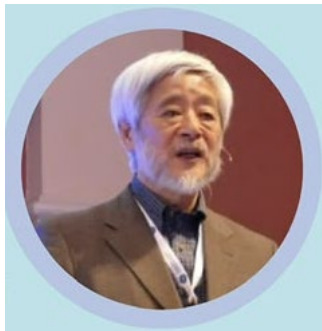


Shanta Memorial Rehabilitation Centre

10th Ashok Hans Memorial Lecture

***The Role of Persons with Disabilities
in the
Development of Universal Design in the Digital Age***



Speaker

Hiroshi Kawamura

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Chair, International Commission on Technology and Accessibility (Rehabilitation International)*



Chair

Joseph Kwan

Vice President Asia-Pacific (Rehabilitation International)

Date: 18th July 2026

Time: 6. 30 p.m. IST

About Hiroshi Kawamura, Speaker

Hiroshi, Kawamura is our speaker for today. He is a long-term board member of DAISY Consortium, a global partnership of the organization committed to creating the best method of publishing for people who are blind or print disabled and he has also served DAISY in several other positions, including as an ambassador for DAISY in the disability inclusive disaster risk reduction sector. Kawamura helped coordinate the global forum on disability in the information society in Geneva and in Tunis, which has been followed by international conference on DIDRR and on site collaborative research. Under Kawamura, the forum focused on empowering all community residents by providing accessible and easy to understand in order to inform scientific knowledge of DIDRR in DAISY multiple form format. Kawamura arranges the Asia-Pacific meeting on DIDRR in Sendai, Japan in April 2014 in collaboration with UNESCAP, Nippon Foundation and Rehabilitation International. He has worked as a professional librarian at the University of Tokyo library since 1970

About Ar Dr Joseph Kwan, Chair

Joseph Kwan, an architect and consultant has more than 40 years of experience in international architectural practice having worked in Australia, United Kingdom, France and now over 30 years in Hong Kong. Joseph is the founding director of UDA Consultant Ltd and a **Universal Design and Accessibility** consultant in Hong Kong since 2005. Joseph is an expert and resource person to UN-ESCAP on the promotion of inclusive design and accessible tourism in Asia and the Pacific. He was a member of the ISO Working Group on the drafting of the standard ISO:21542 (2011/2021) *Building Construction - Accessibility and Usability of the Built Environment*. He was a member of the Hong Kong Government's *Rehabilitation Advisory Committee (RAC)*, a convener of the *Rehabilitation Programme Plan* Task Force on Accessibility and the chairman of RAC Subcommittee on Access. He has lectured extensively in the field of access and universal design at the local, regional and international level, giving lectures in 33 countries.

Introduction by Joseph Kwan

Hello ladies, gentlemen and friends. I see from the participants' list that I know many of you, so it is wonderful to have you joining us tonight. Thank you, Asha Hans for hosting this particular 10th Ashok Hans Memorial Lecture where we have Hiroshi-san from Japan speaking to us. I am with the Rehabilitation International Asia-Pacific Region, and I think I like to have a chance of meeting all of you in the future, to discuss how we can further develop and collaborate with RI Asia-Pacific. India has a huge population, and a huge interest in disability and accessibility. I believe we can certainly work closer together to promote equality and inclusion in the region. So, without further ado we are very fortunate this evening to have Hiroshi Kawamura speak to us on the role of people with disabilities in the development of universal design in the digital age. Interesting topic, in the fact that we must look at the role of people with disabilities, and not only the able-bodied persons on their role in terms of the development of universal design. I'm certain Hiroshi will explain what that is in the

digital age. We are talking so much about AI and technology nowadays that we would certainly like to see how the three elements of PwDs, Universal Design and Digital Technology will come together and benefit everybody in the community.

Lecture by Hiroshi Kawamura

Respected Dr Asha Hans, distinguished members of the Ashok Memorial Committee, the leadership and staff of the Shanta Memorial Rehabilitation Centre and my fellow brothers and sisters with disabilities in India and around the world, honored guests, ladies and gentlemen.

Good evening from Japan where it is now 10 p.m on Saturday night. That we can gather like this across continents without anyone boarding an aircraft is one of the quiet miracles of the digital age and tonight I want to talk about who built this miracle, who is still excluded from it and who must read its next chapter. It is a profound honour to deliver this memorial lecture and to join the distinguished line of activists from across our region who have delivered it before me.

I note with emotion that the first lecture in this series was given by Mansur Ahmed Chowdhury on the 18th of July 2010, 16 years ago to this very day and that among the past lecturers is Anuradha Mohit with whom I have worked side by side in India, in Paris and in Tunis in the common struggle for the right to information for all. Mansur closed that first lecture with a vow that our journey from darkness to light, from dissolution to hope, from exclusion to inclusion would attain its goal of a rights-based barrier-free and inclusive society for all. Tonight, I would like to examine that vow in the light of the digital age and to ask what it demands of us now.

But first, let me pay my tribute to the man whose memory brings us together. Ashok Hans devoted his life from 1985 until his passing in 2008 to the proposition that disability rights are rights, not charity, not welfare, not an afterthought of development, but rights. He founded the Shanta Memorial Rehabilitation Centre in Bhubaneswar, I hope my pronunciation is right or acceptable, and built it into an institution known across India and across the world.

He travelled from rural Odisha to the corridors of the United Nations to carry a simple message. Persons with disabilities must make informed choices about their own aspirations and destinies like any other person. Those who worked with him remember a warm, caring, ever-smiling man. But I would like to draw your attention to something else in his legacy, something that speaks directly to my theme tonight. Ashok Hans was among the early voices calling for the inclusion of disability in disaster response, a campaign SMRC carried to the globe stage. He understood long before it became international policy that when the cyclone comes, when the flood rises, the barriers that exclude us in ordinary times become deadly.

I will return to this insight later because I believe it is one of the most important lessons Odisha has given the world. And Ashok Hans understood something more, that the expertise for removing barriers lives in the people who face them. SMRC has always

been a disability-led organisation. In particular, in participating in the drafting of the Convention on the Rights of Persons with Disabilities and India's own disability laws. ***That is to say, persons with disabilities in Odisha did not wait for accessible systems to be handed down to them. They went and wrote the rules themselves.*** Tonight's theme, the role of persons with disabilities in the development of universal design, is in a sense simply the story of people like Ashok Hans told in the language of technology. Let me now frame the question of this lecture.

Lecture

Universal design as defined in Article 2 of the CRPD 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. It is a beautiful idea, but there is a question hidden inside it that is rarely asked aloud. Designed by whom? For most of modern history, technology has been designed for persons with disabilities at best and without us at worst. The results are all around us. Lamps added after the building is finished. Websites fixed after the lawsuit. Apps that a blind user discovers on the day of release cannot be operated at all.

This is the design first, retrofit later model. In the digital age, it fails faster and at greater scale than ever before because software reaches a billion people before anyone thinks to test it with a screen reader. The disability movement's answer has always been contained in five words, **nothing about us without us.**

But tonight, I want to argue for a stronger formulation. Our role is not merely to be consulted, not merely to test, not merely to advise. **The lesson of the last 30 years, and I have been fortunate to witness some of it at first hand, is that persons with disabilities must be and have already proven ourselves to be the developers, the standard makers, and the leaders of universal design.**

When we lead, universal design succeeds and the whole of society benefits. When we are excluded, accessibility decays into a compliance checkbox. That is my thesis.

Let me offer you the evidence of my own lifetime. I began my career in 1970 as a librarian at the University of Tokyo library where I served for 27 years. A library is a temple of knowledge, but I came to see that its doors were closed to a great many people. Blind readers, readers with low vision, people with dyslexia, people who could not hold a book or turn its pages for them, the shelves might as well have been empty. Later, as chair of the section of libraries for the blind of the International Federation of Library Associations and Institutions, in the first half of the 1990s, I saw that this exclusion was global and that it was most severe in the developing world where fewer than a few percent of published works ever became available in accessible formats.

We came to call this the book famine.

In those days, the talking book was an analog cassette tape. Imagine studying for an examination with a textbook on 12 cassettes. With no way to jump to a chapter, no way to find a page, no way to place a bookmark. They needed navigation. The power to move through a book freely as a sighted reader flips pages. In 1996, six talking book libraries and library consortiums came together to form the DAISY consortium.

DAISY currently stands for the Digital Accessible Information System, but at that time, it stands for the Digital Audio-Based Information System. I had the privilege of serving on its board from the founding as interim project manager in the first years, later as project manager of the DAISY 4.0 project, bringing the technology to developing countries, and as president from 2008 till 2011. But the titles do not matter. What matters is how the standard was made. From the first day, blind readers and other persons with print disabilities were not the test subjects of the DAISY. They were literally its architects. The requirements that defined the entire standard, precise navigation by chapter, section, page, and phrase, with text, audio, and images synchronized, did not come from engineers guessing what blind people might want. It came from blind readers stating what they required. And engineers, many of them themselves, persons with disabilities, building to that requirement.

The user organizations governed the consortium itself. The specification was open, non-proprietary, free for anyone in the world to implement, because the member libraries, accountable to their readers, insisted that access to knowledge must never be locked behind the patent. And here is the point I most want you to hear. DAISY did not remain a special technology for a special population. The concept pioneered in DAISY, structured navigation, synchronized text and audio, reading by ear and eye together, if necessary, flowed directly into EPUB. The mainstream standard, are standards on which the world's e-books are built, and into today's international requirements for born accessible publishing.

Features demanded by blind readers in the 1990s are now used by commuters listening to novels, by children learning to read, by elderly readers enlarging text on their tablets, by anyone who has ever asked a device to read aloud. The whole world now reads the way we said books should work. This is the deepest pattern of the universal design in the digital age, repeated over and over.

The curb cut designed for wheelchair users serves every parent with a plan and every traveler with a suitcase. The subtitle created for deaf viewers is switched on in every waiting room of a hospital, sports bar, an airport, and by millions watching films in a second language. The keyboard interface, the voice assistant, predictive text, optical character recognition, each has roots in assistive technology.

Persons with disabilities are not the beneficiaries of the universal design. We are its

research and development department, and we have been all alone, usually unpaid and usually uncredited. A standard alone, however, doesn't end a famine. Law must follow, and here I want to acknowledge India's leadership before this Indian audience. In June 2013, the world adopted the Marrakesh Treaty, which requires copyright exemptions so that accessible format copies of books can be made and shared across borders. It is often called the treaty that ends the book famine. The disability movement fought for it for years against powerful commercial resistance, and it was fitting that in 2014, the very first country in the world to ratify the Marrakesh Treaty was India. The leadership was not an accident of diplomacy. It grew from decades of work by Indian organizations of the blind and the print disabled, by the Daisy Forum of India and its member organizations, who built accessible book production capacity across the country, and then demanded the legal framework to match.

Today, India's online accessible library connects Indian readers with print disabilities to hundreds of thousands of titles linked to global collection through the accessible books consortium. Indian advocates did not wait for universal design to arrive from somewhere else. They built it, and then they changed the international law to protect it.

When I say that persons with disabilities are the developers of universal design, India is one of my proofs. Let me now turn to the field where Ashok Hans was a pioneer and universal design cases to be a matter of convenience and becomes a matter of life and death in disasters. The statistics are brutal in their simplicity. In disaster after disaster, the mortality rate of persons with disabilities is estimated at twice that of the general populations, and sometimes far higher. In the Great East Japan earthquake and tsunami of March 2011, this was documented with terrible clarity. Warnings that cannot be heard by deaf people, evacuation maps that cannot be read by blind people, shelters that cannot be entered by wheelchair users, procedures that panic rather than protect people with psychosocial and intellectual disabilities.

Every inaccessible link in the chain becomes a cause of death. But I carry with me also a story of hope from the same day, and I would like to share it with you because I witnessed the preparation behind it. From 2003, colleagues and I worked with a community in Urakawa, a small town on the Pacific coast of Hokkaido in northern Japan. Urakawa is home to a remarkable community of persons with severe psychosocial disabilities living in the community. Together, not for them but with them, we developed disaster preparedness materials in accessible multimedia formats using the DAISY technology I have described, with synchronized text, audio, and images that each person could study at their own pace as many times as they wished. The community members themselves decided what the materials should say, filmed their own evacuation drills, studied their own escape routes to high grounds, and rehearsed year after year. They were not the object of the preparedness plan. They were its authors. On the 11th of March 2011, the earthquake struck and a tsunami of more than three meters high hit Urakawa.

On that day, the community members with psychosocial disabilities didn't wait to be rescued. More than 60 of them led the stream of evacuees to higher ground. In Urakawa, not one life was lost.

Persons whom society had labeled as the most vulnerable, the least capable, the ones to be managed in an emergency, walked at the front of the evacuation. Preparation designed by the people concerned turned so-called vulnerability into leadership. The lesson entered global policy step by step, and here I must speak of a chapter of the story in which our host tonight played her own part. Rehabilitation International and the Nippon Foundation co-hosted in the city of Sendai, the Asia Pacific meeting on Disability Inclusive Disaster Risk Reduction under the banner 'Changing mindset through knowledge'

I had the honor of serving as project manager of that undertaking and among those who carried it to success was Dr. Asha Hans herself, as a member of Rehabilitation International's Task Force on Disaster Risk Reduction bringing to it the experience of India and of SMRC, the field Ashok Hans had pioneered. The mind set changed. We resolved to bring to the World Conference was expressed in four words - 'From liability to asset'

Persons with disabilities are not a liability to be managed when disaster strikes we are an asset, Agents and designers of the universal design of disaster risk reduction. And when the nations of the world adopted the Sendai framework for disaster risk reduction in March 2015, that change of mindset was written into it. Persons with disabilities and our organizations are explicitly recognized as stakeholders in the design and implementation of disaster risk reduction.

The first global disaster framework to say so. I'm proud of that achievement, and tonight speaking as a guest of SMRC, I'm glad to acknowledge before her own community the part Dr. Hans played in it and Odisha of all places understand this. This state lost some 10,000 lives to the super cyclone of 1999 and then astonished the world in 2013 when cyclone Fani struck and mass evacuation kept the death toll in the tens rather than thousands. Odisha proved that preparedness saves lives. The next frontier - The one SMRC works on through its program on disasters and climate change, the one Ashok Hans campaigned for is to ensure that this life-saving machinery of warning, evacuation, and shelter is universally designed. Audio warning in accessible formats, in sign language and easy to read language, evacuation plans made with persons with disabilities in every village, shelters that everyone can enter and use with dignity.

As climate change makes the Bay of Bengal more dangerous decade by decade. Disability inclusive disaster risk reduction is not a specialized welfare topic. It is the sharpest test of whether our society's system are truly designed for all and it must be read by persons with disabilities because, URAKAWA teaches us that the community that designs its own survival survives.

Now, let me speak of the present moment and of the technologies reshaping all our lives. I have lived through several technological revolutions, the cassette, the CD, the personal computer, the internet, the smartphone. I say to you with full seriousness that technology of the current decade, above all, artificial intelligence carry the

greatest potential for the inclusion of persons with disabilities. That I have seen in more than 50 years of work - A blind person today can point a telephone camera at the world and hear it described. Speech is transcribed into captions in real time in more and more languages. Text is simplified for readers with intellectual disabilities. Voices are synthesized for those who have lost their own. A person who can move only their eye can write, work, and publish. These are not prototype in laboratories. They are in the market today, often at the price of an ordinary telephone.

For the first time in history, the marginal cost of making information accessible is approaching zero and yet, you know, the and as well as I do. At the very same moment, new barriers are being built at unprecedented speed. Essential services, banking, government benefits, railway tickets, examinations, healthcare are moving to digital-only channels that many cannot use. Identity systems demand that you bring a camera, defeating persons who are blind or have facial differences.

Artificial intelligence is trained on data in which we are underrepresented or misrepresented, and then makes decisions about our employment our credit our benefits. And inaccessible paper form, excluded, excluded as one office at a time and inaccessible digital platform excludes us a nation at a time at the speed of software development. This is why the development in Indian law in the last two years deserves the world's attention. And I want to salute the Indian advocates, several of them past speakers in the lecture series whose dedication and advocacy produced them

In November 2024, in the Rajiv Rathuri case- The Supreme Court of India held that accessibility standards under the Rights of Persons with Disabilities Act must be mandatory, not aspirational; a floor below which no service may fall. And in 2025, in the judgments on accessible digital sync, the Supreme Court declared the right to digital access is an intrinsic component of the right to life and liberty. Under article twenty one of the Constitution. Think about what that means. The highest court of the world! The world's largest democracy has said that in the digital age digital access is not a convenience. It is life itself.

Meanwhile, the European Accessibility Act has since 2025 made accessibility a binding condition of the European market for digital products and services. The legal architecture of the digital age is being rebuilt around the accessibility, and it is being rebuilt because persons with disabilities went to court, to parliament and to the standards bodies, and demanded it. But law, like standards, is necessary, and not sufficient. Every one of these instruments will be implemented well or badly, depending on who is in the room when the system are designed. And who is in the room turned out to be a harder question than we sometimes admit. Let me speak honestly about tension inside our own movement. The tension between universal design and assistive technology, optimized for one particular disability. And the related more delicate tensions of representation.

Consider sign language. The legal recognition of national sign languages demanded by the CRPD is a historical victory. It brings public funding, the development and spread of a standard national sign languages and the right of deaf children to receive basic education in sign. I celebrate this without reservation. But look at what can happen in

implementation. In some countries, particularly, I observe in the developing world, the association of those who use the national standard sign language as their first language comes to be treated as the sole representative of all persons with hearing disabilities. Yet, the great majority of persons with hearing disabilities are hard of hearing, or late-deafened people who are not fluent in sign. They cannot take part in the sign-based communications of the very organization deemed to speak for them. And so their first demand, captioning, quietly slips down the national agenda. Nobody intended this outcome. It even contradicts the bilingual philosophy that the world federation of the deaf itself advocates.

The lesson is that the criterion of organizations of persons with disabilities is necessary, but not sufficient. The emerging international trend rightly asks for more. Organizations led by the full diversity of the persons concerned, and accountable to all of them. The present representation in other words must itself be universally designed. A Daisy or EPAB document, combined with a screen reader or playback application, gives a braille reader navigation, storage and search that paper Braille could never offer. And the very same field and same file drives, synthetic speech, large print and refreshable braille display. Reading and writing in braille has not been displaced by universal design, it is being realized within it. The specific and the universal are not enemies if the platform is designed for diversity from the beginning.

Can we achieve the same for sign languages? That is a purpose of a research and development effort my colleagues and I are now pursuing which we call the Sign Sync APOP project. The vision is to bring synchronized sign language into the mainstream, accessible publishing platform so that a single standard publication can present text audio images and sign language video in synchronization, just as daily synchronized text and audio thirty years ago; a deaf child could then read the same textbook as every other child in sign language, and written language, together. Through bilingual literacy a hard of hearing reader could follow the same publication through text and captions, and all of it would be searchable, navigable, and, preserve and preservable. Our method follows the lessons of this whole lecture. First, to confirm that necessity and effectiveness of such a platform with deaf and hard of hearing communities themselves. Second, to define precisely the gap between this vision and today's standards. Third, to build upon the systems that already exist in [EPUB] and W3C synchronized media standards.

Undertaking new development only where it is truly needed, with sign language, users and other persons with hearing disabilities participating as co-developers from the first day. If we succeed, the platform that is ending the book famine for blind readers will bring will begin to end. It's for deaf readers as well. And one more tension between the universal and the specific will be resolved in the only way it ever is: by the leadership of all people concerned. Which brings me to my conclusion. What is our role now? I'll answer with five concrete propositions.

First, persons with disabilities must be present in the engine room of the technology as engineers, designers, product managers, data scientists, and entrepreneurs, not only as consultants and testers. I say especially to the young persons with disabilities

of India, a nation that surprised the world with software talent. The accessibility of the next generation of technology will be decided in rooms you can be in. Study science and technology. Join the companies; found the companies. Your lived experience is not a limitation to be overcome. It is rare and precious engineering knowledge that no non-disabled colleagues can replicate.

Second, our organizations must sit in the standard bodies. The W3C, the ISO, the national standards institutions, the committee drafting rules under the Disability acts, and its successors. Standards are where universal design is actually written. DAISY succeeded because organizations of users governed the standard. The model must be repeated for artificial intelligence, for digital identity, for smart cities, for every platform on which daily life now depends and participation must be resourced. Accessibility of the meetings themselves, funding for DPO experts, capacity building because a seat at the table is meaningless if you cannot afford to sit in it.

Third, procurement is power. Governments and institutions should refuse to buy what all citizens cannot use. If public money speaks with one voice - no accessibility, no contract - the market will learn universal design with remarkable speed.

Fourth, universal design must be born, not bolted on. Every product should be accessible on the day of release; tested before release by persons with disabilities who are paid for this expertise. Retrofitting is the most expensive and least dignified way to achieve accessibility, and in disasters as we have seen, retrofitting arrives too late.

Fifth, and finally leave no one behind. Within our own movement, universal design in the digital age must reach the women with disabilities in a rural village; the person with an intellectual disability, the person with psychosocial disabilities, deaf, blind persons; indigenous persons with disabilities. Those whom even our own advocacy sometimes forgets. And whom SMRC, to its great credit, has always placed at the center, from women with disabilities to disabilities inclusive climate action. The digital divide runs not only between disabled and non-disabled but along the line of gender, poverty, language, and geography. A universal design that stops at the city limit is not universal.

Ladies and gentlemen, let me close where I began, with Ashok Hans, and with the vow taken in the first of these lectures sixteen years ago, tonight. Ashok Hans believed that persons with disabilities must shape their own destinies. In his lifetime, that conviction built an institution in Bhubaneswar. In the years since the same conviction held by thousands of advocates in India and around the world has built treaties, roads, standards, and technologies; the talking book that navigates like a print book; the treaty that lets it cross borders; and the constitutional rights to digital access; the evacuation led by those once written off as helpless.

None of these was a gift. Every one was designed, demanded, and built with persons with disabilities leading. That is the role of persons with disabilities in the development of universal design in the digital age: not recipients, not afterthoughts; but architects. So let us renew Mansur's vow of 2010 in the language of our decade. That we will move from digital darkness to digital light. From exclusion at the speed of software to

inclusion by design, and that we will build with our own hands our own code and our own leadership an information society that is, rights-based, barrier, free and inclusive for all.

Thank you very much.

Comments by Joseph Kwan

I have benefited from this talk, and especially I'm sure that the young people who are here would agree that the problem with us, in terms of sign language, is to get people to come and learn sign language interpretation. When we go out for a meeting we sometimes just don't get people who have sign language skills to interpret for us. So, it's still something that needs to develop. And I think we need to pay a lot more attention than we are doing today.

Q&A

Elaborate on the use of the daisy model for application regarding AI and digital Identity.

Hiroshi Kawamura

Yes, it's a very important and strategic question and we have to investigate the current situation and the gap between our requirements and the reality. So it's broad, and mainly because the inside of the AI system is not open.

So, and the secret has been on the, kind of characteristics of the current AI designing, so it requires a lot of work to identify, query, and the what should be done for the open development of ai. But definitely, it is one of the most critical Issues that we are facing in next few years.

I want to learn from the reality and the collaborators of disability community to identify what we can do, and what we should do!