

Breaking down the Barriers: Current Challenges to Disability Equality

Propelled by the adoption of the UN Convention on the Rights of Persons with Disabilities (CPRD) in 2006, the movement for equal rights irrespective of disability has made remarkable progress in many parts of the world. At minimum, there is more visibility. There is more awareness of the human rights of persons with disabilities, including their rights to equality and non-discrimination. At the level of legislative and policy frameworks, the disability equality movement is grappling with a number of challenges in translating the principles of the CRPD into practice. Among the most serious of those are issues around legal capacity, independent living, and access to information and communications technologies (ICT) on an equal basis.

ERT spoke with Mr Hiroshi Kawamura, Founder and President of the DAISY Consortium, Japan, which is a leading assistive technologies developer, and Ms Kapka Panayotova, Director of the Centre for Independent Living based in Sofia, Bulgaria.

ERT: You are widely recognised as a leading expert on the rights of persons with disabilities. Can you begin by telling us how you developed into one of the most prominent authorities in this area? What life experiences and major influences played a role on the way to your present position?

Hiroshi Kawamura: When I was working at the largest library system in Japan – the University of Tokyo Library – as a professional librarian in late 1970s, I had three incidents that opened my eyes on issues of persons with disabilities, and that they could be encouraged to focus on what they have rather than what they lost. Firstly I lost my mother in law who lived with my family, who suc-

cumbed to cancer after three years of terminal care at home. My wife and I did our best to enrich her life. Not long after the funeral of my mother in law, one of my colleague librarians who won the table tennis championship of the University of Tokyo lost one of his legs due to sarcoma. I thought about him and proposed to make the library accessible for wheelchair users as soon as possible. The University Union, the library chapter in particular, immediately picked up my proposal and agreed to establish a library committee on accessibility to work on the physical accessibility of the library building. While, as a committee member, I was planning to make our library accessible for wheelchair users, we were informed that the first blind candidate had successfully passed the examina-



tions in Braille. It was surprising that I could not find any accessible titles, in Braille or in audio tape, among six million titles of the library holdings. So, a 19 year old blind student opened my eyes on the issues faced by people with disabilities. Since then, I have been collaborating with this man, to change the library, the publishing industry and the society in order to guarantee access to human knowledge for everybody.

Kapka Panayotova: I guess I should start with my parents – they made me the way I am: strong, stubborn, curious about things around me and eager to be free. When I was seven months old – it was in 1957 – I got polio. I was one of the last victims of this nasty virus; it was a short while later that the Communist Government of Bulgaria got the vaccine and started its application on children. My situation was really bad at the beginning. Lots of surgeries, rehab, and doctors and nurses around in my childhood made me hate hospitals and medical centres but also helped to recover my body as much as it was possible. I walk with crutches now and as I get older things deteriorate – the Post-Polio Syndrome is after me. But I’m not complaining about that – other things drive me mad.

I was raised as a normal child, and a regular family member – with a lot of love and support but also with all the duties and obligations to the family as everybody else. I had to clean my room, go shopping, and throw out the rubbish. Neighbours were often appalled – “what kind of parents can make the poor kid do these things?” I started reading and writing at the age of four and my mother – she was a teacher – tried to get me to school earlier. The school entry age at that time in Bulgaria was seven. Due to my disability I was referred to a special school, which was nothing like the special schools in Britain or Germany, it was, and still is, a sort of warehouse where kids learn nothing but parents are told that both teaching and rehab are provided. I was taken to Momin Prohod – a place 100 km away from Sofia – and left there. Apparently, as we left the house I started crying and didn’t stop for days, declined food and didn’t sleep. The staff at the rehab centre couldn’t cope and called my parents to come and take me home. That was the end of institutional care for me. My mum arranged to get me enrolled in the school she was teaching at and thus – being educated with my non-disabled peers in a mainstream school – I managed to graduate from an English Language School in Sofia and Warsaw University later on. My



parents always encouraged me to stand firm for what I believe in, to speak for myself and to be as independent as possible.

In 1993 I got a chance to study at the Johns Hopkins University in Baltimore, Maryland. There I met many disability leaders running independent living operations. And I realised that this was what I wanted to do myself. When I got back home in Sofia, I set up a Centre for Independent Living (CIL). We were registered in 1995 and here we are still, a trouble maker for governments when they do not do the right thing. We advocate for disability rights and provide support for those disabled people who want to be independent and manage their own lives.

ERT: The UN Convention on the Rights of Persons with Disabilities which was adopted in 2006 has been celebrated as a powerful instrument that has shifted the paradigm of thinking about disability at the international level. Has this Convention contributed to shifting the paradigm on disability at the national and local levels in your countries, Japan and Bulgaria (even though Japan has signed but not yet ratified it)? If yes, in what way? If not, why not?

Hiroshi Kawamura: Yes, the CRPD has triggered a discussion to change the paradigm. I expect a revision of the Basic Law for Persons with Disabilities by the end of this year. This will allow the National Diet to ratify the Convention.

The Japanese disability community contributed a lot to CRPD, in particular ICT accessibility in which I was involved. Our journey to CRPD in Japan started with the UN ESCAP¹ Decade of Persons with Disabilities in Asia and the Pacific, 1993-2002. I established and

took the chair of the ICT Working Group of the First Decade which contributed to the ICT accessibility part of the Biwako Millennium Framework of the Second Decade of Disabled Persons of ESCAP, 2003-2012. Since 2002, I participated in the WSIS² process representing the DAISY Consortium and the ICT accessibility initiatives in Asia and the Pacific. I took the responsibility of the Disability Focal Point of the WSIS Civil Society on behalf of the DAISY Consortium which is legally established in Switzerland, although actually I have been based in Japan. Our major contribution to the CRPD is the inclusion of language on “universal design” in the disability context,³ to reflect the united one voice of persons with disabilities formulated by the Global Forum on Disability in the Information Society in 2003 and in 2005. If you closely trace the WSIS 2003 preparatory process, until the last prep-com, you will see that needs and demands of persons with disabilities were not reflected in the strategic documents in an appropriate language because of the absence of disability in the Millennium Development Goals. Our struggle was around putting proper language on ICT accessibility issues and solutions in place in the context of WSIS strategic documents to solve the Digital Divide. Speaking of my own role, my contribution to CRPD is seamlessly connected to WSIS. Likewise, it is very common for Japanese active contributors to contribute a lot to CRPD through international channel, but we have done less through national channels.

Although Japan has not yet ratified CRPD, we have achieved a major revision of the Copyright Law in 2008 reflecting the new paradigm set out by the CRPD. So far, more than one hundred laws have been revised to meet the requirements of CRPD.

Last month, the Prime Minister appointed the Disability Policy Committee which is chaired

by a blind professor – the same man who opened my eyes on disability 35 years ago.

Kapka Panayotova: As far as Bulgaria is concerned, the Convention is just a token thing, even though Bulgaria has ratified it earlier this year. No change whatsoever. Frankly, I personally expected to see more human rights related changes in the process of EU accession. Politicians highjacked the language of the social model of disability and maintained the same old practices of parallel public systems for disabled people: institutions, special schools, etc. Even physical accessibility is not provided for – sidewalks, buildings, buses, everything is inaccessible for disabled people, not to mention services like education, or employment. Physical accessibility is easy – you build stairs and a ramp next to them: as simple as that! It serves the elderly, baby pushchairs, everybody. I still keep asking why it doesn't happen. And my answer is it has to do with POWER: no one wants to give up power and control over disabled people's lives. Accessibility would be the first step to independence; people will go out and see the world, the opportunities, a different future for themselves, and will start demanding. I've seen it happening with the guys who started coming to CIL, sharing our vision for independent living. Once you take them out of their houses, parents, therapists, you can't stop the process. However, everybody is scared: parents are worried about their "sick" children; service-providers think of their business; policy makers worry about the political routine; administrations don't know how to do things differently... And here we are: saying the right things while doing what we are used to.

But to have the UN Convention is a brilliant thing: it is the main tool in the hands of active disabled people who want change and do not agree with the traditional percep-

tions of being "sick", "vulnerable", or "objects of care". Bulgaria has not ratified the Optional Protocol, so we can't file a case with the Committee, but we can sue the government or any entity for discrimination on the ground of disability using the Convention in the Bulgarian courts of law, no matter how unreliable they are.

CIL is very active in promoting the Convention, addressing both disabled people and the public at large. Politicians and public servants will be forced to learn about it from the pressure we put on them. I guess this is how democracy works – and I believe nothing better has been invented so far.

ERT: From the point of view of non-discrimination and equality, what most important norms have been incorporated in the national laws of your country to ensure equal participation of persons with disabilities in all areas of life? Where are the most important challenges that remain to be addressed?

Hiroshi Kawamura: "Equal access" and "reasonable accommodation" are key norms incorporated in Japan's national laws to ensure equal participation. The challenges are dissemination of the concept of equal rights among both the general public and persons with disabilities, in particular those with intellectual disabilities, psycho-social disabilities, learning disabilities and older persons with disabilities. In addition, budget is another most critical challenge.

Kapka Panayotova: Regretfully, the Bulgarian legislation does not even promote equal participation of disabled people. The definition of disability still refers to diagnosis and health condition, and there is no mention of barriers. Special facilities for disabled people enjoy good funding and charity contri-

butions all the time. Assistance allowance is worth €25 a month – worth not much more than to buy bread for the family. Family members were made personal assistants for a minimum monthly salary; social assistance is available as an annual service offered on a project basis by service providers. Wheelchair users ride their “vehicle” for ten years before they are entitled to a new one, while accessibility adjustments of the living space are supported with up to €300 paid by the government – anything above that must be covered by the person concerned. Poverty among disabled people is huge. Briefly, the whole approach to disability policies should be changed in Bulgaria, but there are not many drivers of change. Therefore, the process is slow.

ERT: Can you explain, for an audience of non-experts on disability, what is Augmentative and Alternative Modes of Communications (AAC) and are there minimum standards of access to AAC for persons with different types of disabilities?

Hiroshi Kawamura: Everybody has different abilities. The communication methods a person may use are determined by persons in the community. In most cases, speech and writing are dominant methods of communication. Stored information for knowledge is the basic asset of our civilization which has been transferred to contemporary communities.

AAC is a concept to bridge the mismatch between the communication abilities a person with disabilities has and the dominant communication methods in the community. One most popular AAC example must be Dr Stephen Hawking’s communication device. Dr Hawking manipulates a word processor with an adapted keyboard attached to his electric wheelchair to write

his speech and generate a synthetic voice to present his speech. Another example of AAC is a set of symbols for communication in place of speech or written language and this can be used by persons with intellectual disabilities. A sign or a body language is often used among people with different languages. Current ICT development opens up opportunities to bridge the gap above mentioned. To make the most of the potential of ICT development in the AAC arena, it is crucial to develop international standards and guidelines to avoid fragmentation of AAC.

Kapka Panayotova: I wouldn’t dare – being paired up with Hiroshi – to elaborate on that. But I know that AAC is today’s tool to overcome barriers in communication between people, to compensate the deficit of the body caused by the impairment. This is what Bulgarian disabled people are deprived of. Let me give you an example. A young fellow with cerebral palsy and speech problems has been diagnosed with mental disability at the age of five because “he can’t speak, and is incommunicable”, according to his disability document. This “diagnosis” took him to a special school where no one even tried to communicate with him. Now he is 22 years old and really incommunicable, with a severe social disability. This is what AAC could have prevented.

ERT: Persons with disabilities are particularly vulnerable during political and humanitarian crises, such as the post-electoral violence in Kenya in 2008, or the Somali refugee crisis in the same country in the summer of 2011, as well as in disasters, such as the catastrophic tsunami and nuclear disaster in Japan in 2011. What legal and policy measures should be in place to safeguard persons with disabilities in these cases?

Hiroshi Kawamura: The vulnerability of persons with disabilities lies in both physical access and information and knowledge access. Essentially, in mass casualty natural disaster situations, the rescue operation has extremely limited ability to save the lives of the most vulnerable people due to the fact that the first responders must ensure their safety before they operate in the disaster zone. In addition, as we have learned again and again, most of the victims are killed within one hour of the incident. Following the first hour, neighbours in the community who have survived may save lives of others in the disaster area. Legal and policy measures to save lives of vulnerable people including persons with disabilities during disasters should focus on empowering those vulnerable people, with effective enforcement to encourage persons with disabilities to take part in the disaster risk reduction, from the planning stage through preparedness drills and the reconstruction process. The law should require accessibility guidelines for disaster risk reduction documentation, evacuation routes and shelters, and disaster alerts to be set out and the necessary budget should be provided. Use of copyrighted materials for disaster risk reduction documentation needs to be guaranteed legally as a fair use in an accessible format so that all vulnerable people may have access to the information and knowledge necessary to save their lives during disasters. Regarding political and humanitarian crises, I have no actual expertise, but I suppose that an empowering approach to accessing information and knowledge is valid in this area too.

Kapka Panayotova: We had an earthquake in Bulgaria, too. It was in the night of 22 May 2012. Luckily, there were no casualties, just ruined buildings. Last year we had floods in several areas of the country. No one knows how to handle disabled people in such cases.

You know what, I think they'll let us die – sorry for being so cynical, but this is the reality here. And I think we can learn a lot from our Japanese brothers and sisters.

ERT: What are the most important global issues within the area of mental capacity? What are in your view the major challenges in the enactment of mental capacity legislation?

Hiroshi Kawamura: The methods of access to information and knowledge as well as of communication methods are diverse. Accessible interactive multimedia development has great potential to bridge the current gap between readily available methods and methods that are required by a person with disabilities who cannot make or cannot communicate his or her decisions. We must re-examine the way to deliver knowledge, in particular legislation, contracts and scientific information that are currently delivered only in written language, and must promote publications in accessible multimedia which guarantee alternative methods of understanding the contents, such as reading aloud, sign language, enlarged text or easy-to-read versions. In this respect, it is strongly recommended that scientists and engineers work in close collaboration with disability communities such as those with CP⁴, dyslexia, autism, dementia and psycho-social disabilities. The DAISY community learned a lot from a self help group of persons with severe psycho-social disabilities in Japan and the autism community in the USA. In addition to above mentioned technology development, legal measures should be established to protect the rights of persons with disabilities who are not able to make decisions or not able to communicate their decisions.

Kapka Panayotova: We have a heated debate in Bulgaria on legal capacity and sup-

ported decision making. It has been triggered by Article 12 of the Convention and Bulgaria is among the countries that fall far behind in their compliance with this Article. In Bulgaria, it is quite easy to declare a person legally incompetent – a diagnosis and doctor’s opinion before a court that the person cannot be responsible for his/her actions are enough. Once being declared legally incapable, the person has little chance to have such a ruling reviewed and repealed. Thus people are deprived of their basic human rights – to make choices, to own and manage property, to have a family, etc. And this is often for life. If a family member is granted guardianship, there is a slight possibility that they may request a review of the position. This happens, albeit very rarely. However, once a person with intellectual disabilities or mental health problems is institutionalised, and the guardian functions are placed with the director of the facility, even that slight possibility of reversal is gone. These people will never enjoy their rights to vote, to choose where to live and whom to live with, or what kind of assistance to have. The situation in Bulgaria is in severe violation of the whole Convention because legal capacity is the key to all other rights.

ERT: What are the most important global issues in the area of information and communication technologies aimed at persons with disabilities? What is your vision for the future of these technologies?

Hiroshi Kawamura: Implementation of CRPD and WSIS plans of action in standard development, i. e. development of universal design in combination with assistive technologies, is the key issue. For cutting off the chain of the newly developed digital divide, and for the development of technologies that create digital opportunities in the inclusive human

centred society, the role of standards that guarantee accessibility for diverse categories of persons with disabilities is crucial. Accessible ICT will stimulate participation of persons with disabilities in the R&D process that will result in better meeting their demands and increasing their participation. I do believe that if all stakeholders respect and implement the CRPD, we will be successful in developing one of the pillars of the inclusive society.

Kapka Panayotova: I do believe that technologies are a powerful tool for the independence of disabled people – I wouldn’t walk without crutches, and wheelchair users can’t make it without their wheelchairs. You know, it was entirely unthinkable for a disabled person to drive a car just 20 years ago. Nowadays you can see people with quite severe impairments sitting in the wheelchair, steering the wheel with a finger, and driving their cars. It would have been impossible to have Adolf Ratzka, a severely disabled Swedish man, at a conference in Vidin, Bulgaria, talking about his studies in the U.S., his work in Latin America, and about independent living and peer support. This would have never happened without technologies being so advanced as to help compensate for the deficit caused by the impairment.

I don’t think though that we need “information and communications technologies aimed at persons with disabilities”. We are talking about universal design and this means technologies and products that are useful for everyone. For example, I communicate by Skype with both disabled and non-disabled people in Bulgaria and around the world.

Crucially, no amount of sophisticated technology can replace self-esteem and self-confidence – technical aids can make happen what people want for themselves but they need to make their decisions in the first

place. My disabled fellows need to believe that they can make it through life despite the disability, that they have the same rights as other members of society, and that they are as valuable as every other human being. Technologies will be useless if there is no political will to make a policy change.

ERT: In this issue of *The Equal Rights Review*, several articles deal with the right to independent living enshrined in Article 19 CRPD. Do you think that caring for persons with disabilities in institutions violates the right to independent living? Should all institutions be abolished and replaced with other forms of care?

Hiroshi Kawamura: The right of choice is always important. As long as the right to choose to live independently is guaranteed, some persons with disabilities may choose well designed institutions that may meet their specific needs.

Kapka Panayotova: Institutional care constitutes – by all means – a severe violation of basic human rights as defined nowadays. It takes away the control of one’s life and places the decision-making power into the hands of the institution’s staff – management, therapists, social workers, etc. People have to obey the rules of the institution, and those rules shape their daily life, schedule, diet, everything. An institution doesn’t contribute to any personal development whatsoever. It is oppressive and a terrible invasion of privacy. Disabled people need support and services, not care. This need exists irrespective of age, even though age is a factor in defining the nature of the support and services themselves. For example, children may need more or different support compared to adults. Care means a degree of control, whereas support means respect for one’s wishes and aspirations, gentle guid-

ance, contribution to the efforts made by the supported person. Should all institutions be abolished? Yes, all institutions – certainly those funded by governments – should be abolished and care should be replaced with individual support. We can’t stop private entities from setting up institutions and having their residents cover the costs, but if people have resources on an individual basis, they would be able to choose whether to pay for institutional care or go for community living with personal assistance. Briefly, the key words are individual support, including help from peers more than from experts and professionals, barrier-free environment in and outside the living space, societal acceptance, equal treatment, and finally, proper technical aids, which *inter alia* can compensate for the deficit caused by the impairment.

ERT: How can new and emerging technologies contribute to independent living? Can you give us some examples of promising experiments, or good practices?

Hiroshi Kawamura: Tele-working or working at home and remote participation are good examples while equal access to transportation and the built environment is also crucial. Remote caption and other relay services are another good practice to support persons with sensory disabilities. Penetration of accessible low cost networking including mobile telephone networks and digital TV broadcasting will make it possible for more and more persons with disabilities to live independently.

Kapka Panayotova: Both existing and emerging technologies can contribute to independent living – any item that gives control to the individual is helpful. But I keep insisting that individual and group empowerment of the disabled should be given as high a priority as technologies and indeed

higher, in order to have disabled people aware and educated to use them for independent living, not just for fun or fashion. I don't know of any experimental work in Bulgaria but, honestly speaking, Bulgarian disabled people have no access even to the existing technological solutions, not to mention new inventions.

Instead of an example of a good practice, a "bad practice" comes to mind. A new parking regulation will enter into force in September this year in Sofia. It has to do with the disability cards and special parking spaces – it's called preferential parking regulation. However, if you are a disabled person, it will not be enough for you to find a disability-marked parking space and make sure you have displayed your disability card. You will have to sit and wait for someone to come over in person to certify that you, the car user, are the same person who is in possession of the disability card. They will then place a paper inside your car next to your plastic disability card. If you are in a hurry and can't wait, your car will be clamped or towed away. This whole regulation is a step backwards. The right thing to do here would be to introduce a technology making it easier for everyone including persons with disabilities, and increasing independence and control over our lives by enabling communications.

ERT: If you were in charge of the national budget of your country, what priorities would you include with a view to improving the position of persons with disabilities?

Hiroshi Kawamura: Firstly, I would put priority on the implementation of CRPD through government investment on R&D and government procurement policy to ban new buildings, transportation, ICT products and services that are not accessible. Secondly,

I would procure accessibility guidelines of government publications and websites, guaranteeing that all new published information is accessible for everybody. Thirdly, textbooks, training manuals and examinations that are conducted by the government will be made accessible. Those are achievable targets with measurable outcomes in relatively short terms with relatively light budgets. This knowledge-based approach would encourage participation of persons with disabilities to improve their position in the society.

Kapka Panayotova: Fortunately, I'm not in charge of big money, but if I were I would have tried to allocate funds to opening up the mainstream public systems – education, transport, built environment, employment – and make them friendly for disabled people. It would not require much more money than is spent now on funding parallel systems, meaning special education, special transport, or special enterprises. Current budget allocations need reshuffling along with radical changes in the regulatory framework. Secondly, I would push for gradual but decisive reform of the welfare system: inclusion allowances should be separated from welfare payments. Can you believe that a disabled person in Bulgaria today is entitled to a monthly integration allowance amounting to between €15 and €17? The rate is linked to the government-defined "subsistence living income", which is €33 per month and which has not changed for the last three years. This is ridiculous, isn't it? Given the total lack of accessibility in the country, what disabled person could manage to get "included" by means of such "support"? This amount is but a minute contribution to the family budget made by the disabled family member. I can give you dozens of similar examples that prove the need for radical policy reform. But going

back to the budget discussion, I would put enough money (whatever is enough!) into proper training of support professionals – occupational therapists, social workers, etc. Given their crucial role in the process of inclusion, these persons need to be well aware of the social and human rights model of disability, to learn about “support” vs. “care”, to be familiar with the technological solutions that may help disabled people to become more independent, and with the personal assistance mechanism. And last but not least, I would make sure that peer support is well provided for so that experienced and self-confident disabled people can form support networks for their less confident brothers and sisters and help them by sharing experience and building their self-esteem, and by providing guidance through the systems and encouragement when things get rough. A tenth of the overall disability budget should go for monitoring and evaluation performed by mixed teams of disabled and non-disabled consultants. All these things can happen through pilot projects which should later on become a long-term policy with prospects for improvement.

If that happened, a whole new establishment would emerge. Disabled people would become and behave as clients, as citizens – demanding choices and quality because they would be given access to resources under their control. As things stand today, it would be pathetic to report on how you spend your €15 for integration, but if you had a thousand Euro for personal assistance or other services, you would have to report on spending them – with evidence of the expenditures. The current disability industry that brings benefits mostly to the business managers and experts would have to operate in a competitive environment depending on the clients who would be in control of the support provided to them with public money, and not on the government directly financing service providers. I wouldn't say that this would cost society less – though it might – but it would certainly result in better effectiveness and efficiency of public investment, and higher value-added for society as a whole. The world would become a different and better place to live. But most people are scared of change and powerful vested interests are a barrier to change. Therefore, at this time, I am sceptical.

Interviewer on behalf of ERT:
Dimitrina Petrova

1 Economic and Social Commission for Asia and the Pacific.

2 World Summit on the Information Society.

3 According to Article 2 (Definitions) of the CRPD: “‘Universal design’ means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. ‘Universal design’ shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.” See also Article 4(f), obliging state parties to “undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines”.

4 Cerebral palsy.