

GESS learning note:

Assessing the extra cost of disability in education for children with disabilities in South Sudan

Nithya Srinivasan, Marcella Deluca, and Aryn Lalji



Introduction

Girls' Education South Sudan (GESS) is an inclusive programme aiming to transform the lives of a generation of children in South Sudan – especially girls and those in the margins of society – through education. As a part of this programme, Leonard Cheshire conducted a short exploratory research. The overall aim of the research was to ascertain the extra cost of disability faced by girls with disabilities and their families, coupled with the societal and structural barriers that exacerbate their access to educational interventions. The research also aimed to assess the use of different social protection elements (especially cash transfers) in improving access to quality education for children – particularly girls – with disabilities.

The first phase of this research involved an in-depth literature review on social protection and inclusive education in fragile and conflict areas, particularly in the context of South Sudan. This was followed up with discussions with key stakeholders including representatives of the Ministry of Gender, Child, and Social Welfare (MoGCSW), the Ministry of General Education and Instruction (MoGEI), UNICEF, World Bank, World Food Programme, International Organization for Migration (IOM), South Sudan Union of Persons with Disabilities Organization (SSUPDO), South Sudan Women with Disabilities Network (SSWDN), South Sudan Association of the Visually Impaired (SSAVI), Protection for Disability Rights (PDR) Organization and BRAC South Sudan.

For field work, we partnered with FORCIER consulting, a firm experienced in data collection and management in multiple countries in Africa. Field research on disability is challenging, particularly in areas affected by fragility, conflict and violence. We faced several challenges while beginning the second phase of our research, which involved qualitative and quantitative research with students, parents and teachers. One of the key challenges was the lack of adequate and reliable data on children with disabilities in South Sudan, particularly following classification according to the Washington Group Questions. Coupled with difficulties accessing rural areas and regions outside the capital cities and school closures due to Covid-19, identification and targeting our sample respondents posed a major challenge. Deep-rooted stigma against disability, particularly disability by birth, is also a major challenge in conducting field work in these regions. Greater investment in advocacy, education, monitoring and evaluation and data collection is needed at the local and national level. However, due to funding cuts by the UK Foreign, Commonwealth and Development Office (FCDO), the data collection activity had to be suspended after the identification stage.

This learning note sets out our key learnings from the first phase of the research, involving secondary research and interviews with multiple stakeholders in South Sudan, and the beginning of the second phase of the research, dealing with identification of the sample for field work.

Key learnings

1. Greater investment is needed in the collection and dissemination of inclusive statistics.

There is an urgent need to invest in collecting and recording data on disability in South Sudan, in particular through the use of the Washington Group Questions (WGQ). There was some data on children with disabilities in schools in South Sudan via the EMIS system to start with. However, this data was not sufficient for identifying our sample since it did not follow the WGQ classification, and also had not been updated according to recent records and admissions. For example, children with various disabilities were grouped together, and the term 'mental disability' was used for intellectual and learning-related disabilities. This does not follow the rights-based approach or classification. In addition, 70% of children with disabilities are out-of-school in South Sudan (similarly in several other countries affected by conflict) and no reliable data on disability exists for this group of children.

Lack of data on children with disabilities makes it difficult to develop inclusive education and social protection programmes specifically targeted towards them. This results in many programmes and initiatives duplicating efforts in terms of data collection, monitoring and evaluation as well as delays in the implementation of specific policies and cash transfers. Investing in inclusive statistics as a part of nationwide data collection efforts is a crucial first step in documenting cases and types of disability in each region. This will greatly benefit policy makers and development sector organisations in developing targeted outreach programmes and policies.

2. Inclusion should be a central part of social protection schemes and programmes.

Social protection falls within the ambit and workflow of the Ministry of Gender, Child and Social Welfare (MoGCSW) in South Sudan. The MoGCSW, in partnership with UNICEF and the World Bank, developed a National Social Protection Framework in 2012. The Government of South Sudan approved the National Social Protection Policy Framework in 2015 in collaboration with the Government-led National Social Protection Working Group (NSPWG). This was composed of UNICEF, the World Food Program, the International Organization for Migration, the World Bank, International NGOs, and the Inter-Agency Cash Working Group (IACWG).

UNICEF, in partnership with the MGCSW and the World Bank, operationalised the framework through national social protection mapping as well as training for NPSWG members on social protection in 2019. It also ensured linkages between the IACWG and the NSPWG. The newly designed framework aims to safeguard the South Sudanese population inclusively while expanding livelihoods opportunities and improving employment returns. In this respect, the government allocated 1% of the annual budget to finance the framework through the MoGCSW.

It is reported that cash transfer programmes supported improvements in the lives of 60,000 people in South Sudan (Enfield, 2018). In addition to unconditional cash transfer programmes in South Sudan, conditional cash programmes as cash-for-work have also assisted grants from 2014 to 2018 (Thomas et al., 2018). However, key informants highlighted that social protection programmes in South Sudan are predominately based on vulnerability and poverty. As one key informant noted:

“Social protection programmes in South Sudan target persons on the basis of their vulnerability, and hence, poverty of the household has been central to reaching out to beneficiaries. While inclusion of women has been a part of one of the Social Protection programmes (i.e. World Bank’s safety net programmes), inclusivity – whether through the lens of gender or disability – is not central to the design of many cash transfer programmes yet.”

There is a greater need to target women, children and adults with disabilities as beneficiaries of cash transfers. This is because these groups are generally poorer and more vulnerable within their communities due to additional social and cultural barriers. Research has also shown that cash payments to women and girls in the household decrease intra- and inter-household inequality, and improve the health and educational outcomes of children in the family. Therefore, inclusion needs to be at the centre of design of social protection policies and programmes in South Sudan.

3. More funding is needed to increase the breadth of the programme and range of beneficiaries covered through social protection schemes.

One of the key informants noted:

“The breadth of these programmes needs to increase – many programmes focus on certain statuses classified as 'poor' and further target villages within those poor states, which leaves out many poor and vulnerable beneficiaries in the other regions marked as relatively well-off.”

Difficulty in accessing many regions and poor transportation further amplifies inequalities and need in a country like South Sudan which has recently been affected by conflict. In addition, in light of Covid-19 and accompanying job losses and school closures, large numbers of people have been pushed into poverty. This highlights an urgent need to increase the number of conditional and unconditional cash transfers and the development of safety net programmes reaching larger numbers of people in the country.

4. Greater interaction is needed between multiple stakeholders and donors, including sharing of monitoring and evaluation data, identifying and targeting beneficiaries, and coordination on transfer amounts.

In South Sudan, the last few years have seen several UN organisations and international NGOs contributing towards relief and poverty alleviation efforts. The table below details the current social protection interventions within South Sudan.

Table 1: Brief overview of social protection programmes

Programme and funder	Duration	Programme type	Benefit level	Beneficiaries
SSSNP – World Bank	2019 – 2021 (anticipated)	Public works and unconditional cash transfer	US\$3/day (urban) US\$2.40 per day (rural) for 90 days per year	390,000 individuals (anticipated)
SNSDP – World Bank	2017 – 2019 (closed)	Public works	US\$3 per day (urban) US\$2.40 per day (rural) for 90 days per year	48,507 households (approx. 291,000 individuals)
GESS – DFID	2014 – 2019 (second phase 2019 – 2024)	Cash transfers to schoolgirls	Approximately £20 per year per girl	355,457 girls
BRACE II – DFID	2016 – 2020	Cash-based transfer for asset creation (public works)	US\$40.50 per month per household for 6 months	268,304 individuals
Food for Assets – WFP	Ongoing	Cash/food-based transfer for asset creation (public works)	US\$40.50 per month per household for 6 months, or 34kg per month per household	520,150 individuals
Urban Safety Nets – WFP	Ongoing	Cash-based transfer for training	US\$10-60 per month per household for 6 months (according to household size)	80,112 individuals
School Feeding Programme – WFP	Ongoing	School meals	One third of nutritional requirements	412,118 children

Source: UNICEF, 2019

However, the existence of multiple donors and providers of cash transfers creates some other challenges. As noted by a few key informants from government ministries and donor organisations:

“The social protection system in South Sudan involves multiple stakeholders and schemes which creates tensions due to the difference in transfer values that are being provided to the beneficiaries. Further, each partner is using a separate system to record their outreach and transfers which makes it difficult to ascertain how much is actually going to a particular beneficiary inclusive of all programmes. Right now, we are trying to develop a monitoring and evaluation system which integrates all these efforts. Data is key and we need a system where all programmes speak to each other.”

This highlights the need for greater coordination between the different programmes and the need for increasing outreach, particularly in light of Covid-19. A key informant interview explains the impact of Covid-19:

“Covid-19 has further driven up the demand for social protection, which poses a major challenge to the ministry and puts strains on its resources. Many programmes and their funding have been put on hold due to Covid-19 – further increasing the gap between need and action.”

5. Stigma associated with disability needs to be addressed, in particular stigma related to disability by birth and towards children. This can be done by greatly increasing advocacy at the national and regional level, providing and encouraging greater support to organisations of persons with disabilities.

There is deep-rooted stigma and discrimination against persons with disabilities in South Sudan. Children with disabilities may be hidden at home and experience neglect and abuse. In general, persons with disabilities have a lower social status than non-disabled persons, which contributes to their widespread exclusion (Rohwerder, 2016). Children with disabilities are treated differently and are often enrolled much later into schools than non-disabled peers. Consequently, they are more likely to underperform. The way in which their impairment was acquired also plays a role. There are reports that those who acquired impairments because of conflict are treated differently from those who acquired a disability at birth.

These attitudes and stigma act as a major barrier in implementing programmes and policies for children with disabilities, particularly children with intellectual disabilities, who are even more stigmatised.

This results in large numbers of children with disabilities remaining unidentified ('hidden away') and their disability type recorded incorrectly. This underrepresentation further makes data collection, identification and targeting challenging.

Organisations of persons with disabilities (OPDs) can play a key role in advocating and lobbying for disability rights. However, they are hampered by limited outreach in rural areas, lack of capacity and limited co-ordination between actors (Rapid Disability Assessment, 2012). There is therefore an urgent need for increasing efforts towards awareness building and advocacy, as well as providing increased support to local and national OPDs.

6. The needs of girls with disabilities should be specifically addressed through contextualised programmes and services.

Women and girls with disabilities face double discrimination. Due to endemic stigma and discrimination, women and girls with disabilities are seen as less eligible for marriage. As a result, their needs are often deprioritised within the family, and they are less likely to attend school compared to boys (Disability Assessment Report, 2012). Girls and women with disabilities are particularly vulnerable to experiencing violence, neglect and abuse. This can harm life chances and general well-being, and contribute to exclusion from education.

Girls with disabilities (and persons with disabilities in general) are not prioritised. Some conditional cash transfer programmes even highlight that households must have a non-disabled individual to comply with the programme's conditions. This further increases discrimination. The Gender Support and Development Project targets poor and vulnerable women; however, it does not have a specific focus on girls with disabilities. The project focuses on labour-intensive works, skills development and participation in income-generating activities. It has resulted in slow but positive gender impacts including improved nutrition, increased spending, increased enrolment of girls in school, and women taking control of household spending. However it is unclear how girls with disabilities benefit.

There is limited capacity to respond to the needs of women and girls with disabilities. There is a lack of specific legislation, and the Government of South Sudan has not yet ratified the UN Convention on the Rights of Persons with Disabilities. There are few assisted programmes by international aid agencies and there is a lack of monitoring and evaluation. All of this has increased barriers experienced by women, specifically girls and women with disabilities. They are excluded from mainstream education, health, and other services, and experience stigma - making them vulnerable and dependent (Rohweder, 2018). Gender-based violence is also highly prevalent, and has seen an increase during Covid-19, adding to the challenges for providing and ensuring access to education for girls.

There is therefore an urgent need to prioritise girls with disabilities and their specific challenges when designing and implementing social protection and development assistance programmes in the country.

7. Gender and disability inclusion should be made central to education programmes, with a greater focus on the implementation of existing policies.

Barriers to accessing education are further exacerbated for girls with disabilities living in rural areas, due to insecurity and gender discrimination. South Sudan National Disability and Inclusion Policy (SSNDI) highlights that girls and women with disabilities are less likely to access education due to the stigma around disability and vulnerabilities, which demotivates parents to send their child to school (Republic of South Sudan, 2013). The role of girls in some communities prevents them from accessing education. However, social stigma and negative social perceptions are also attached to disability. This is coupled with long distances to schools, a limited number of institutions to cater to all types of disabilities, insecurity, lack of availability of assistive devices and digital interventions, and lack of trained teachers to work with children with disabilities. All these factors can prevent access to education (South Sudan Association of the Visually Impaired, 2016).

A key informant interview emphasised the perceived societal gender roles within the context of South Sudan:

“The cultural aspect...makes them not to be in school. In some communities, up till now, they believe girls are not to go to school, they are supposed to remain at home and take care of the siblings and the housework. As for the boys, they think that the boys are supposed to be at home and take care of the animals and be trained on how to protect their families”.

Menstrual health management (MHM) in schools is also of primary concern for females reaching puberty as they need adequate sanitation facilities. Strikingly, 57% of schools do not have toilets, and the rest are impoverished (MoEST, 2015). There is a stigma attached to MHM, which forces girls to stay at home and miss school days. In addition, gender-based violence (GBV) against girls and women is a continual and alarming issue in South Sudan, with one-fifth of women being directly affected by it. Sexual violence and harassment are commonplace. The remoteness of schools further undermines a girl's safety and inclusion in school, as they are often harassed, physically abused, or raped. Incidents of GBV are seldom reported and often result in school dropouts for girls (UNICEF, 2018).

Making education more inclusive both from a gender and disability perspective, by incorporating the challenges and needs of girls and children with disabilities, is extremely important. Constant efforts need to be made to bridge the gap between policy and practice.

During the first two years of the GESS programme (2019-2021), Leonard Cheshire has been able to embed disability inclusion into all output areas of the programme. This is critical for the long-term sustainability of disability inclusion in the South Sudanese Education System. A close working relationship has been established with several sections of the MoGEI, especially the Directorates for Planning, Statistics and Gender and Inclusive Education. This has had a significant impact, contributing to sustained change in policy planning and several government systems.

Central to our impact has been our close collaboration with MoGEI. Leonard Cheshire made substantial contributions to the finalisation of the National Policy on Inclusive Education, and also supported the development of a Framework for an Implementation Plan, which was shared with the Director General for Gender and Inclusive Education. We have also established a network of ten Disability Champions across all ten states. The network will engage with the state authorities to ensure that disability inclusion remains on the agenda. A proposal has been put forward to MoGEI for the establishment of a National Thematic Working Group on Inclusive Education. This will be chaired by the Director General for Gender and Inclusive Education and co-led by Leonard Cheshire. The group will meet on a monthly basis to ensure that the inclusive education agenda is sustained at all levels of the GESS programme.

We have also engaged with MoGEI to strengthen the relationship with the Ministry of Health, in order to promote the establishment of a referral system for children with disabilities who currently have limited access to health and rehabilitation services and coordinated provision of assistive devices. The discussions heightened awareness of gaps in the system.

8. Availability and access to assistive devices and technologies needs to be improved. Sustainable investments should be created in access, mobility and infrastructure.

Children with disabilities (especially girls) face a number of barriers. These barriers include a lack of resources to meet the enhanced costs of disability (e.g. payment for transport and/or assistive devices), lack of accessibility, transport and safeguarding concerns. There are also blockages at the policy level such as the lack of implementation of policies, lack of capacity for disability inclusion at ministerial level, financial barriers and a lack of data.

Despite the high expectation of disability prevalence in South Sudan (based on observations by experts on field) there is very little access and awareness about assistive devices and technologies in South Sudan. Most devices are imported and donated by international NGOs, are largely focussed on physical disabilities and impairments due to war, and available in more urbanised parts of the country. Some of these thoughts were further elaborated on by our key informants:

“For children with disabilities, the concern is access, mobility and infrastructure. Physical access to institutions and buildings is not available, infrastructure on the roads is unfriendly and mobility is extremely difficult.”

“Speaking with children with disabilities who were able to come out of hiding and access public services, we realised that there is a huge dearth of resources. For example, there are just 1 or 2 sign language interpreters in the whole state of Central Equatoria, which is a relatively well-off state in South Sudan.”

“Even before creating specific cash transfer programmes, it's crucial to conduct research to know the whereabouts of these children, their current levels of empowerment, detailed social and cultural perceptions etc.”

Investing in increasing in-country supply of assistive devices, technologies and services, especially in regions outside the capital cities, is necessary to reach the goals of access, mobility and infrastructure. There is also a need for assistive devices and technologies produced with locally available resources. Disability-friendly infrastructure in particular can greatly decrease out-of-pocket expenses and individual fixed and marginal costs. Sustainable long-term investment in this is a crucial first step. Specific cash transfers to offset any individual costs may also be necessary to put children with disabilities on a level playing field with those without disabilities when it comes to accessing schools and health facilities.

9. Increasing outreach to rural areas

There are huge inequalities between rural and urban areas within the different regions in South Sudan, in terms of educational attainment, health, access to services and awareness and perceptions of disabilities. For example, even among the assistive devices and services available, most, if not all, are concentrated in the urban cities. Awareness of and access to assistive devices is extremely low in rural and peri-urban regions. Advocacy and awareness campaigns need to be carried out in several communities and regions to bridge this gap and create demand as well as support supply of devices and services, given that we already know there is a huge need in South Sudan.

Conclusion

The findings of this study aim to help the GESS programme and MoGEI to support the needs of children with disabilities more effectively and assist in the development of a differentiated cash transfer strategy (within the broader social protection programme). The study also aims to create greater awareness of the challenges involved in supporting the inclusion of children with disabilities into mainstream social protection interventions, and to influence education policy in South Sudan.

Our preliminary exploration of the gender, disability, social protection and education landscape in South Sudan so far has indicated that there are multiple existing gaps that need to be targeted. Firstly, a lack of adequate inclusive statistics makes it hard to find and target beneficiaries. There is a need to collect and consolidate data across the country.

There is also a need for greater synergies between the different donors and international organisations working on social protection and inclusive education programmes in South Sudan. This includes coordinating transfer amounts, sharing data, and focussing on diverse regions in the country to avoid reinventing the wheel.

Inclusion also needs to be central to the design of social protection schemes, which have traditionally focussed on poverty reduction. The specific challenges faced by women and girls with disabilities must also be kept in mind while developing cash support programmes.

There is also a lot of stigma surrounding disability in South Sudan, particularly disability by birth. The Government and civil society organisations need to invest in advocacy to destigmatise disability and empower and support OPDs to do so.

Lastly, there is a need to focus on the three areas of access, mobility and infrastructure through increasing the breadth of devices and services available in the country, creating more locally produced assistive devices and technologies, focussing on sustainable investments in infrastructure and transport accessible to all, and increasing outreach to rural areas.

References

Carter, B. et al. (2019). K4D Helpdesk Report, Institute for Development Studies, Social Protection Topic Guide. Available at: [link](#)

Enfield, S. (2018). K4D Helpdesk Report, Institute of Development Studies: Cash Based programming in South Sudan. Available at: [link](#)

Ministry of Education, Science and Technology, South Sudan (2015). Girls' Education Strategy for South Sudan, 2015–2017. Available at: [link](#)

Republic of South Sudan (2013). South Sudan National Disability and Inclusion Policy. Ministry of Gender, Child, Social Welfare, Humanitarian Affairs and Disaster Management. Available at: [link](#)

Rohwerder, B. (2018). Disability stigma in developing countries. K4D Helpdesk Report. Brighton, UK: Institute of Development Studies. Sida. (2014). Disability Rights in Sudan and South Sudan. Sida.

South Sudan Association of the Visually Impaired (2016). South Sudan UPR report. Available at: [link](#)

Thomas, E., Gworo, R., and Wani, K.G. (2018). Cash-based Programmes and Conflict: Key areas of interaction and options for conflict-sensitive programming in South Sudan. Conflict Sensitivity Resource Facility (CSRF). Available at: [link](#)

UNICEF (2018). Strengthened Integration of Disability Programming in Maternal Newborn Child Health and Nutrition Services in South Sudan (2018-2021).

UNICEF and South Sudan Ministry of Gender, Child and Social Welfare (July 2019). Mapping and Analysis of Social Protection in South Sudan. Available at: [link](#)

World Bank (2019). South Sudan Overview. Available at: [link](#)