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August 2019
AVSI & PROTECTION

In partnership with CUMM and OVCI, AVSI implemented a one year emergency project funded by AICS. Main activities:

• Training on prevention & early detection of disability for hospital and PHCC health staff
• Training on identification, basic assistance and referral of disability cases for PHCU health staff
• Training on Inclusive Education for 50+ focal point teachers
• Awareness campaigns on sensitization of local communities about disability and inclusion
• **Research on Disability and GBV**
RESEARCH ON DISABILITY

Why do this empirical field study?
- To increase visibility of a vulnerable group, Persons with Disabilities (PwD), that is often overlooked or believed to be marginal despite representing at least 15% of South Sudan’s (SSD) population
- To raise awareness on community/family coping strategies and to support existing structures that provide assistance and opportunities of inclusion for PwD, in a bid to strengthen local safety nets

What did AVSI do?
- Literature review
- 29 key-informant interviews and 11 focus group discussions in Rumbek and Cueibet
- Validation workshop with 50 key stakeholders including government, community leaders, NGOs, CBOs and PwD
DISABILITY IN SOUTH SUDAN

- At least 1 in 10 people has a disability in SSD
- 40 years of conflict has left a legacy of physical, sensory and mental disabilities where 15% of HHs in SSD have a PwD

<table>
<thead>
<tr>
<th>Disability</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>35-52%</td>
</tr>
<tr>
<td>Vision</td>
<td>20-33%</td>
</tr>
<tr>
<td>Hearing</td>
<td>12-15%</td>
</tr>
<tr>
<td>Mental</td>
<td>8%</td>
</tr>
<tr>
<td>Intellectual</td>
<td>2%</td>
</tr>
<tr>
<td>Speech</td>
<td>4-7%</td>
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</tbody>
</table>

Source: HI, 2018

- Torture, arbitrary detention, sexual violence, killing, and forced displacement has resulted in high levels of psychological distress: SSD has 13th highest suicide rate in the world
- Illiteracy, social stigma and cultural beliefs have led to very poor treatment and widespread neglect of these vulnerable persons
Situation Analysis of PwD in Rumbek and Cueibet (Western Lake State and Gok State)
SITUATION ANALYSIS

• Over 1 in 4 households have a PwD in Cueibet
• Vulnerability is related to the ability of PwD’s nuclear and extended family to protect and provide for them
• Unlike other parts of SSD, Dinka culture dictates that any disabled person that is forced to beg for food brings great shame to the family
• Vulnerability is also dependent on one’s cultivation abilities

“A deaf is less disabled because he is able to cultivate.”
SITUATION ANALYSIS

Education

• Literacy levels for PwD are significantly lower than those without disabilities: 85.0% of females and 57.8% of males with a disability cannot read or write.

• Access to education depends on:
  ➢ the type and/or degree of impairment
  ➢ socio-economic status of a family
  ➢ physical accessibility of schools, distance, and attitudes

• Children support PwD within household by providing care and labour compromising school enrolment and attendance.

“Before South Sudan’s independence, children with a disability did not pay community contribution [school] fees.”

Source: (MoEST, 2014)
SITUATION ANALYSIS

Education

• Neglect and undervaluation of education for Children with Disability (CwD)
• Family with limited resources prioritize children without a disability, greater ‘return on investment’
• Stigma reduces parents’ desire to send CwD to school
• Majority of teachers in schools have no teaching diploma or certificate, let alone training on inclusive education

“Crawling to school took me a full day, so I stayed… sleeping in the tukul where they stored the blackboards. My mother brought me food every evening.”
SITUATION ANALYSIS

Livelihood and Employment

• Unstructured or weak social security mechanisms in SSD

• Limited livelihood opportunities due to:
  ➢ Already very limited job market
  ➢ Lack of education and skills to perform non-agriculture work
  ➢ Physical barriers to cultivate
  ➢ Poor accessibility of working environment
  ➢ Discrimination by employers and colleagues
SITUATION ANALYSIS

Livelihood and Employment

• PwD profile:
  - 89.3% no work experience, 4.5% employed and 6.2% run a business
  - Persons with intellectual impairments least likely to be employed (7.7%) and most likely to be unpaid worker

• Caregivers also forced to stay at home

“When Chol was young, I took him and his younger sister with me to the restaurant where I was working. His sister took care of him and I could make some money. Now Chol is too big to carry him along, so I stay at home, taking care of him.”
SITUATION ANALYSIS

GBV, Abuse and Neglect

• Female PwD face double discrimination due to traditional gender role restrictions and limitations of their disability

• PwD have an increased risk of physical, sexual and psychological violence.

• Those with intellectual disabilities or mental health problems are more at risk of abuse and mistreatment due to social neglect

• Low community participation due to physical or sensory barriers and stigmatization

“It is culturally unacceptable to rape a woman with a disability. But, it is very likely for a woman with a disability to have a child as a result of rape.”
SITUATION ANALYSIS

Food Security

• HHs with PwD experience higher rates of food insecurity
• In Cueibet, on average 38% of HHs have a poor food consumption score (FCS). This increases substantially to 60% for HHs with a PWD (2019)

Discrimination in Humanitarian Assistance

• PwD sometimes do not receive what is intended for them – lack of direct targeting and distribution
• Difficulty in accessing those more vulnerable PwD in rural areas
SITUATION ANALYSIS

Beliefs on the causes of disability at birth

• Result of unhappy marriage
• ‘Test’ from God
• Climate change – rain in the wrong season
• Some born to resemble ancestral animals
• ‘Evil eye’

“I saw with my own eyes, a woman gave birth to a baby with a closed hand, inside the baby’s hand was a pill. The mother had tried to commit suicide but the pill stayed with the baby instead. Now the child cannot open his hand.”
What is working?
Current support networks for PwD
CURRENT STRUCTURES (FORMAL AND INFORMAL)

Family
- Personal Care – eg. feeding, bathing
- Financial support

Livelihood
- Small trading (eg. sale of alcohol, livestock)
- Rentals (eg. Ox ploughs)
- Tailoring
- Cooking (for sale)
- Adapted practical skills (eg. Carpentry, bike repairs)

Education
- Occasional limited training on inclusive education given to teachers and government
- Rumbek Girls School modified and now accessible
- Class mates assist CwD in transport to and from school

Rehabilitation/ Health
- Service provision - Rehab centre at Rumbek State Hospital - free wheelchairs, prosthesis and physiotherapy

Community
- Gifts/Charity in form of food and money from community members and Church
- Community members help with practical needs such as water collection and transport
What can AVSI build on?
Effective Solutions
SOLUTION 1: LIVELIHOOD SUPPORT

**HOW?**

- Target families with PwD to receive farming equipment (eg. Ox ploughs) that can be rented out for money or in exchange for labour
- Provide ‘business’ training for PwD that are engaged in income generating activities, identifying beneficiaries through the church community (gatekeepers) and existing vocational training centres eg. St Monica’s Centre
- Share knowledge and empower PwD through workshops with ‘successful’ PwD as ‘ambassadors’
- Introduce quotas (Eg. require that all AVSI farmer groups have at least one PwD or family that supports a PwD)

**WHY?**

- Builds on existing networks and (personal/community) achievements
- Substitutes family member not earning or cultivating due to care of PwD
- Improves food security through income generation or increasing yield from PwD land
- Raises awareness and stresses PwD’s abilities rather than inabilities
SOLUTION 2: EDUCATIONAL SUPPORT

HOW?

• Ensure that all schools where AVSI and partners carry out construction work is adapted to physical needs of CwD (Accessible latrines, ramps, 1 adjusted table per classroom)

• Ensure that a fixed percentage of girls receiving cash transfers for attending school in other educational programmes, has a disability

• Empower CwD through motivational workshops with ‘successful’ PwD

• Provide inclusive education module in existing teacher training programmes

• Establish and support a ‘buddy system’ that incentivises children to help their disabled peers

WHY?

• Not operationally difficult for organisations already working in schools

• Provides an accessible environment incentivising attendance and allowing both parents/ carers to work

• Improves overwhelming CwD gender gap in schools

• Begins to combat social stigma and decreases drop out rates
SOLUTION 3: SOCIAL INCLUSION

HOW?
- Map rural communities with PwD during all data collection surveys
- Train enumerators in order to share knowledge on services available when encountering a household with a PwD

WHY?
- Very limited cost, if any at all
- Helps track and monitor vulnerabilities
- Raises awareness on PwD rights