

South Sudan Women with Disability Network's Data Collection/Survey Report from June 2016-2017 August 2017.Funded by EU Commission.

The majority of respondents from both surveys do not have access to either a specialist for financial medical or social assistance device. The percentage of respondents who indicated that the use of a specific device would help them or the PwDs in their household better cope with the demands of everyday life decreased significantly from the baseline to the endline survey whereas others options such as treatment, medication, and surgery seemed to be of high importance to respondents indicated they do have access to these because they are too expensive, whereas endline respondents tended to indicate that they do not know where to find such devices.

The most common reason respondents cited for lack of schooling in both baseline and endline was high school fees. As compared with the baseline,a much lower percentages also indicated that PwDs are not accepted in school, that teacher are not able to teach PwDs, or that school is not accessible respondents from the endline survey indicated tha schools are the most difficult service for PwDs to access other services. Difficulty for PwDs to access other services such as sanitary facilities, water points, and health facilities as well. Among those who felt excluded or very excluded, the majority felt that their disability was the cause for their exclusion. A large percentage of respondents from both the baseline and the endline reported being members of a DPO and it is possible that DPO membership is contributing positively to their sense of inclusion however, a high percentage of respondents from both surveys feels that they or their household member face restrictions to participating in community activities due to their disability, although it is also worth noting that this percentage dropped significantly from the baseline to the endline.

Respondents from the endline survey had lower awareness of ,and trust in the effectiveness of laws and government bodies that exist to protect the rights of PwDs. Whereas in the baseline study the most commonly mentioned source of information about laws was DPOs,the most commonly mentioned source for the endline whereas community leaders and DPOs were ranked second to last.

- The majority of respondents suggested that they do not think PwDs are free to involve themselves in national issues in South Sudan. A plurality of individuals from the baseline study reported that PwDs sometimes receive assistance when their rights are violated(42%),whereas a plurality from the endline think PwDs hardly ever receive assistance (42%).The majority of respondents from both surveys y think financial and materials support would help PwDs realize their rights. Insecurity in some areas
- Negative Cultural perceptions
- lack of assistive devices
- lack of Road
- pathways for PwDs
- Bad roads
- lack of special needs schools
- and teachers
- Inaccessible school facilities and infrastructures (ramps, toilets for PwDs)
- Poverty
- Long distances to school

- Negative attitudes towards PwDs

Challenges

In addition to the challenges related to accessing public spaces, FDG respondent reported a number of challenges that they face as parents of children with Disabilities. Challenges include missing community events and other social events because they have to stay at home with the child, finding transportation to take their children to the hospitals or center, looking for work because they cannot leave their children at home alone, registering children in schools, financially providing for their children, finding and affording treatment, and accessing rehabilitation center. Transportation challenges were mentioned most often by respondents, who explained that it is particularly difficult to move around with their children with disabilities once they are too big to carry.

To further explore feelings of inclusion at the community, qualitative survey participants were asked how included they and their family feel in their community. Among those who responded that they feel somewhat excluded or very excluded, 83% in the baseline and 85% in the endline felt that their disability was the cause for their exclusion. When asked whether they are a member of a DPOs, 49% of respondents in the baseline and 44% in the endline said they are. The DPOs may be contributing to increases in felt acceptance, but there is no clear correlation between level of DPO membership and respondent's level of felt acceptance.

The result of the 2008 census indicated that PwDs made up 5.1% of the population of then southern Sudan however, underreporting of disabilities is thought to have been likely during the conduct of the census. According to the South Sudan Union of People with Disabilities, close to 11% of the population of South Sudan are probably, in fact, affected by disabilities, representing over one million PwDs. Within camps for internally displaced persons (IDPs) alone, it is estimated that there are up to 250,000 PwDs.

Physical impairments, such as loss or limited use of limbs, account for the majority of disabilities reported followed by vision impairments, and hearing impairments. According to the national Disability Assessment conducted by Forcier in 2012, only 12.2% of severe disabilities in South Sudan are acquired at birth, conflict accounts for 21% of severe disabilities, while many others are caused by preventable or interacted disease—notably, eye diseases account for 23.5% of disabilities, and polio for another 21%.

In both surveys the majority of respondents confirmed that someone in their household lives with a disability or disabilities, although the percentage was higher in the endline 93% than in the baseline 78%. Similarly, a high percentage of the respondents from the endline reported that they personally live with a disability to 74% in the baseline. Across the baseline and endline surveys, the majority of respondents reported that they have a physical disability. The second largest group in both surveys have a visual disability and the third largest have a hearing disability. The prevalence of the other types of disability, including epilepsy, speech or language disabilities, mental and intellectual disabilities, and cognitive was much lower in both surveys.

The main causes of health conditions leading to disability in South Sudan.

Responses from FGD participants seem to mirror the responses from the qualitative survey and confirm the findings of Forcier's 2012 assessment, which suggested that physical impairments account for the majority of disabilities reported, followed by visual impairments and hearing impairments, and that a low percentage of disabilities are acquired at birth in South Sudan. Respondents from the FGDs were much more likely to mention that they or the PwDs in their household incurred their disability as a result of illness or injury that they were born with the disability. Not all FGD respondents mentioned or knew the exact illness that had led to their or their household member's disability, but those that did reported the following: Malaria, cancer, glaucoma, hydrocephalus, and stroke. For some respondents, it was unclear whether the disability had been present since birth, whether illness at or around the time of birth led to the disability, or whether the disability had always been present and simply did not become apparent until later in development.

When asked to explain the common explanations for cause of disability in South Sudan, FGD participants mentioned the following: being born with the disability, accident, conflict/war (explosion), drug abuses, poor nutrition and poverty, premature births, lack of prenatal care, being administered the wrong medications by doctors, lack of immunization, meningitis, and trachoma infections. Some respondents mentioned that people do visit witchcraft or witchdoctors and seemed to suggest that witchdoctors can be the cause of disability. One respondent explained that some people go to the witchdoctors if they have not given birth, and that they then end up with a child with disabilities. Another explained that going to a traditional doctor can cause disabilities, so what they believed.

Attitudes towards different types of disabilities from communities in South Sudan.

Those who said their children or PwDs recreational activities are impacted by their disabilities mentioned issues such as troubles coordinating with friends, trouble demonstrating ideas and expressing creativity, dependency, need for heavy supervision, trouble moving around. Those who said their children had been excluded from childhood activities due to speech impairment, their being discriminated against because people think PwDs are useless, and exclusion at home due to other siblings getting preferential treatment. Another respondent mentioned that it depends on the disability, and that mentally disabled children are more excluded.

The barriers and challenges (e.g., physical/environmental, socio-cultural, economic, legal, institutional, policy, political, etc.) faced by persons living with disabilities and their families in South Sudan.

Respondents were also asked about the impact living with disabilities has on PwDs and their household. Respondents mentioned a myriad of challenges, including the following: risk of accident, risk of corporal punishment due to lack of respect for PwD's rights, stigma which leads to isolation, lack of opportunities to get a job, lack of mobility, lack of teaching methods, inadequate teachers, and specialized schools, lack of support from government, abandonment, dependency, lack of health or rehabilitation centers outside

of the states of south Sudan or supportive institutions, lack of awareness about PwDs, discrimination after the conflict/war 2013, lack of treatment and medicine, and ability to get married.

To ascertain whether there is a difference in the effect of living with disability between males and females, FGD respondents were asked to what extent girls and boys have different experience living with disabilities. When asked to extent girls and boys have different experiences of disability. FGD participants had varied responses. Some respondents explained that in their view, living with disabilities is worse for girls with disabilities. Some mentioned that is more difficult for girls because living with disabilities makes it difficult for them to get married or do domestic work. Other talked about how girls face high risk of rape, pregnancy, and gender based violence. One respondent explained that when a girls with disabilities reaches puberty, she requires assistance that families sometime do not provide. As a result, some girls with disabilities end up on the streets and starting commercial sex or begging where they have experience raped, physical violence and pregnancy. And respondent talked about how people think girls with disabilities are free from HIV/AIDs, which is what contributes to the higher risk of rape or defilement.

Because of both physical barriers and social exclusion. PwDs in South Sudan are one the most marginalized groups in society. PwDs are among the most disadvantage in terms of access to education with the 2008 census revealing both lower literacy rates and reduced school attendance among PwDs. Distance, limited accessibility of school facilities, and lack of assistive devices are major physical barriers to education for PwDs; in addition, few teachers are trained to address special needs, and negative social attitudes discourage parents from sending children with disabilities to school. As such, the 2012 South Sudan Annual school Census found that only 1.37% of enrolled pupils were children with disabilities exacerbated by low levels of education, livelihood opportunities for PwDs are also limited. The National Disability Assessment of 2012 revealed that of respondents with Disabilities were unemployment, and the 2008 census similarly reported lower levels of economic activity among PwDs. Politically, PwDs face further exclusion, with their voice rarely being heard in political decision making. Alongside widespread marginalization, PwDs in South Sudan have to contend with both verbal and physical violence. According to the National Disability Assessment, 82% of person with Disabilities experience daily incident of nervousness and anxiety, while 12% experience physical violence. Women with Disabilities are particularly vulnerable, experiencing higher levels of psychological, physical and sexual violence.

Legal Protection

The legal protections granted to PwDs in South Sudan. It explores respondents sentiment towards laws intended to ensure respect for human rights among PwDs. Although a number of respondents had an idea of where to report human rights violations, less than a quarters of respondents in both the baseline and endline said that they know if the government has laws that protect the rights of persons with disabilities. The proportion of the respondent who reported knowing of government regarding PwDs

decreased slightly 5% from the baseline to the endline, with 23% at the baseline as compared to 18% at the endline.

Those who responded that they did know the government has laws which protect the rights of persons with disabilities were then asked where they heard of these laws. In the endline, responses indicated were fairly evenly distributed across the different sources although responses community leaders are top source of their information about government laws, followed by the authorities (i.e. the gov't itself) DPOs and finally, NGOs. Specifically, they were asked to what extent they feel the laws of South Sudan protect PwDs and whether or not protection has increased or decreased over time. All FDG groups but one agreed there is no laws that specifically protect PwDs.

Such as gender, age, ethnicity, geography (including those who are nomadic, live in IDP camps, rural and urban settings), and type of disability interact with the barriers faced by persons with disabilities in South Sudan

The sub-section below provide basic information on socio-economic demographic of the survey respondents and program beneficiaries including age, gender, education and migration status. We also present information on the following indicators: ethnicity, household composition, relative wealth, and asset ownership. Several health aspects were also addressed, such as ownership mosquito nets, access to toilet facilities and latrines, and drinking water sources. We find that the survey population is largely representative of the South Sudanese population in terms of age and gender distribution and education attainment, with expected significant differences between men and women in terms of their levels of educational attainment.

Researcher conducted interviews in Juba town, Munuki and Kator for the endline survey, and in Kator and Munki for the baseline survey. A total of 542 individuals participated in the endline survey was 37.8%, 49.6% were males and 50.4% were females. The gender breakdown for the baseline survey was 37.8% male and 62.2% respondents.

The average age of respondents who participated in the endline survey was 35, with men having a slightly higher average age of approximately 37 compared to women at 34. The baseline survey respondents also had an average age of 35, with women and men having roughly the same average age.

Respondents were asked about their living or migration status, and whether they had always lived in Juba or considered themselves to be IDPs or migrants. The majority of respondents from both the baseline and endline survey reported that they have always lived. The responses from the endline survey were more varied than those of the baseline, with higher percentages of respondents identifying as IDPs, returnees, and South Sudanese migrants.

Challenges/Barriers IDPs Families for PwDs.

There are many people with disabilities who are living in the IDPs around South Sudan and outside of the country where the diasporas live and no awareness done regardless of rights of people with disabilities living in camps and also their protection in different environment e.g. access to toilets,

education, water and health services or Centre's for a refugees with disabilities in South Sudan, Uganda and neighboring countries, barrier in terms of communication especially for the deaf community/Hearing Impairment, the blinds/Visual Impairment cannot move without directions by the helpers and the physical disabled cannot without wheel chairs and crawls.

- Lack of understanding between parents and children with disabilities or adult with disabilities
- Families or relative members are having negative attitudes towards children with disabilities or PwDs
- Some of the family members can't send their own flesh blood children to school regardless of his /her disability and they see of no use to educate them in good schools yet children who are non-disabled are equally taken to good schools. This comes in that when a parent is having a negative attitude towards a disabled child and thinks that the child has no future in anyway.
- Serious discrimination towards a child with disabilities especially Deaf blind or Mental Retarded disability and albinos are not sent to school or included in the community activities. e.g public places or festivals, or events especially in villages of south Sudan
- Communication barrier that is to say Sign Language between family members and the Deaf children or adult.
- Lack of life skills for children with disabilities and lack of sanitation because no helpers to teach them about hygiene be it home or community especially young girls in adolescent stages eg they experience Menstruation periods with Disabilities.

SSWDN's priorities and challenges in relation to disability inclusion in South Sudan.

South Sudan Women with Disabilities Network (SSWDN) is a registered national NGO that brings together all categories of women with disabilities in South Sudan. **SSWDN** has offices at Tongpini opposite THESO office and was established in 2012 with the aim to raise standards of livelihood of women with disabilities in areas of Human Rights Advocacy, Health, Education, Emergency and Relief, Prevention and Rehabilitation programmes like HIV/AIDS.

Mission: *Empowering women with disabilities through activities that raise their standards of living.*

Vision: *A community where all citizens are equally entitled to enjoy their human rights and have access to opportunities for self-advancement.*

SSWDN has a clearly defined governance structure with clear roles and responsibilities of the various organs. There is in place a Board of Governors which is responsible for the overall governance and strategic direction of SSWDN's operations in South Sudan. SSWDN also has a full-time Executive Director and three other staff. We have a Personnel Policies and Procedures (PPP) manual that guide decisions around HR and financial resources management.

South Sudan Women with Disabilities Network are having a challenge whenever going to for the field work and visiting homes for disabled children, the communities and different places in the states of South Sudan as well. We normally use public transport and some time we fail to get due to transport being so

expensive because many times they increase public transport due to insufficient needs in the country. Insufficient salary for the staff members and sometimes if they volunteer they don't take the full potential to help them in terms of Mobil or field program on disability side hence they drop out from the job or quit.

Lack of enough materials to support SSWDN in the office and difficult to work with the blind staff so they need technology help through braille's and deaf person need full time sign language interpreters in the office and Sometimes if they volunteer one or two interpreter they don't normally keep around due to insufficient payment towards their job attained. So deaf people end up missing the information. There is a challenge of paying the office because we don't have enough space to do all the activities required for and we were funded by EU commission last year but the project got done last year in August 2017.

South Sudan Women with Disability Network's collect disability disaggregated data

The South Sudan Women with Disabilities Networks (SSWDN) organized a two days training for 12 PwDs identified by SSWDN among the different DPOs. Ten of the 12 PwDs acted as data collectors, overseen by two Forcier Researchers. The training covered topics such as respondent selection, sampling methodology and review of smartphone data collection techniques, After the training was complete, the survey was pre-tested and each enumerator was expected to complete six interviews per day. Including sign language interpreter to serve for the deaf persons while the trainers and the social workers guides blind people.

Evidence gaps about the experiences of people with disabilities living in South Sudan.

- The experienced of people with disabilities living in South Sudan and there are several challenges due to lack of laws to protect the rights of PwDs in public laws/policies and the life or freedom of expression. So this brings or create bad thoughts cognitively emotionally and socially in their minds to a state of trauma.
- Political structure in the government are not included for persons with disability and no one to represent for PwDs in parliament.
- Inclusion Education policy is there but not implemented since after the cabinet minister signed.
- The National Disability Policy is there in South Sudan but not implemented and lack of funds to supported the implementation and the government was depending on the international community worked with PwDs in South Sudan to support this implementation but they did not work out.