Comment in support of Disability Questions in the DHS.

This comment is made by the USAID Coordinator for Disability Inclusive Development. The data revolution is underway. It is offering policymakers, donors, academics, businesses, and citizens unprecedented new opportunities to make informed decisions for better lives and better development. The inclusion of disability questions to the DHS is a great opportunity to ensure that disability is part of the data revolution. Disability data will enable a transformational change in data activities for improving accountability, better planning and providing services.

Accountability:

The UN Convention on the Rights or Persons with Disabilities (CRPD 2006) has now been ratified by 142 State Parties.

* To implement the *CRPD* countries need reliable disability data. Article 31 of the CRPD requires State Parties to collect statistical and research data to identify and address barriers faced by people with disability, to formulate and implement policies, and to help assess progress implementing States Parties obligations under the Convention.
* The USG delegation to the United Nations General Assembly High-Level Meeting on Disability and Development (2013) was led by Secretary of State John Kerry. The outcomes document from this meeting calls for improvements in disability data collection. It notes that without good quality, adequately disaggregated and internationally comparable data, it is not possible to assess whether development goals have been achieved. The availability of such data is also essential for the development of effective development policies.
* The UN High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013) report “Leave no one behind” makes a strong call for better collection of disability data. The Post 2015 agenda discussions are most likely to include disability making disability data and evidence essential for implementation.

Disability Data Matters:

* Persons with disabilities make up 15% of the global population, and 80% of them live in developing countries. This means that an even larger percentage of the population in the countries where USAID works is likely to have a disability (e.g., 20% or 1/5 of the overall population in 2008 Uganda DHS.) Yet they remain a largely invisible population. Excluding such a large portion of the population is likely to inhibit actual achievement of foreign assistance and development goals.
* USAID Disability Policy calls for the mainstreaming persons with disabilities into USAID existing programming – i.e., removing barriers for full participation and access to meet citizen and country needs, rather than creating discrete programs that focus only on a person’s disability. Including the disability module into the core DHS questionnaire(s) is a natural entry point and opportunity for mainstreaming through an existing mechanism that could further both USAID policy and programming across countries and sectors.
* The DHS provides a unique opportunity to collect population-based data on disability prevalence by area of functionality and age on a large scale. To comply effectively with USAID policy, Missions need data to understand the scope of the problem and the size of the population affected in order to inform program design, budget and resource priorities, and strategic decision-making.
* All USAID awards include a mandatory OAA disability clause instructing partners to make every effort to include persons with disabilities, and develop a plan for their inclusion. The data would help both partners and USAID project managers, AORs/CORs, and Program Office staff better comply with Agency policy.
* Lack of birth registration for children with disabilities means that we don’t know who we are missing. It also means that results reporting may be based on inaccurate data. For example, education sector calculations and results related to school enrollment are based on the percentage of the number of children projected to be eligible for school enrollment who are actually enrolled. The projections are based on birth registration. If children with disabilities are not registered, then we are basing our success rates on an inaccurate denominator, and thus are not reaching the goals we think we are reaching. Further, we are perpetuating their exclusion and invisibility.
* Birth registration is also integrally linked to inheritance rights and succession planning. These issues are critical for both HIV and OVC programming, but also land tenure/land reform programs, conflict resolution and community-based conflict mitigation (in some places, 80% of conflict is often connected to land disputes), protection and return of IDPs, and gender-related equality and empowerment goals (inheritance rights, and conflict between civil and customary law.)
* Research shows that persons with disabilities are at higher risk for HIV and gender-based violence. Yet they are often excluded from GBV and PEPFAR interventions. Even when programs nominally state that they will include persons with disabilities, this is rarely operationalized or implemented in practice.

The Disability Questions:

* The disability questions/module could be included in the core DHS questionnaire(s), but be triggered only in those households where the respondent indicates that someone in the household has a disability.
* There are a number of disability questions being used globally. However, the Washington Group (WG) questions have been extensively tested both cognitively and in the field in several countries around the world. The WG short set questions are seen as the international standard for measuring disability (see the United Nations Statistical Division (UNSD), Principles and Recommendations for Population and Housing Censuses (2nd Revision) Section VI-8: disability, Characteristics pages 178-183; see: [http://unstats.un.org/unsd/demographic/sources/census/docs/P &R\_Rev2.pdf](http://unstats.un.org/unsd/demographic/sources/census/docs/P%26R_Rev2.pdf)).

Type of Information Needed:

* There is a large gap of information related to the prevalence of disability in countries where USAID works (new data);
* There is also a lack of information as to how disability correlates with other socio-demographic and health data collected by the DHS (mining and new analysis of existing data);
* Ending Extreme Poverty. People with disabilities are often among the most vulnerable and poorest of the poor, and face a myriad of challenges. In order to achieve USAID’s goals to end extreme poverty, we must reach and include people with disabilities.

Other Interested Stakeholders

* USAID sectors including Health, DCHA (DG, DCOF, Peace & Stability, etc.), Education, OFDA, E3 (economic growth and livelihoods);
* Other international bi-lateral/multilateral donors (DFID, DANIDA, DFAT, World Bank, etc.)
* UNICEF, WHO, and other UN agencies and Missions (including Peacekeeping missions who have discrete child protection, social protection, and GBV prevention and response mandates);
* Implementing partners, NGOs such as Handicap International, Mobility International, ICRC, IFRC, and associated Red Cross national societies;
* Human Rights organizations.
* Disabled People’s Organizations
* Researchers and academics.