PAQ (Previously Asked Questions)

Crowd-Mapping for Inclusion: *Increasing access to HIV/AIDS awareness, prevention and services for people with disabilities in Uganda*

Disability is a complex, cross-cutting issue that often produces more questions than answers. Despite our team's diverse and extensive background and experience, developing an approach to tackling sensitive issues like sexual and reproductive health (SRH) and HIV/AIDS, for a population that routinely experiences social, economic and physical barriers to inclusion, was not an easy task. As it turns out, explaining the concept to others also produced a lot of questions. In an effort to limit the head-scratching and confusion that sometimes accompanies innovation we've compiled a list of PAQ's (Previously Asked Questions) that help to explain our idea as it stands at this point in the design phase.

Q: Who is the "we" that you talk about developing and implementing this project with?
A: With support and input from The National Union of Disabled Persons of Uganda, researchers from the University of Massachusetts Boston will collaborate with the experts from The College of William and Mary's research lab, AidData and partners from UNICEF's U-Report team.

Q: Why do you need so many people to tackle this project?
A: The team-approach to the research blends resources, expertise and capacity; allowing multiple stakeholders to engage and contribute.

Q: What exactly is crowd-mapping and where did that term come from?
A: Crowd-Mapping is a twin-track, or two-step process, that combines SMS-based, mobile crowd source technology with geocoding/geomapping methods. Essentially, our proposed project uses mobile phones to survey a community of people with disabilities in Uganda about their access to, and experience with SRH and HIV/AIDS development projects and activities; while at the same time coding and mapping donor presence in the area. Mapping these key points will allow us to accurately target services for people with disabilities.

Q: That sounds like a good way to collect information and share it with development agencies and donors, but how do you know it works?
A: One of the many benefits of working with this diverse group of experts is that they've already independently tested these methods and have ongoing projects, relationships and programs in this area of Uganda. In fact, AidData UNICEF Uganda worked together on the U-report application that launched in 2011 and provided an outlet for mobile phone users throughout the country to actively participate in tracking country-wide development project activities via SMS text message. The data collected through U-Report helps to improve program monitoring and evaluation and produces "geocoded" data that maps outreach efforts and identifies gaps.

Q: But… if they've already done this project, why are you doing it again?
A: While the technology and methods have been piloted and produced great data, the focus has never been specifically on targeting people with disabilities as participants. We mentioned before that our project addresses the "lack of voice in disability inclusive

development"; this is a way to ensure that people with lived-experience, are the source of the data.

Q: Why is data so important?
A: Disability inclusive development is an emerging area of study and research. There's not enough information out there to help donors and development agencies to ensure that their programs are reaching people with disabilities- and if there is information, it's usually not collected until the end of a project (during the evaluation), which creates missed-opportunities.

Q: Why did you decide to focus this project on sexual and reproductive health and HIV/AIDS?
A: Contrary to antiquated misconceptions; people with disabilities do have romantic relationships and consensual sex putting them at risk for sexually transmitted diseases, including HIV/AIDS. Additionally, having a disability makes an individual more vulnerable to sexual violence and less likely to receive adequate healthcare, education and support around these issues.

Q: How do you know all of this information?
A: Our project doesn't have to prove that disparities in development exist, nor do we need to justify HIV/AIDS prevalence and risk for people with disabilities. Researchers and experts across the globe have collected this information and published their findings and the 2030 global agenda for sustainable development includes targets aimed at improving outcomes both in areas of disability and sexual and reproductive health.

Q: What do you mean by lack of voice in disability inclusive development?
A: You might think that the voices of one billion individuals would be loud enough to call attention to the critical needs of people with disabilities across the globe; unfortunately, despite being the world's largest minority population, people with disabilities are often excluded from conversations that directly impact their physical, social and economic wellbeing.

Q: Who benefits?
This is a timely issue, with global investment and multiple beneficiaries. While people with disabilities are at the center of this projects design and implementation, and will ultimately benefit from the intended increase in donor investment that comes with new data, the focus is on collecting information for development stakeholders. UNAIDS reports that Funding for HIV/AIDS in Uganda remains predominantly donor funded. The national AIDs Spending assessment report (NASA 2012) shows that government of Uganda contributed 12%, development partners contributed 68% and the balance of 20% was financed from private sources including out of pocket. With Uganda having been identified as a "Fast Track" country that can make an impact in helping to eradicate AIDS as a public health emergency by 2030, and recent data showing that 1.5 million people are living with AIDS, addressing services for those most vulnerable will have collective impact.

Additional benefits include...

For people with Disabilities:

- The participants have increased access to technology and timely information. This helps to ensure that they are aware of, and can participate in, projects and activities in their communities
- Talking about disability is still taboo in many areas across Uganda, the SMS approach to information sharing enables information sharing, but also protects privacy

For NGOs and DPOs:
- The project relies on relationships with NGOs and DPOs (Disabled Peoples Organizations) in country to recruit participants. This helps to build organizational capacity and establish relationships between diverse stakeholders.

For Government and Policy Makers:
-The 2014 pilot of this program noted above reported that the reaction to the data collection efforts was very positive. Ugandan government and policy makers have worked towards building a more inclusive society and this helps them to track their progress and identify gaps and areas of increased need or focus.

For the Global Development Community:
-This project aligns with a number of the Sustainable Development Goals, specifically those focused on integrated-decision making (5.5- including vulnerable groups; 10.6 least developed countries and 16.7 aims to responsive, inclusive, participatory and representative decision-making at all levels).
-The project also aligns with CRPD and contributes to the ability of individuals with disabilities to participate in activities that directly impact their lives.

The goal of this project is to engage people with disabilities in Uganda as change-makers. By providing information about how development efforts are reaching them (or not) and answering questions about the impact of projects and activities in their communities, this population, who is often silenced by stigma, has their voice amplified.

Q: Can you share more about your team and their experience?
A: We are a transdisciplinary team made up of researchers, advocates, academics, and development actors with both local (context-specific knowledge) and international (development/technology expertise). This project will be action-oriented and participatory in nature blending expertise from the field through the National Union of Disabled Persons of Uganda and UNICEF and expertise in methodology through AidData and the University of Massachusetts Boston.

More about us:
Leading the project design process is Ashley Coates, PhD candidate in the School for Global Inclusion and Social Development at UMass Boston. Ashley's research focuses on systems change in inclusive development with a focus on vulnerable populations, specifically individuals with disabilities.

Providing project guidance and connecting people, ideas and resources, is Assistant Professor in the School for Global Inclusion and Social development, Valerie Karr, PhD. Valerie's areas of research and interest include: social innovation, international disability

rights advocacy, inclusive development, social enterprise, youth inclusion movements, families and culture, program development for autism spectrum disorder.

Bringing unparalleled knowledge of development data collection, analysis and sharing is the team from AidData, a development lab at the College of William and Mary. AidData's previous work with geomapping and coding serves as inspiration and the team offers an exceptional level of technical assistance. They have tracked over 6 trillion dollars from more than 90 donor agencies. The detailed information they publish helps to improve development conditions around the world.

UNICEF Uganda's U-Report group has conducted similar SMS-messaging based data collection studies and supplies critical technical and cultural knowledge to the proposed project. Their team will support recruiting and implementation of the research in-country.

None of the above individuals and organizations would be able to design or implement a successful change-effort without our partners at the National Union of Disabled People of Uganda. NUDIPU exists to promote the equalization of opportunities and active participation of PWDs in mainstream development processes. This is pursued through participation in policy planning, capacity building, awareness enhancement and resource mobilization. In addition to sourcing participants and facilitating the in-country research this organization helps to ensure that individuals with disabilities are consulted, included and engaged throughout the process.

More about our work:

As we mentioned in our PAQ's, part of the strength of this project is the knowledge that our team has developed through piloting of similar or complementary projects. While we are still in the planning phase of this project, it is unclear how the pieces of the puzzle will fit together to ensure the best possible outcomes- but, what we do know, is that lessons learned from previous and ongoing projects can help us to thoughtfully plan for the future.

DREAM Project: AidData is planning to pilot the DREAM project in the fall of 2017. This effort responds to the current state of HIV/AIDS service delivery and seeks to lower the barriers to entry for domestic policymakers and development partners to access and use timely, comprehensive and disaggregated data to better identify at risk communications. The outcome is a decision support tool (DST), which will present a holistic view of the HIV/AIDS epidemic at a subnational level and support planning, implementation, monitoring and evaluation- all in one easy to use tool. AidData also has experience geocoding data in Uganda and their experience gained from 2014 project working with the technology and individuals in Uganda provides helpful technical and cultural foundations for our work going forward.

As it stands, the goal is for UNICEF Uganda's U-Report application to lead the way in SMS-data collection for Crowd-Mapping. The project, launched in May 2011 saw the population of U-reporters grow to 89,000 in under a year. This tells us that the technology is sound and that the citizens in the area are willing to take action and help stakeholders to access progress towards development indicators. According to an overview of U-report from 2012,

the application offers a cost-effective, easy to implement means of assuring shared accountability.

No One Left Behind Data Tracking for Development: NOLB is a collaboration between our researchers from UMB and the AidData team. Together they developed a methodology that helps to present an overview of the disability inclusivity of donor agency's active development portfolios. The pilot, conducted in 2016, surveyed active portfolios from The World Bank and the Department for International Development and used indicators derived from the sustainable development goals and targets to quantify inclusive development efforts. The project produced valuable data that has been shared broadly and published in the peer-reviewed Knowledge Management for Development journal. This experience will not only contribute to the research methodology development for the Crowd-Mapping project, but also illustrated the value of working collaboratively as a transdisciplinary research team.

Moving Forward:

We are realistic about the capacity of our team as a whole and know that to effectively undertake this initiative we will have to budget time and fiscal and human resources. We are confident that beyond the design phase we can manage those challenges in the same thoughtful, innovative way we approach all of our research. We are willing to try, fail and make adjustments knowing that as long as we keep people at the forefront of our decision-making the details, however complicated, can be worked out.

Still have questions? E-mail: ashley.coates001@umb.edu