to people with depression. Students with depression should be provided with the necessary level of assistance and they can go back to their normal lives. Maybe in the future, this is a request to you, we would like you to include mental diseases in the broad sense of the word. We would like you to include people who are suffering from depression. So we would like you to have some kind of remarks or maybe figures and also possibilities for assistance for students suffering from depression. They are really suffering. They are crying and I do hope that these students will be saved. In the future, maybe next year, maybe in the following years, we would like you to cover these people. In order to do that, you have to change the definition. It's not an easy task, I understand, but still I would like you to exert your personal effort to do that. One more request is you talked about the number of bearers of mental disability with that certificate. We would like you not to raise that kind of question. Withdrawn students do not come to schools, so they do not disclose their problems. They do not talk to the student affairs division, so there are many things that we have to bear in mind in thinking about figures in these statistics. Still, there are many students who are suffering who do not have the disability handbook or booklet. Mainly, they are students suffering from depression, so I would like to communicate that to you. The next question is to Jim.

Hearing your speech, I was thinking that if we persons who are doing work for disability services can share our knowledge give presentations at the AHEAD conference, it is very good for us. You know that UNESCO says that there are 3 billion

persons and one tenth means three hundred million persons with disabilities in Asian countries. So in Asian countries there are many persons who are disabled and I have many, many friends over there. If AHEAD Asia, or something, as it is called, if we can share the knowledge at the AHEAD conference, it is very good for us not only in Japan but also all over Asian countries. Please remember Asian countries, where there are many persons who are with disabilities. In Japan, China, India and other, developing countries, the bad situation for persons with disabilities must be changed. If AHEAD Asia is held, there may be a little change for the persons with disabilities but this small change makes a big change for the future.

Moderator Kitamura: Well, thank you. I must ask Jim to answer your question. Mr. Tanikawa, do you want to say a few things, too?

Tanikawa: Yes, I would like to be brief. We have data in the category of others, which also includes psychiatric diseases and psychosomatic diseases. You mentioned that, yes, we should provide some information about that but our services do not directly support students. Our services are for universities. What we have to do is to provide services for the universities so that they can handle these students with disabilities better. We have a network operation committee and the members are professors involved in social welfare and, yes, we have the input saying that we have to treat psychosomatic or depressed students as disabled students.

Moderator Kitamura: OK. Jim, please?

Marks: Thank you. Someone once said that we have to think globally and act locally. I think that's really true, that the strength in AHEAD is actually an association with people who have different issues to face locally. We need to create greater networking. I can tell you that the AHEAD board of directors is very much interested in thinking about disability issues beyond the confines of the United States and Canada. We're not sure how to do it, exactly. I would love to hear ideas on how we can better build bridges between different countries and to try and address the issues of accessibility to higher education for people with disabilities on a global level. It's very important, so thank you for your question.

Moderator Kitamura: Thank you. When I look at the website of AHEAD, we can see the presentation materials because all the presenters are obliged to provide the information on the website - in English, though - so that you can also see the conference contents. However, you must first learn English to read them. But even for the AHEAD conference, the United States is geographically very wide. The gasoline price increased dramatically last summer, so they were thinking about having some electronic or videoconferencing because they couldn't travel so much because of high gasoline prices. Maybe we can think of a network or videoconferencing worldwide,

rather than just inside the United States. I saw so many hands up in the audience. How many of them? Are there 5 hands already? OK, then, 5 hands. Please limit your question to 3 minutes, including the answer. OK? Starting from Murakami-san? Murakami-san is the chairman of the Tokorozawa-shi Teotsunagu Oyanokai, which is the parents group for children with mental retardation.

Murakami: Thank you. My name is Murakami from the Tokorozawa-shi Teotsunagu Oyanokai. Thank you very much for your substantial presentation but I think that we have the special act to provide opportunity for disabled peoples' higher education. However, still, in Japan we are lacking the quantity and quality of services for disabled people. The reason is that the Japanese government does not ratify the convention. I think Japan is the only country among developed countries which has not ratified the convention. I wonder why. What is the reason for that? Professor Terashima, what do you think of this? Why hasn't the Japanese government ratified it?

Moderator Kitamura: Sorry, this is a very difficult question. Would you like to answer this?

Terashima: I heard Japan government would ratify the convention probably soon. I'd like to pay attention barrier between Ministries will be eliminated or not at that time.

Sakamoto: I am Sakamoto. My question is to Jim. The first question is about how you mentioned the student who graduated about 10 years ago and came back with a great suit, proud-looking. How did you know he looked great, handsome and proud-looking? The second question is about the fact that you have 1,000 students with disabilities, so what is the employment situation there? Mr. Tanikawa and Professor Terashima, I'd like to as Japanese situation, too.

Moderator Kitamura: Did you hear the first question? The first question was about how you mentioned the student who graduated about 10 years ago and came back with a great suit, proud-looking. How did you know he looked great, handsome and proud-looking? That's the first question.

Marks: I'm having problems with my device. I only caught the part about how I know that the young man is handsome. I know because he told me so. One other thing I wanted to say quickly, and I wish I heard the question better, but the United States has not ratified the convention on the rights of people with disabilities, either, and I hope that will change soon.

Moderator Kitamura: That question was about the employment. For disabled students who graduated from your university, what is the situation for employment? Can they be employed right away? Or is there any system that you use to introduce employment?

Marks: Yes, we do work with employment. We form a relationship with vocational

rehabilitation. We also have an office on campus for career services and we try many things. Right now the employment situation in the United States is very bad. A lot of people are losing their jobs because of the economic downturn and things are not looking good. That competitive environment makes it more difficult for people with disabilities, but we try. We have several different programs to help with that. For example, we bring in recruiters from government agencies or large corporations to come to campus to specifically interview and meet with students with disabilities. We do things like holding fairs where employers come to hire people but, as I said, with the economic downturn, many things are difficult right now. We're always working at employment. One other quick thing I wanted to mention in relation to that is a philosophy of disability service has a lot to do with the success for people with disabilities and actually getting jobs. We work hard to promote independence and autonomy for the students that we serve so that when a person leaves our university and they're going to a corporation or an employer to find work, they come as a person of resource and responsibility and ability. We don't want them assuming that everything's going to be done for them or that everything's going to be taken care of. We want people who are contributors, who can make things happen for themselves. So in our service delivery we work to promote self-determination and that makes a big difference, as well.

Moderator Kitamura: Thank you very much. Mr. Tanikawa, would you like to make further comments?

Tanikawa: When I first assumed the office of the manager of the section, the size of the annual budget was the size of my annual income. I'm very happy. Jim is laughing! We had to start with the program in which we were able to enhance the understanding within the faculty. We conducted a questionnaire survey among the cooperating people. We were not able to have a high response rate but we received answers from large companies. A correction - many of the corporations which accepted employment and returned the answer had employment of high school graduates, not university graduates. Many people inquired about the fact that we receive and disclose information regarding university graduates as to the employment at the university or, viewing this from the corporate side, certainly the effort is not sufficient. So we are committed to further research in this area.

Moderator Kitamura: Thank you. Mr. Terashima, what do you think?

Terashima: This is a very difficult issue. I am not able to answer in a short while, but when I was working for the rehabilitation center we had the assisted employment services based on referrals. Compared with that, the university students have a much better chance. For example, in the case of physical disability, they are university

students and intellectually they are high. there is no problem. In the case of blind people, it is difficult. The situation in the university is about the same as the case of the rehabilitation center.

In the case of profound disabilities, these get more and more difficult to get a job, so this is another area. Different things are conducted in order to mitigate this situation. Social Firm Japan was established just the other day. This is a niche area where people can get in. For example, establishment of web pages using the internet - these are the companies where we have hope. There could be an increase in the number of companies to be candidates for employment. The situation here is like that. We are not able to be optimistic here but still, we have hope.

Moderator Kitamura: Thank you. We have very limited time. Could you raise your hand if you have any questions? We still have three people. We'll go to the right-hand side to start.

Oikawa: I am from Tsukuba University of Technology and my name is Oikawa. My question is to Jim. In Japanese universities, we have support coordinators. An increasing number of people have taken up jobs as coordinators for students with disabilities but I think it is important to develop these people in terms of their skills. In the United States for coordinators, in what ways are you developing their skills? Do you have any set institutions or are there any organizational approaches or are they not receiving any training? Do you have short seminars or training or do they have to have some kind of degree?

Marks: Disability service coordinators come from all walks of life. For example, I learned in elementary education course. I have extensive background in journalism and philosophy but nothing to do with disability specifically except that I am a blind man and know disability from that perspective. The Association of Higher Education and Disability has many programs for professional development. That's the main purpose behind the annual conference and between the other seminars and things we have going on. There are also regional groups of AHEAD throughout the United States. For example, in Montana, we have AHEAD of the Northern Rocky Mountains. It brings speakers in to teach one another. We also share information on a listserv that's in English - it's on the computer - where ideas are discussed and questions are asked and answered. There are many companies now that provide professional development training opportunities. AHEAD did look at professional certification but we decided it was more difficult than it was worth doing but in the process of looking at certification we developed training modules to try and make sure that disability service coordinators have a certain level of knowledge and ability. It's an important question and there will be many solutions to that problem in the future. Thank you.

Moderator Kitamura: Thank you very much. I think somebody in the first row...

Questioner: My question is to Mr. Tanikawa. I was very encouraged with the lecture by Ms. Takahashi. My son is starting at medical school and he is suspected to have Asperger syndrome. 3 months ago he was diagnosed as such. As I said, he is a medical student. As Mr. Jim mentioned, he wants to learn medical science. He wants to learn to become a researcher but the medical courses in Japanese universities are courses for the medical profession. So it is not that my son has the hope to graduate. He's not interested in looking at patients, so he's not interested in clinical practice. Is it possible, do you think, to get into universities just to learn, just to do research?

Tanikawa: I'm not so sure about the actual status of your son but among ourselves, we are holding workgroups depending on the types of disability. We have established a group for developmental disorders and we have psychiatrists involved in that subgroup. One thing that was mentioned was that among medical students, there are some people who are not interested in clinical practice but rather interested in medical science. They have to pursue their career in research. That's the kind of thing that was mentioned by the psychiatric doctor. There could be some courses within the university, I'm not sure which ones, but you might want to speak to that psychiatric individual. I'm not sure of the actual courses that are provided. Ms. Takahashi, would you like to comment?

Takahashi: Well, I belong to the medical department of the university and am looking at the situation. In the 5th or 6th year, medical students will have to have hands-on experiences to go beyond the clinical practice. So, if students are able to accept that, they can go into basic study. In the case of biotechnology, students of the science department and industrial chemistry can come into the areas. For example, if your son is not very good at interpersonal skills, in that situation it is possible for your son to move to other departments and be involved in the basic study of medicine. It is possible for your son to take the test to be a doctor, after then, he may study basic medicine.

Moderator Kitamura: Thank you. This is the last question.

Yasuda: My name is Yasuda from Nihon Fukushi University. I have a question for Jim. On Montana University or AHEAD, do you have any specified stipulation about services for students with disabilities? Do you have any declaration or rules, official ones?

Marks: In terms of what we do for each student, there are rules and regulations that specify certain things. For example, in the original civil rights law, section 504 of the Rehabilitation Act of 1973, in the regulations it says that students with disabilities can use audio recording devices – it actually says a tape recorder, although nobody uses tape recorders anymore – but you can use audio recording devices in lectures and there are other certain stipulations. Our guidance mainly comes from the United States

Department of Education on the interpretation of the law and its application to post-secondary education. Our services to individuals are really done on a case-by-case basis. We look at diagnostic information from medical or psychological authorities. We interview the student to ask about function and then we come up with a set of recommended services to give that student equal footing. Those services are pretty routine and I've heard many of them mentioned today – things like extended time on exams, the use of computer technology, alternative formats to print, sign language interpreters and real-time captionists and caption media. There are all kinds of different sorts of services that match how the disability impacts study. It's a case-by-case, common sense approach to what we do.

Moderator Fukatsu: Thank you. I'm sure that you have more questions but I'm sorry, time is limited. We must wrap up the panel discussion. Once again, thank you very much for your participation. Thank you. You can go back to your seats. Thank you for your participation to all the panelists.

Closing Address

Fumio Eto
Director, Training Center
National Rehabilitation Center for Persons with Disabilities

Thank you for your introduction. My name is Eto, the director of the training center. Today we have had a special seminar of WHO collaborating center titled “Learning and Living Support for Students with Disabilities in Higher Education.” Thank you very much once again for your participation in spite of this being a holiday. We are so surprised to see so many people turning out. First of all, I would like to say thank you to Mr. Jim Marks of Montana University. Based on his experiences being blind, he has been positively involved in services for disabilities. He has been very active as the director of the disability services at the University of Montana. I pay great respect for his achievements. I think his presentation encouraged so many people who have been working in the disability student services and also employment support services.

In the United States, even though he mentioned that he didn’t have good data, we were informed that about 10% of the overall students in tertiary education are disabled students. Meanwhile, it is only less than 1% in Japan. However, some of the universities are currently working very hard to invite more students with disabilities.

Also, Mr. Tanikawa of the Japan Student Services Organization shared with us data regarding students with disabilities in Japan. A variety of disabilities such as visual impairment, hearing impairment and physical impairment as well as developmental impairments such as autism and psychosomatic impairment including higher brain dysfunctions – each disability has different needs and we need to have reasonable accommodation for each case. There are many more issues and challenges we have to overcome on campus.

Following Mr. Tanikawa, Dr. Kondo of the University of Tokyo Research Center for Advanced Science and Technology and also Dr. Kazuko Takahashi of the Research Center for Child Mental Development as well as Prof. Terashima of Urawa University and Mr. Ohama of the Japan Spinal Cord Foundation have contributed greatly to this discussion. Time was limited, so I am sure that all the panelists and also people in the audience want to share more thoughts with us. However, I hope that this seminar will be one part of a system that promotes services for disabled students. Once again, I would like to thank all 5 panelists, including Mr. Jim Marks, and also the audience, which has participated and stayed until the end of this seminar. Thank you very much. This

concludes the seminar.