

# CITIZEMPOWER

## RECOMMENDATIONS FOR SUPPORTING INCLUSIVE CITIZEN-GENERATED DATA INITIATIVES

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This year as the world embarks on a Decade of Action to achieve the Agenda2030 and Sustainable Development Goals (SDGs), citizen-generated data (CGD) initiatives led by young people, persons with disabilities and civil rights defenders are more important than ever. The COVID-19 crisis has placed a spotlight on the inequalities deeply rooted in our societies and the challenges faced by governments to respond to the needs and rights of their communities, particularly the most marginalised and excluded who have been worst affected by this pandemic.

As the world recovers and rebuilds, citizen-led data and inclusive partnerships with government and institutional data bodies will be critical to ensure that no one is left behind and the SDGs remain on track. By collaborating to collect disaggregated data, civil society, governments and service providers can further enable participatory, evidenced and effective responses to current and future crises.

These recommendations provide guidance on how to ensure more inclusive and effective implementation of CGD initiatives and partnerships that engage communities effectively, and especially young people, persons with disabilities and civil rights defenders.

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## RECOMMENDATIONS

### **Inclusive Partnerships and Effective Collaboration:**

- Partnering with community based organisations - Organisations of Persons with Disabilities (OPDs) or youth-led organisations - to design research and data collection processes will ensure the right questions get asked based on their priorities and needs. This results in stronger data being collected through a deeper rapport these organisations have with their communities, and ultimately better insights will be generated.
- Establishing diverse and cross sector partnerships to design and generate data can help to ensure that citizen-generated data informs a broad range of programmes and policy decisions, for example partnerships between OPDs and authorities such as the National Census Bureau can help to ensure disability data is desegregated, analysed and counted in the census and will inform policies that support persons living with disabilities.

### **Spotlight from Uganda: Using WG questions in the national census**

A coalition of OPDs, including the National Union of Disabled People of Uganda, the National Association of the Deafblind of Uganda, Mental Health Uganda as well as the National Disability Council, worked with the Ministry of Gender, Labour and Social Development to advocate for the inclusion of the Washington Group (WG) questions for the first time in the country's national census. In 2014, the National Bureau of Statistics included six of the WG questions in the national census. The disability prevalence rate went from 3.5% from the 2002 census to 13% in 2014, with the introduction of the WG questions.

### **Data Access and Disaggregation:**

- Collecting disaggregated data - for example by disability, gender and age - enables evidence-based advocacy campaigns, to implement and monitor inclusive policies that adhere to principles of Leave No One Behind and other international frameworks, such as the United Nation Convention on the Rights of Persons with Disabilities (CRPD).
- Ensuring all data collection measures include the Washington Group Questions (WGQs) on disability statistics will enable data to be disaggregated by difficulty or functional limitations and this data becomes globally comparable. It is imperative that enumerators are properly trained on how to administer the WGQs correctly.
- Collecting feedback through digital platforms has opened up access to data in new ways, but also comes with new risks. Communities need to be supported and safeguarded to access data platforms securely and have their human rights protected online.

### **Spotlight from Madagascar: Youth generated data and accountability**

The Development Alternative has trained young volunteers in Madagascar, who are making development programmes where they live better. They monitor programmes to record improvements using the [DevelopmentCheck](#) phone application created by Integrity Action, and speak to community members about what they think. The volunteers then take these suggestions back to development organisations and work with them to fix problems. So far the young volunteers who are part of the Development Alternative programme in Madagascar and Uganda have worked with 308 community members to monitor and improve 18 projects worth £97 million.

Find out more about the Development Alternative here:

<https://restlessdevelopment.org/the-development-alternative/>

## Resourcing and Funding:

- Short-term, non-continuous and restrictive funding is often the norm for organisations leading citizen-generated data initiatives. More flexible funding streams from donors will enable organisational growth, helping to build capacity on the production and use of citizen-generated data.
- Inclusion must be budgeted from the start, to ensure there are enough resources allocated to support the active and meaningful participation of communities throughout data collection initiatives, including the most marginalised or excluded.
- Donors should mandate disaggregated disability data in all required reporting materials and provide the resources to make this feasible to ensure more inclusive programming and policies.

### Spotlight from International Non Government Organisations: Using Washington Group Questions (WGQ) in humanitarian and development settings

In a study conducted by Humanity & Inclusion and Leonard Cheshire, both organisations reflect on the important influence of external funders, many of which call for the inclusion of the WGQ in upcoming grant proposals. DFID and DFAT in particular are putting plans in place to require the use of the WGQ for programmes such as Water, Sanitation and Hygiene (WASH) and Sexual and Reproductive Health, and not just those specifically targeted at persons with disabilities. Leonard Cheshire's study revealed the contemporary use of the WGQ by NGOs and DPOs while identifying and analysing the strengths and limitations of their use in development contexts. Humanity & Inclusion's study revealed how the WGQ perform in different humanitarian settings / sectors of intervention to identify persons with disabilities while determining the necessary process for humanitarian actors to collect useful and quality data using the WG questions. Find the full summary and findings here:

[https://humanity-inclusion.org.uk/sn\\_uploads/document/2018-10-summary-review-wgq-development-humanitarian-actors.pdf](https://humanity-inclusion.org.uk/sn_uploads/document/2018-10-summary-review-wgq-development-humanitarian-actors.pdf)

### Find out more:

[Inter-Agency Standing Committee's Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action.](#)

[CIVICUS Monitor](#) - tracking civic space globally.

[Youth Collective](#) - brings together youth-led and youth-serving civil society organisations, to radically shift how development works and to ensure young people have the support and resources to lead change.

[Washington Group on Disability Statistics.](#)

Inclusion Counts: Disability Data Tracker Tracker

[Center for Inclusive Policy's Getting the Data: How much does aid money support inclusion of persons with disabilities?](#)