"E-Participation of Social Groups as Means for Social Inclusion: Persons with Disabilities"

Expert Group Meeting on E-Participation: Empowering People through Information and Communication Technologies (ICTs)

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CONTENTS

Introduction[1]

Persons with disabilities are a very heterogeneous population, cutting across all age, economic, national, ethnic and cultural groups, yet exposed to similar risks of exclusion across the world and among the most vulnerable groups.

While the relationship between disabilities, lack of education, exclusion and unemployment has emerged as a key driver of poverty, the Millennium Development Goals did not mention disability or any objective specifically reflecting the social and economic inclusion of one billion persons living with disabilities around the world.

The beginning of this new millennium, however, brought a greater understanding of the considerable challenges faced by persons with disabilities: traditional policies and programs based upon medical or social welfare models were replaced by a Human Rights approach to disability, best embodied by the Convention on the Rights of Persons with Disabilities (CRPD) now signed by 156 countries.

In this context, information and communication technologies (ICTs) present not only new risks of exclusion, but also unprecedented promises for the inclusion of persons with disabilities in all aspects of society with considerable implications from a Human Rights and social development standpoint. ICTs may be unavailable, inaccessible or out of reach financially for persons with disabilities, creating further risks of exclusion; but they can also support entirely new assistive solutions, social networks and information services to foster the full participation of persons with disabilities in society at an ever decreasing cost.

This paper, developed for the Expert Group Meeting organized by the Division for Social Policy and Development, Department of Economic and Social Affairs of the United Nations in Geneva on July 24-25, 2013 on "E-Participation: Empowering People through Information and Communication Technologies (ICTs)", will review 1/ the scope of the potential for e-participation of persons with disabilities, 2/ the challenges and opportunities for such e-participation, and 3/ policy making to promote the e-participation of persons with disabilities and key success factors in establishing such policies.

In doing so, this paper aims to demonstrate that leveraging ICTs for a greater participation of persons with disabilities in society requires adequate policies and programs to mainstream the accessibility of ICTs for persons with disabilities, laying the foundation for their full e-participation in society.

[1] WHO – World Bank, World Report on Disability, 2011

1. Why the e-participation of persons with disabilities matters

a. Disability and ICTs

While older medical definitions of disability were generally accepted till the end of last century, Article 1 of the CRPD establishes the contemporary notion of disability: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which *in interaction with various barriers* may hinder their full and effective participation in society on an equal basis with others." This definition makes it abundantly clear that the elimination of barriers is a pre-condition to ensuring the full participation of persons with disabilities in society.

Barriers are obvious and relatively easy to understand when dealing with physical accessibility to the built environment or public transportation – for instance if no accessible ramp or elevator is available for a person using a wheel chair. However, *ICT barriers* to access information and knowledge, while more subtle, can present similar insurmountable *barriers* to access information and knowledge for persons with disabilities. Those barriers can be a significant factor of exclusion in the context of knowledge societies: A television program or emergency announcement may not be signed or captioned for a deaf person, a web site or data base may be inaccessible to a screen reader user, a bank ATM may be too high for a person in a wheel chair to operate its keyboard, or a mobile phone may not offer alternative user interfaces for persons with dexterity issues, low vision or cognitive challenges.

A quick review of the global usage of ICTs in all sectors of society shows the considerable risk of exclusion that accessibility barriers may cause:

- 6.5 billion mobile phones in use
- 2.3 billion Internet users
- 1.4 billion TV sets
- 1.2 billion Personal Computers
- 2.2 million ATMs or one per 3,000 persons worldwide

In addition to market dynamics, ICT usage and digital contents and services are promoted by governments in most countries with national broadband plans and the promotion of computer usage in schools and across all sectors of society. Leaving persons with disabilities behind is simply not acceptable from a Human Rights standpoint and is not an option from an economic and social development perspective.

b. Disability demographics

Against this proliferation of ICT devices, applications and services, one billion persons around the world are experiencing multiple barriers with a variety of degrees. And while the *World Report on Disability*

published in 2011 by WHO and the World Bank establishes the number of persons with disabilities at 15 percent of the world population, many countries with poor census methodologies based upon medical rather than functional questions, continue to grossly underestimate their population of persons with disabilities. This, in turn, decreases the sense of urgency among policy makers, industry and civil society to address the need for accessibility and ICT accessibility in particular. Key facts which impacts any consideration to promote the e-participation of persons with disabilities:

- One billion persons live with a disability, 2/3 with a severe disability[2] which translates into ICT accessibility issues
- 80 percent live in the developing world where ICT products and services are more expensive in relation to income per capita
- Over half of persons aged 65+ live with a disability, the fastest growing population segment[3], often living with multiple disabilities, making the use of alternative modes of communications more difficult
- Disability affects all age groups: 13 percent of all public school students K to 12 in the United States live with a disability[4]

Despite the evidence of those global numbers, many countries continue to produce censuses showing disability prevalence of 1 to 2 percent of their national population, a fraction of their likely real numbers.[5] Addressing those discrepancies, the UN Group on Disability Statistics[6] has brought considerable leadership in revising data collection methods. Those need to be implemented in more countries. Governments and the private sector need to obtain proper demographic data in order to implement effective policies and programs.

c. Poverty, isolation, vulnerability, exclusion

Global surveys from a variety of international organizations show that persons with disabilities are among the most vulnerable groups in society due to their isolation, lack of communications, inability to receive a proper education and as a result, inability to make a living. The World Bank estimates that more than 20 percent of the world's poverty is directly linked to disability. Unemployment rates for persons with severe disabilities, such as blind persons, reach over 70 percent in most OECD countries. Yet, for instance, with contemporary ICT based assistive solutions such as screen reader on phones or computers, Braille readers and speech recognition, blind persons can excel in a number of professions as is proven by a large number of successful blind political leaders, entrepreneurs, executives or professionals around the world.

ICTs and mobile technologies in particular can break isolation for persons with disabilities, even in the most remote and underserved rural areas of the world, enhancing personal safety, creating new ways to

[2] WHO –World Bank World Report on Disability - 2011
[3] U.S. Census Bureau
[4] U.S. Department of Education
[5] Measuring Disability Prevalence, D. Mont et al, World Bank, March 2007
[6] UN Washington Group on Disability Statistics

accessing vital information, and supporting basic inclusion in the daily life of family and local social groups.

The potential upside of effectively promoting the e-participation of persons with disabilities is therefore considerable, touching upon a variety of disabilities, life situations, technologies and stakeholders with the potential to transform the dynamics of exclusion for hundreds of millions of persons around the world.

Removing barriers to usage is therefore an utmost priority.

2. Challenges for the e-participation of persons with disabilities

a. Solutions to make ICT devices, applications and services accessible

While beyond the context of this memorandum, examples abound of well-known, proven accessibility solutions for various types of impairments; for instance:

- Visual / Text-to-Speech
- Hearing / Video Relay Service with sign language, captioning
- Speech / Peer-to-peer video for sign language
- Dexterity / Voice recognition for controls and input
- Cognition / Icon interfaces / Text-to-Speech

From an ICT industry, government and civil society perspective, the following services can be made accessible today:

- Web sites
- E-books
- Television
- Computer interfaces
- Mobile and fixed phones
- ATMs and electronic kiosks
- e-government electronic services
- Public displays and messaging
- Digital interfaces for consumer products

b. Lack of focus of governments on ICT accessibility

Despite the availability of those solutions, their promotion by States Parties to the CRPD and actual availability is generally weak around the world. For instance, the latest CRPD ICT Accessibility Progress

Report published by G3ict and Disabled People's International shows the following degree of implementation among States Parties to the CRPD:

Are there any dispositions among Country laws, regulations or government supported programs promoting digital accessibility, the use of ATs or provisions for reasonable accommodations in the following areas?	No	Minimum	Partial	Substantial	Full
Judicial Information and Legal Procedure	74.4%	9.3%	9.3%	4.7%	2.3%
Health Services	70.5%	6.8%	13.6%	9.1%	0.0%
Voting systems	63.0%	10.9%	13.0%	10.9%	2.2%
Emergency Response Services	61.7%	12.8%	12.8%	8.5%	4.3%
Independent Living	56.5%	21.7%	10.9%	10.9%	0.0%
Higher Education	47.8%	26.1%	17.4%	8.7%	0.0%
Reasonable Accommodation at Workplace	46.8%	19.1%	17.0%	17.0%	0.0%
Rehabilitation Services	46.7%	20.0%	15.6%	17.8%	0.0%
Primary and Secondary Education	44.7%	27.7%	23.4%	4.3%	0.0%

Source: G3ict – CRPD ICT Accessibility Progress Report 2012 – Survey of 52 States Parties to the CRPD

Similarly, few governments have policies and programs to promote the accessibility of the information infrastructure including regulated services:

Are there any dispositions among Country laws, regulations and government supported programs promoting digital accessibility, the use of ATs or provisions from reasonable accommodations in the following areas of ICT products and services?	No	Minimum	Partial	Substantial	Full
Public Building Displays	74.4%	14.0%	11.6%	0.0%	0.0%
Copyrights Exceptions	74.4%	7.0%	9.3%	9.3%	0.0%
Wireless Telephony	69.6%	10.9%	17.4%	0.0%	2.2%
ATM or Kiosks	68.9%	22.2%	4.4%	4.4%	0.0%
Fixed line Telephony	62.2%	15.6%	15.6%	6.7%	0.0%
Digital Talking Books	62.2%	15.6%	17.8%	2.2%	2.2%
Transportation Public Address Systems and Services	59.1%	13.6%	20.5%	6.8%	0.0%
Web Sites	38.3%	38.3%	19.1%	4.3%	0.0%
Television	34.1%	38.6%	22.7%	4.5%	0.0%

Source: G3ict – CRPD ICT Accessibility Progress Report 2012 – Survey of 52 States Parties to the CRPD

In fact, the same report shows that only 36 percent of States Parties to the CRPD have a definition of accessibility which includes ICTs or electronic media in the country laws or regulations compliant with the definition of accessibility in Article 9 of the CRPD.

c. Market considerations and role of Civil Society

The role of various stakeholders in promoting ICT accessibility is complex. For persons with disabilities to experience accessible ICTs, the concomitant availability and affordability of the following elements must occur:

- An accessible information infrastructure (web, phones, TV, ATMs, voting machines etc.) – mostly regulated
- Accessible and free contents and services provided by private and public entities (financial, e-government, e-commerce, e-health etc.) – mostly unregulated excepted for e-government in still a minority of countries
- The availability of an assistive technology and ICT accessibility eco-system providing adequate Assistive Technologies support in the three main channels of education, rehabilitation and community centers and employment programs

At country level, achieving the above outcomes implies that various stakeholders be involved in the design and support of e-participation strategies including government agencies, Internet and mobile service providers, broadcasters, education institutions, publishers, web site operators, private sector entities such as banks and transportation companies, and most importantly, organizations of persons with disabilities representing the whole spectrum of persons living with disabilities.

d. Affordability

Affordability is often mentioned as a critical barrier for persons with disabilities to accessing ICTs. Such observation encompasses a variety of situations:

- Persons with disabilities are more likely to live in poverty than other segments of the population. As a result, the cost of ICTs and associated services may be out of reach.
- For persons with disabilities who require assistive technologies, the cost of personalized custom solutions, such as hearing aids, alternative and augmentative communications devices, and any other sophisticated assistive device may be out of reach. And while the cost of products may decline over time, the cost of support services will always remain a high cost component and, in many countries, simply unavailable for the time being due to lack of expertise.
- However, as Universal Design progresses around the world, and mobile technology user interfaces gain in popularity, basic accessibility features are increasingly embedded in commodity products. Features such as text- to-speech, peer to peer video for sign language or speech recognition, at least for simple processes such as commands, which were out of reach financially for most users a few years ago, are basically free today. It is therefore important that national policies be implemented to leverage as much as possible those market forces to benefit

persons with disabilities. This includes making sure for instance that mobile service providers offer accessible handsets and services, and funding through public procurement text-to-speech development in minority languages for which no such software is available.

e. Interactions between affordability, relevance and accessibility: the example of broadband services

While ICTs are increasingly affordable, the interaction between their price and perceived value compounded by a lack of awareness of their benefits, low levels of education and technology literacy creates complex barriers. A relevant example is that of broadband services which serve as the main conduit for e-Health, e-Education, e-Commerce and e-Government services. While those contents and services may be very useful to persons with disabilities, unfortunately, a large proportion of persons with disabilities do not in fact adopt broadband Internet services.

In 2010, the United States Federal Communications Commission (FCC) surveyed the population of non-adopters of broadband[7]. Key results show that:

- One third of the U.S. population has not adopted broadband at home although it is available in most cases
- 39 percent of those non adopters have some type of disability, more than twice the proportion of =U.S. citizens living with a disability: 15 percent
- Only 35 percent of senior citizens (those over the age of 65) have broadband-at-home

Similar gaps are observed in other countries: UK, close to 50 percent of non-adopters of broadband live with a disability. In South Korea, adoption gaps are also observed.

Analyzing those results remains challenging but anecdotal input from organizations of persons with disabilities points to the following interrelated causes:

- Most often, services are not affordable, due to a low economic status
- Service providers marketing, sales, services, equipment and programs are not accessible and cannot be read or interacted with
- Lack of awareness or what's available on-line and perceived relevance and value to their lives

Perceived affordability may, therefore, be linked to a lack of perceived value of broadband services and awareness of their potential benefits, which is also likely a result of limited inaccessible marketing and services. The same is certainly true for elderly persons who are far behind in adopting broadband in comparison to the rest of the population.

There are, however, examples of successful approaches by industry and service providers to resolving those issues. For instance, similar gaps in adoption have equally affected the adoption of mobile telephony by seniors and persons with disabilities. Several large scale success stories show that the

[7] FCC Report by John Horrigan, February 2010

efforts of mobile manufacturers and service providers who designed and marketed their products and services following universal design principles enjoyed excellent market response. The latest report by NTT DoCoMo[8] on the sales of its universally designed Raku-Raku product line shows its popularity among seniors and persons with disabilities: more than 20 million new Raku-Raku subscribers have been sold in Japan since the inception of the product line. Meanwhile, Japan's Ministry of Information shows that the penetration of mobile services among the 70+ population dramatically increased. Similarly, AT&T in the U.S. and Orange in Europe have experienced significant success by adopting Universal Design principles for their products and services with significantly increased usage among seniors and persons with disabilities.

f. Universal Design and the role of assistive technologies

Promoting Universal Design is thus a critical success factor for the long term e-participation of persons with disabilities. As a reference, Article 2 of the CRPD provides a sound direction for policy makers and industry: "*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."

The same article, however, also specify that "*Universal design* shall not exclude assistive devices for particular groups of persons with disabilities where this is needed", a recognition that not all accessibility features can be embedded in the design of all products and of the need for assistive technologies customized to individual situations.

Among Assistive Technologies (ATs), there are many variations between highly sophisticated standalone condition-specific solutions and simple alternative user interfaces to facilitate the use of commodity ICT products such as phones or PCs. While the first category can be extraordinarily expensive, simple AT tools for mass market commodity ICT products are becoming increasingly affordable. In addition, certain accessibility features which did belong to assistive technologies in the past are now embedded in universally designed products, mobile devices in particular: embedded accessibility helps all mobile users in situational disabilities when unable to see, touch or listen to their devices.

However, providing individualized AT solutions to persons with disabilities requires significant labor costs for assessing, customizing, delivering, training and supporting those. The cost of AT services often represents a multiple of the cost of the technology itself. Making AT products available to persons with disabilities requires much manpower and know-how: the investment required is first and foremost in developing expertise and human resources for education, rehabilitation and community centers and employer's support.

According to the CRPD ICT Accessibility Progress Report, AT availability is very limited in most developing nations or nations with a low HDI ranking. Even when they are free, such as open source screen readers, ATs or embedded accessibility features in commodity products oftentimes remain unused due to a lack

[8] M-Enabling Summit 2013. www.m-enabling.com

of awareness and training of teachers or rehab professionals. Policy makers should not be led to believe that technology and cheap AT products alone will suffice to have ATs used by persons with disabilities. Well-thought out policies, programs and investments in training and human resources in the various channels of the AT support eco-system are required.

3. Policy making to enhance the e-participation of persons with disabilities for social inclusion

a. Priority areas

In order to increase e-participation of persons with disabilities, governments need to develop coordinated policy efforts to mainstream the accessibility of ICTs and ICT-based contents and services. Such policies should include:

- Incorporate in their disability laws and regulations and definition of accessibility which includes ICTs
- Developing and implementing policies to make the information infrastructure accessible notably mobile phones and services, television and e-government web sites
- Promoting the production of accessible contents and services including by leveraging public procurement policies
- Promoting Assistive Technologies and building a services and support AT eco-system in education, rehabilitation and community centers and for employer's support
- Supporting the development by civil society and government agencies of contents and services with a direct usefulness for persons with disabilities. While most persons with disabilities typically use the very same sources of information than anyone else in their daily lives, dedicated web sites, social networks and information sources focused on specific areas of disability can be very useful to break isolation, facilitate peer to peer support, provide useful disability related information and promote Disability Rights and advocacy.
- Finally, supporting technology literacy training programs organized by civil society

b. Success factors for e-participation policies and programs for persons with disabilities

While analyzing via regression analysis success factors which may explain positive outcomes, the following elements were present in countries where the best e-participation outcomes for persons with disabilities occurs:

- Participation of persons with disabilities in policy making and monitoring
- Awareness raising campaigns and capacity building
- Participation of the country in International Standards Development Organizations

- Financial support of organizations of persons with disabilities capacity building and participation in policy making

Without those processes in place, conversely, positive outcomes seem limited or non-existent.

c. The road ahead: UN agencies support of e-participation policies and programs for persons with disabilities

Across the UN family, different agencies address various aspects of an e-inclusive agenda for persons with disabilities in their specific areas of competency. Examples are:

- ITU's accessibility standardization and development activities
- WIPO work on accessible publishing: publishing standards and access to published materials, and recent completion of the international treaty on copyrights limitations
- WHO and World Bank's World Report on Disability, chapter six of which discusses information accessibility and makes recommendations in line with the CRPD
- World Bank training for staff on disability policy, and inclusive policies in country work
- UNESCAP disability and accessibility regional seminarsUNDESA Secretariat for the CRPD, Inter-Agency Support group and Expert Group meetings
- UNDP disability focus of its development agenda
- UNESCO work on accessibility in education and infostructures (libraries, museums and other)
- UNICEF task force on assistive technologies
- OHCHR work with the Committee on the Rights of Persons with disabilities in steering country reports and reviews
- ILO programmes promoting reasonable accommodation in the work place
- UNPAN activities in e-government and public procurement

At country level, however, a minority of countries have engaged in policies and programs promoting e-participation for persons with disabilities in a holistic way. This results in isolated initiatives with few opportunities allowing for a coordinated and comprehensive approach among multiple stakeholders.

Since 2012, the ITU, WHO, WIPO, UNESCO, ILO, UNDP and G3ict have held informal meetings with country donors and private industry to discuss how to best coordinate activities at country level in order to best leverage existing programs and local resources. This agenda, called "UNITE (United Nations Information Technology Engagement) for Persons with Disabilities" seeks to:

- In coordination with UN Country Teams, use its convening influence to help stage multi-stakeholders processes to develop and monitor policies and programs including government agencies, disabled persons organizations and the private sector
- Help raise awareness of the potential upside of e-participation of persons with disabilities
- Offer benchmarking on the progress of ICT accessibility among States Parties to the CRPD

- Support countries in developing effective policies by sharing good practices and proven solutions
- Offer model policies as a foundation to develop local policies and programs

As of July 2013, the following steps were completed:

- Identification of stages of readiness in developing e-participation policies and programs among States Parties to the CRPD
- Development of five model policies with funding from ITU, UNESCO and G3ict for:
    - Web accessibility
    - Electronic communications including mobile telephony and data services
    - Television
    - Public procurement
    - Accessible ICTs for Education
- Review of policies by groups of leading international experts
- Testing of three draft in Colombia with MinTIC and national organizations of persons with disabilities (April 2013)
- Secured financial commitments from the private sector to fund multi-stakeholders policy review meetings in six countries between September 2013 and June 2014
- Organized further meetings at the Conference of States Parties (COSP6) with the objective to enroll additional participants (July 2013)

The UNITE program is run by G3ict and its meetings open to all interested organizations from the UN System, government agencies, organizations of persons with disabilities and other civil society participants including the private sector. Its strategy is to engage in a multi-stakeholders approach to developing e-participation for persons with disabilities at local, national and international levels.

G3ict paper for UNDESA Expert Group Meeting, July 24-25, 2013, Geneva
"E-Participation of Social Groups as Means for Social Inclusion: Persons with Disabilities"
Tables at page 7

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Health Services	70.50%	6.80%	13.60%	9.10%	0.00%
Voting systems	63.00%	10.90%	13.00%	10.90%	2.20%
Emergency Response Services	61.70%	12.80%	12.80%	8.50%	4.30%
Independent Living	56.50%	21.70%	10.90%	10.90%	0.00%
Higher Education	47.80%	26.10%	17.40%	8.70%	0.00%
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Source: G3ict – CRPD ICT Accessibility Progress Report 2012 – Survey of 52 States Parties to the CRPD

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Wireless Telephony	69.60%	10.90%	17.40%	0.00%	2.20%
ATM or Kiosks	68.90%	22.20%	4.40%	4.40%	0.00%
Fixed line Telephony	62.20%	15.60%	15.60%	6.70%	0.00%
Digital Talking Books	62.20%	15.60%	17.80%	2.20%	2.20%
Transportation Public Address Systems and Services	59.10%	13.60%	20.50%	6.80%	0.00%

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