



Digital societies: implications for disability inclusive development

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**Data-Pop Alliance** is a global coalition on Big Data and development created by the Harvard Humanitarian Initiative, MIT Media Lab, and **Overseas Development Institute that brings** together researchers, experts, practitioners, and activists to promote a people-centered Big Data revolution through collaborative research, capacity building, and community engagement. As of February 2016, Flowminder Foundation has joined Data-Pop Alliance as its fourth Core Member.



DATA

on · Promoting

A three-step plan for using data right in an age of government overreach For the first few decades of its existence, the Wai tional Security Agreeme was quice department with use primary lob lamping an eye on the Soviet Union. Its enenty was well defined and monitation: Its principal tools were plone tags, any planest and biden microphones. After the attacks of September 11, all of that changed. The work differ energy beams a different network of indvidial terretion. Anyone in the world could be a legititic terretion. Then some the world could be a legiti-

By Alex "Sandy" Pentland

new digital communication channels proliferated. The exp

was just beginning. The NAA's slid tools apparently no longer seemed sufficient. In response, the agency adopted a new strategy: collect veryphing. As former NSA director Earth Alexander once put it, when you are looking for a needle in a hapstack, you need the whole hapstack. The NSA began collecting bulk phone call rec-

#### DATA-POP ALLIANCE'S APPROACH AND RESEARCH QUESTIONS

We consider Big Data not just as large datasets, but as a sociotechnological phenomenon driven by an **ecosystem** of:

- 'crumbs' about human behaviors and beliefs;
- capacities of digital devices, ever more powerful computing power and analytics tools for collecting, aggregating, and analyzing data; and
- vibrant communities of actors involved in generating, governing, and using data.

### DATA-POP ALLIANCE'S APPROACH AND RESEARCH QUESTIONS

# **Scoping exercise:**

- looking at the feedback loop between existing data types and the rights/needs of the communities that are creating that data;
- studying how the Big Data ecosystem can help inform a more people-centered 'data revolution' and promote the SDGs



## DATA-POP ALLIANCE'S APPROACH AND RESEARCH QUESTIONS

# **Possible research questions:**

- What sorts of data exist about persons with disabilities and their environments?
- In what ways can that data be used (and how has it been used so far) to understand the situation of persons with disabilities?
- What are some key areas in which data is lacking, and what kind of interventions might close those gaps?
- How can Big Data help us better understand disability and empower persons with disabilities?

# APPROACHES FOR GATHERING AND ANALYZING DISABILITY IN DIGITAL SOCIETIES

# Useful approaches and tools:

- Crowd-sourcing
- Geographic information system
- Text mining / sentiment analysis
- Network analysis

# How can we explore and strengthen the feedback loop between existing data types and the needs of the communities that are creating the data?

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督 Gabriel Pestre / m March 1, 2016 / Se Blog	
This is the first in a series of blog posts on our ongoing work exploring the applications and implications of Big Data and disability. This serves as an initial scoping of how Big Data can contribute to various research areas related to disability. This will form the basis of a White Paper (forthcoming) exploring the ability of the Big Data ecosystem to monitor and understand the state of research about persons with disabilities and their environments.	
A large number of persons with disabilities are faced with barriers to actively participating in society: they are denied their rights to "be included in the general school system, to be employed, to live independently in the community, to move freely, to vote, to participate in sport and cultural activities, to enjoy social protection, to access justice, to choose medical treatment and to enter freely into legal commitments such as buying and selling property," according to the UN Human Rights Office of the High Commissioner. These people are commonly labeled "invisible" and continually are sidelined in communities.	
In the past ten years, there has been a revolutionary and global shift in the approach by UN member states to ensure that persons with disabilities receive and enjoy the same rights, equality, and dignity as everyone else. The United Nations Convention on the Rights of Persons with Disabilities of 2008 called for the promotion, protection, and enjoyments of all human rights and freedoms by all persons with disabilities, and respect for their	

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#### [ crowd sourcing + geographic information systems ]

- What are the locations of schools/jobs that accommodate the needs of people with disabilities?
- Do persons with disabilities live further, on average, than the general population from schools/jobs that meet their needs?
- How does the metric above vary between cities/countries, and does that correlate with the type of policy those places have regarding schools?

### [crowdsourcing]

- How do turnout rates of persons with disabilities compare to those of the general population?
- In surveys, does expressed desire to vote or be engaged in politics/governance align with observed turnout rates?

#### [ text mining ]

- How is disability discussed in political speeches, discourse, the press, etc?
- Can analysis of media articles, court cases, etc, reveal patterns of discrimination?
- How do these biases evolve over time and place, with respect to laws and policies?

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## [ network analysis + text mining ]

- Can use of hashtags on social media how people interact with and within communities of persons with disabilities?
- What can we learn from people's behaviors and beliefs that can complement existing data sources?

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#### [geographic information systems]

 How can new data sources (GPS on smartphones, data from cellphone towers, fleet tracking on taxis and rideshares, etc.) be used to study or optimize how persons with disabilities can navigate cities and travel.

#### [crowdsourcing]

- Is the digital / sharing economy (Uber, TaskRabbit, etc.) breaking or creating barriers to participation for persons with disabilities?
- How can we compare the accuracy and coverage of crowdsourced data (for example, can we observe differences between user-reported data and business-reported data)?

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#### IMPLICATIONS OF INNOVATIVE DATA SOURCES FOR DISABILITY

- Who owns or controls the data?
- How can/should data be shared safely?
- What are the privacy rights of the individuals and groups involved?
- How does experimentation work in a real world context?
- Who is missing from the data?



- UN DESA/Division for Social Policy and Development/Secretariat for the Convention on the Rights of Persons with Disabilities (SCRPD), in collaboration with Data-Pop Alliance, created a working group on Disability and Digital Societies
- We are writing a white paper on Disability and Digital Societies jointly with the members of the working group.
- The working group will submit a proposal for a side event at the 9th session of the Conference of States Parties to the CRPD, 14-16 June 2016

