How can digital information contribute to achieving the SDGs for persons with disabilities?

Side event of COSP9, 15 June, 8-9:30am, UNHQ CR 11

Background paper

1. Introduction

Digitization — the mass adoption of connected digital technologies and applications by society — can play a major role in leaving no one behind. People with cell phones in remote villages with no telephone wires can now call each other and others beyond their villages, respond to SMS surveys and get alerts from services they signed up for. For people with disabilities, digital technologies can improve their participation. People with poor or no vision can find each other in public spaces with the help of cell phones and they can access information online with text to speech applications. People with hearing difficulties can send text messages, like SMS or Messenger, to contact each other. Persons using wheelchairs can find out online which transport stations are accessible. But there is another opportunity of digitization for disability and development which remains untapped: the capacity to generate evidence to empower people with disabilities, and to implement, monitor and evaluate progress towards the SDGs for persons with disabilities. Indeed, the emergence of new forms of gathering information, particularly large scale digital information - like social media, crowdsourced information, apps - has the potential to provide new insights and a better understanding of the situation of persons with disabilities.

In this paper, we seek to answer the following questions:

1. What sorts of digital information exist about persons with disabilities and their environments?
2. In what ways can this information be used to understand the situation, characteristics, needs, expectations and aspirations of persons with disabilities?
3. In what ways can this information be used to better understand the barriers and obstacles experienced by persons with disabilities, as well as options and opportunities, for improvements and transformations necessary to implement the 2030 Agenda and achieve the SDGs for persons with disabilities?
4. What are some key, priority areas of the SDGs in which evidence for policy making is lacking and what kind of digital innovations could be used to close those gaps?

2. Large scale digital information: opportunities for empowering persons with disabilities

The table below summarizes different types of digital information, with specific examples, and discusses possible opportunities for using this information to implement, monitor and evaluate the SDGs for persons with disabilities. SDGs 3, 4, 8, 10 and 11 are those for which digital information seems to be more readily available.

Table 1. Illustrative examples of digital information which can contribute to implement the SDGs

Examples of digital information	How can it be used to empower persons with disabilities?	Relevant for:
Crowdsourced information on the locations of accessible health facilities	To produce a worldwide map of accessibility of medical facilities, share information with persons with disabilities and administrators of health facilities	SDG 3 (health and well-being)
Information gathered by health workers using apps	To capture the differences between adults, youth and children with disabilities and those without disabilities in the areas of health, education, social life, livelihood and empowerment	
Information in real-time from sensors in prosthetics	To better understand how persons experience the use of these prosthetics, which could in turn be used to improve the health and well-being of these persons	
Crowdsourced information on the locations of accessible schools	To produce a worldwide map of school accessibility, share information with persons with disabilities and schools administrators	SDG 4 (education)
Information on how persons with disabilities interact with digital e-books online	To understand the learning habits of persons with print disabilities could help remove barriers that prevent persons with disabilities from reading and learning, foster inclusive educational practices	
Information gathered by health workers using apps	To capture the differences between adults, youth and children with disabilities and those without disabilities in the areas of education	
Number of downloads/views of e-books	When mapped by location, it may assist in identifying locations where persons with disabilities are not accessing eBooks	
SMS free disability pools (e.g. U-report)	To pool information on the barriers experienced by children and persons with disabilities in schools	
Crowdsourced information on the locations of accessible work places	To produce a worldwide map of accessibility of work places, share information with persons with disabilities and with public at large for increased awareness	SDG 8 (employment)
Information gathered by health workers using apps	To capture the differences between adults, youth and children with disabilities and those without disabilities in the areas of employment	

Examples of digital information	How can it be used to empower persons with disabilities?	Relevant for:
Apps where people worldwide can report of incidents of discrimination and negative attitudes against persons with disabilities	To map the locations of these incidents to identify places where awareness campaigns are needed	SDG 10 (equality)
Computational text analysis of reports and news online on incidents of discrimination and negative attitudes against persons with disabilities		
SMS free disability pools (e.g. U-report)	To pool information on the barriers experienced by persons with disabilities	SDG 10 (equality)
Information gathered by health workers using apps	To capture the differences between adults, youth and children with disabilities and those without disabilities in the areas of health, education, social life, livelihood and empowerment	
Sentiment analysis/reporting of experiences of persons with disabilities in social media	To gather information on the challenges faced by persons with disabilities in their daily lives and their opinions on how to achieve better inclusion of persons with disabilities	
Number of downloads of applications commonly used by persons with disabilities	When mapped by location, it may assist in identifying locations where persons with disabilities are not accessing assistive applications	
Business records of sales of assistive devices	When mapped by location, it may assist in identifying locations where persons with disabilities are not accessing assistive devices	
Crowdsourced information on the locations of accessible subway and train stations, accessible public and green spaces	To produce a worldwide map of accessibility of transport and public places, share information with persons with disabilities and administrators of health facilities	SDG 11 (inclusive cities and human settlements)

3. Case studies

Below, we discuss examples of digital information which may contribute to the implementation, monitoring and evaluation of the SDGs.

3.A. Crowdsourcing applications on accessibility

Crowdsourced information, i.e. information obtained through solicited contribution from numerous, anonymous volunteers toward some coordinated aim, can offers new insights into economic, attitudinal, or environmental barriers experienced by persons with disabilities. The actual opinions of people who face these barriers to participation can also provide a deeper understanding about how these barriers manifest in everyday life for persons with disabilities. This use of crowdsourced data could help identify places, areas, transportation, and applications accessible or inaccessible to persons with disabilities. The crowdsourced data can also aid in analysis of compliance with accessibility standards, which can be used to promote more inclusive economies, cities, and societies. This is perhaps the digital information which is easier and ready to be tapped to assist in the implementation of the SDGs for persons with disabilities, especially goal 4 (accessible school environments), 8 (accessible work places) and 11 (accessible cities, transport and public spaces), as many crowdsourced applications already exist to gather information on accessible physical environments.[1]

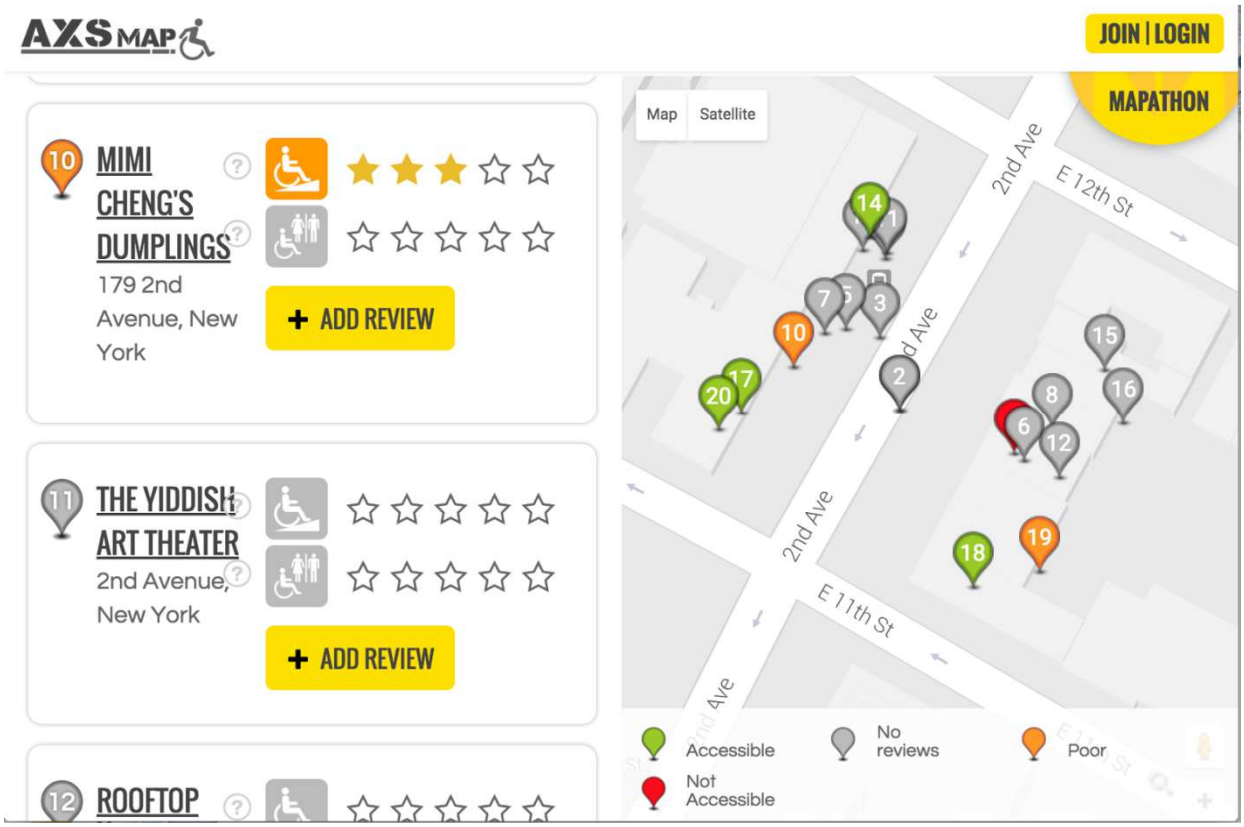
Case in focus: AXS Map and AXS Schools

One such example is AXS Map. AXS Map is a crowdsourcing tool, available on the web and mobile phones, for rating and reviewing places based on their accessibility for persons with disabilities (www.axsmap.com). The first iteration of AXS Map was complete in 2009. AXS Map asks about disability friendly attributes of each place, such as if a venue has a wheelchair entrance, an accessible bathroom, quality of lighting, if it's spacious, if it's seeing eye dog friendly or quiet. These features can have an impact on the accessibility for persons with diverse impairments, such as blindness, low vision, hearing impairments, and mobility impairments, like those using a wheelchair. The AXS Map website and application is available all over the world. It is powered by the Google Places API,[2] meaning that anyplace on Google Maps is on AXS Map. More than 100,000 places worldwide have already been reviewed in AXS Map. AXS Map has grown in less than one year acquiring over 18,000 registered users and over 100,000 crowdsourced reviews in over 170 cities across the world. Information compiled through this app could be used to assist in the implementation of: (i) SDG target 11.7 which calls for accessible green and public spaces for persons with disabilities; and (ii) Article 9 of CRPD which calls for States Parties to ensure to persons with disabilities access, on an equal basis to others, to the physical environment.

[1] For accessible places open to the public see e.g. www.axsmap.com, www.wheelmap.org, www.jaccede.com, www.ableroad.com, http://ha.cnt.gr/index.php and www.rollout.gr. For accessible accommodation, see for instance www.accomable.com.

[2] https://developers.google.com/places/. API stands for Application Programming Interface.

Fig 1. Accessible spots in a few blocks in New York, as reported by the "crowd"



Source: www.axsmap.com

A new initiative, called AXS Schools (www.axsschools.com), is currently at project stage and seeking funding for implementation. The implementation of this application will make it possible for anyone in the world to rate schools accessibility for persons with disabilities on the web and through smart phones. In areas where only SMS is available, data may be complemented through SMS polls. Questions may be asked on "whether your school is accessible" and more specifically, "are children with disabilities able to partake in classes in the same way as everyone else". The SDG target 4.a calls for building and upgrading education facilities that are disability sensitive and provide inclusive and effective learning environments for all. The aim of AXS Schools is to gather that knowledge in a common repository so that it can be used to inform policies and programs to implement SDG target 4.a and the provisions of CRPD on education.

3.B. Online trace data on reading preferences

Online trace data are information passively left behind by humans when using digital devices and services. These unobtrusive traces, which do not interfere with the natural flow of behaviour, can provide knowledge about how persons use online platforms. These data are a potential new source of information on the situations of persons with disabilities. Online trace data from devices and services dedicated to persons with disabilities can provide insights on how persons with disabilities are acting on particular digital platforms, and what their preferences are. As illustrated in the case

study below, online trace data from online libraries can give insights on the most accessible reading formats.

Case in focus: Benetech's Bookshare

Benetech's Bookshare,[3] the world's largest accessible online library for people with print disabilities such as blindness, low vision, and dyslexia, is a global literacy enterprise that seeks to ensure reading experiences for all people, regardless of ability. Before Bookshare was created, most persons with print disabilities read books via audio tapes or braille forms, and only a small percentage of print materials were made available in these accessible formats. A large gap in access to timely and accommodating books persists for persons with disabilities. As converting and delivering books that accommodate persons with print disabilities was expensive and time consuming, persons with disabilities were excluded or faced barriers to participation in education, employment, earnings, and social inclusion. With the creation of disability-accommodating e-libraries like Bookshare, these barriers are slowly being broken.

Operating under the U.S. copyright exemption, the Chafee Amendment, Bookshare is allowed to make books available to people with print disabilities without permission from publishers. The 400,000 digital publications available on the site come in a few formats to accommodate different disabilities text-to-speech, braille, and large print options. These publications are available through schools, public libraries, governments, and disability providers and reach more than 360,000 people in around 50 countries. Bookshare is working towards offering the books in local languages.[4]

A new initiative within Bookshare seeks to expand understanding of reader learning habits by allowing persons with print disabilities to read within the web browser instead of using outside tools or software.[5] This will allow Bookshare to collect and analyze online trace data about reader interactions with the e-books. They hope the information gathered will help increase understanding of which approaches to learning objectives work best for persons with print disabilities—this information could range from the best and most used font for persons with dyslexia in learning certain subjects or why students with print disabilities abandon certain e-books over others. Understanding the learning habits of persons with print disabilities could help remove barriers that prevent persons with disabilities from reading and learning, foster inclusive educational practices and contribute to implement SDG 4.

3.C. Smart sensors in prosthetics

Physical sensors are wearable sensors that generate digital information. Some of the benefits of wearable sensor data from prosthetics include continuous monitoring, which causes the temporal resolution of data to be more frequent than what is currently attainable through sporadic doctors' visits over time. Additionally, complementary technologies such as mobile or online apps could help to monitor this information.

[3] https://www.bookshare.org/

[4] http://www.asia-pacific.undp.org/content/dam/rbap/docs/Research%20%26%20Publications/hiv_aids/rbap-hhd-2015-our-right-to-knowledge.pdf

[5] https://hbr.org/2013/03/big-data-means-more-than-big-p

Case in focus: Össur Prosthetics Sensors

Prosthetics sensors, a relatively new technological advancement in the world of prosthetics, has brought new possibilities in care and health. By systematically transmitting data about the patient's overall health, and early signs of ulcerations or abrasions from wearing the device, and the condition of the device, including wear and tear and usage patterns, the information gathered could be used not only to enhance functioning and mobility of the wearer, but also to inform the health community more widely about the experience of prosthetics.

One particular prosthetic, a machine learning prosthetic produced by Össur, is revolutionizing the prosthetics wearable sensor world. The Icelandic company is at the forefront of this smart prosthetics revolution, and has created the world's first microprocessor joint system that helps its users replicate and improve natural joint function. The first production of these prostheses are of the knee. The sensors allow for an intuitive setup of the knee, with both automatic and manual parameter adjustment, sensor calibration and information on battery status, step count, firmware, among others. Sensors on the artificial knee joint measure the angle and load it bears 1,000 times a second, which modifies the stiffness of the joint constantly while in use, which allow for the smooth swing of the leg on different terrains and at different speeds. This information bout knee function could help medical practitioners to better understand how persons experience the use of these prosthetics, which could in turn be used to improve the health and well-being of these persons and contribute to SDG 3.

3.E. SMS services for real time information

The adoption of mobile phones has occurred at perhaps the fastest rate and to the deepest level of any consumer-level technology in history. In Africa, cell phone ownership grew from 2 million phones in 1998 to 650 million phones in 2011. Tapping into this technology, SMS services can be used for real-time reporting on the needs, experience and perspectives of persons with disabilities.

Case study: Monitoring disability issues in U-Report

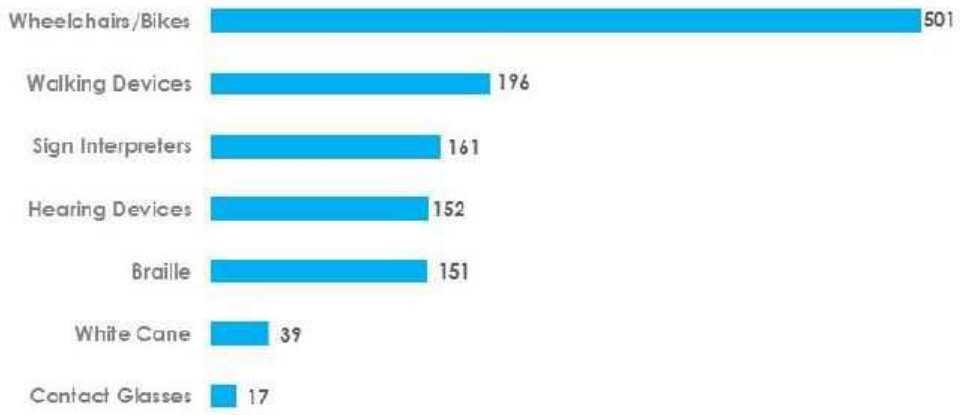
One such service is U-report. Anyone can join voluntarily via sms and report information for free. Those who join receive questions, by SMS, on health, education, water, sanitation, etc. The replies received can be disaggregated by age, gender and district. "U-reporters" have grown from 198,000 in two countries in 2013 to over 2 million in 19 countries in 2016.

In Uganda, U-report has been used to gather information on access to services and use of assistive devices for children with disabilities. U-reporters indicated that poverty and lack of resources are the biggest perceived barriers preventing access.

Fig 2. Example of U-report SMS pool

Question One: Dear U-Reporter! U told us that u know of assistive technology used by children with disabilities in ur community? Can u give us an example of such technology?

Analysis: Results from this poll indicate that wheelchairs are the most common devices used by children living with disabilities in their communities, followed by walking devices such as wooden sticks, crutches among others.



Source: Unicef.

3.D. Apps for health care workers

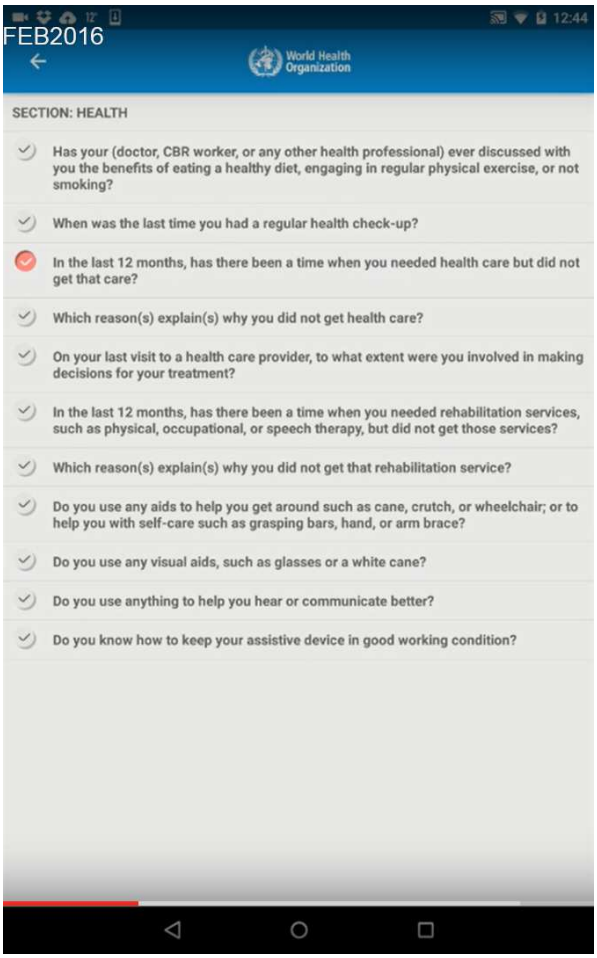
Health care workers often gather large quantities of information about their patients. Many of them, such as rehabilitation specialists, compile health and socio-economic information on persons with disabilities. As internet and mobile devices are becoming increasingly available, these data are often collected through apps and stored in a digital platform. These data can be tapped to better understand the socio-economic conditions of persons with disabilities and the impact of the heath care provided. This understanding would assist the implementation of not only SDG 3 (health) but also SDG 1 (poverty), SDG 4 (education) and SDG 8 (employment).

Case study: WHO Community-based Rehabilitation app

WHO and the international Disability and Development Consortium (IDDC) have worked together to develop indicators to capture the difference Community-based Rehabilitation (CBR) makes in the lives of people with disabilities. The indicators are designed to capture the differences between adults, youth and children with disabilities and those without disabilities in the areas of health, education, social life, livelihood and empowerment. This comparability provides valuable information to CBR managers, policy-makers and donors, which can be used to guide decision making, support advocacy and improve accountability.

Health care workers working on CBR can gather the data on these indicators easily and efficiently with an Android application (app), the WHO CBR App.[6] The WHO CBR App includes over 50 questions but can be customized to include additional questions for supplementary CBR indicators. The information is entered anonymously and temporarily stored until is submitted to the user or send to a WHO platform. The app has been tested in three countries already, Egypt, Guatemala, and Vietnam.

Fig 3. A page of the WHO Community-based Rehabilitation app



4. Challenges and ethical implications

Challenges and ethical implications of the use of digital information for development have already been discussed elsewhere. [7] Two common concerns include violations of privacy and the inaccessibility of the digital information, which can be held by corporations but not be available to the society at large. The reliability of the digital information may also vary. In particular, the information provided may not always be accurate. For instance, cases cited by users of Airbnb in New York City, in which apartments designated as "wheelchair accessible" are in actuality apartments with staircases or steps.[8] There are also concerns on socio-economic biases, as the poorest often to not have access to the devices and the platforms that generate the digital information. But it has also been argued that the digital society has permitted the voice of the most marginalized to be heard. Examples include people living in remote villages that can make their voice heard through SMS surveys, or online platforms for persons with disabilities to network and share their opinions. It must be recognized however that computer/online based data collection could leave out certain persons with disabilities who cannot participate due to a physical or virtual barriers to computer/smartphone use. In addition, certain technologies, like sensors, are expensive and are only available to those who can afford them. For these reasons, use of digital information to gain insights into the situation, experience, needs and perspectives of people will have to be handled and interpreted with care. Given the ethical issues associated with the use of digital innovations to understand disability, it is important to consider how biases or privacy breaches may arise before data collection and analysis.

[6] The App can be downloaded at http://www.who.int/disabilities/cbr/cbr_indicators_manual/en/
[7] http://www.unglobalpulse.org/sites/default/files/BigDataforDevelopment-UNGlobalPulseMay2012.pdf
[8] Golding, B. (2014) " Airbnb Spots Dupe the Disabled on Accessibility: Advocates." New York Post http://nypost.com/2014/11/03/airbnb-spots-dupe-the-disabled-on-accessibility-advocates/

5. The way forward

As the case studies of this paper illustrate, digital information can contribute to the monitoring and evaluation as well as the implementation of the SDGs. But to make it happen, resources must be put in place to make use of this information and to build the capacity in countries to use this information in the national implementation of the SDGs. In addition, disability must be included in discussions on the data revolution initiative and partnerships must be encouraged on innovative ways to use digital information to enhance the inclusion of persons with disabilities.

To fully explore the potential of digital information for persons with disabilities, a roadmap should be traced to gather commitment from the international community. This roadmap could focus on the following steps:

1. Conduct and publish research studies on promising applications of using digital information to implement, monitor and evaluate the SDGs; identify which ones have highest potential to be applied in countries and by relevant organizations;
2. Work with national entities and international organizations to implement the use of the applications selected in 1;
3. Conduct workshops and training activities in countries with the aim at building their capacity to use and analyse the selected applications for the implementation, monitoring and evaluation of the SDGs.

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