Access to Humanitarian Services for People with Disabilities

Situational Analysis in Bentiu Protection of Civilians Site, South Sudan
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# Acronyms and Abbreviations

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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CCCM</td>
<td>Camp Coordination and Camp Management</td>
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<tr>
<td>CDC</td>
<td>Community Disabled Committee</td>
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<tr>
<td>CHC</td>
<td>Community High Committee</td>
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<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
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<td>DPO</td>
<td>Disabled Persons Organization</td>
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<td>DRC</td>
<td>Danish Refugee Council</td>
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<td>DTM</td>
<td>Displacement Tracking Matrix</td>
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<td>GBV</td>
<td>Gender Based Violence</td>
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<tr>
<td>HI</td>
<td>Humanity and Inclusion (new name of Handicap International)</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>IDP</td>
<td>Internally Displaced Person</td>
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<tr>
<td>IOM</td>
<td>International Organization for Migration</td>
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<tr>
<td>IRC</td>
<td>International Rescue Committee</td>
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<tr>
<td>KII</td>
<td>Key Informant Interview</td>
</tr>
<tr>
<td>MOGCSW</td>
<td>Ministry of Gender Child Social Welfare</td>
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<tr>
<td>MSF</td>
<td>Médecins Sans Frontières – Doctors Without Borders</td>
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<tr>
<td>NFI</td>
<td>Non Food Item</td>
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<tr>
<td>NGO</td>
<td>Non Government Organization</td>
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<tr>
<td>PoC</td>
<td>Protection of Civilian</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>UNHCR</td>
<td>United Nations High Commissioner for Refugees</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<tr>
<td>UNMISS</td>
<td>United Nations Mission in South Sudan</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
<tr>
<td>WASH</td>
<td>Water and Sanitation</td>
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<td>WHO</td>
<td>World Health Organization</td>
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In December 2017, an assessment was carried out by Humanity and Inclusion (HI) together with the International Organization for Migration (IOM) in Bentiu Protection of Civilian (PoC) site to increase the understanding of the situation of persons with disabilities in Bentiu PoC, including the barriers and facilitators faced by people with disabilities in accessing needs-based services. Programmatic gaps in the access of people with disabilities to camp management, Water, Sanitation and Hygiene (WASH), Shelter/Non-Food Items (NFI), Health, and Protection services were assessed between December 13 and 20 through ten focus group discussions (FGDs), nine key informant interviews (KIIs), 663 house to house surveys, and 22 direct observations of services.

The assessment targets included not only people with disabilities living within the PoC site, but also their caregivers and families as well as those service providers and protection actors responsible for meeting their basic needs.

A number of barriers to access to services were identified during the assessment, including:

- Gaps in service accessibility are at times exacerbated for those with disabilities as well as among humanitarian aid workers
- Access to information on available services in accessible formats, especially considering high illiteracy rates
- Protection concerns including theft, bribery, robbery and coercion of people with disabilities
- Low participation of people with disabilities in camp coordination, leadership, and management structures
- Obstacles in effective identification of people with disabilities by service providers

Thus, the assessment identified that there is scope for improvement of efforts to create a respectful and sensitive environment for people with disabilities with the support of the site populations as well as humanitarian aid workers. The assessment took into account men and women, boys and girls, as well as the elderly, all with various disabilities including those with visual, hearing, intellectual and mobility impairments, as well as those with mental health problems.

Through the assessment different priorities were identified, including limited access to health care including access to medication adapted to the needs of people with disabilities, and limited availability of rehabilitation services, including assistive devices.

People with disabilities requested improved safety mechanisms, equal treatment, and less discrimination as they are systematically at risk of violence and theft, and are continually discriminated against.

People with disabilities requested increased participation and a stronger representation in camp management to reduce access barriers and discrimination and to create a two-way dialogue with humanitarian service providers, as people with disabilities are not often recognized as equal community members, are not often considered for staff positions, and indicate that they would like to be consulted more extensively by camp management and service providers on decisions that affect them.

People with disabilities and their families require more information about the available services, protection mechanisms, and the rights of people with disabilities, and desire more feedback on their concerns raised to camp management.
People with disabilities report that the following actions could make the lives of people with disabilities in the Bentiu PoC site easier:

- Make access to basic services, such as latrines, easier (63%)
- Increase support to family members (45%)
- Increase recreational and cultural activities (26%)
- Provide non-formal education (19%)

As a result of this assessment, recommendations have been made to improve the situation of people with disabilities living within the Bentiu PoC site. These include:

**General recommendations**

- Donors should promote comprehensive, effective and inclusive actions, through adequate funding and prioritization of programming that takes into consideration issues of inclusion and addresses key identified issues (age, gender, disability). Donor frameworks should include disability rights and access to services.
- Mobilize financial resources to promote inclusive planning and delivery of services (such as establishing disability focal points, training staff on universal accessibility designs, and adding accessibility and disability rights to budget lines).
- Camp coordination mechanisms should deliberately make people with disabilities more visible for all service providers, by systematically capturing disaggregated information about people with disabilities. This can be achieved through the use of the Washington Group Short Set of Questions and through regular participatory situational analyses highlighting the needs of, and challenges faced by, people with disabilities and other vulnerable groups. This data should be presented in assessment reports and the issues identified addressed purposefully in action plans.
- People with disabilities, and other people with functional limitations, should be allocated to accessible and safe environments inside the PoC site and provided with accessible information on their rights, the services they can access, and the assistance they can benefit from.
- Promote and monitor the implementation of inclusive standards through the development of a short, mid and long-term action plan, with dedicated responsibilities and indicators to address the identified challenges. Involve people with disabilities and their representative groups in monitoring the implementation of inclusive standards and in recommending avenues for enhancing equitable service provision.
- All service providers should report on the access and participation of people with disabilities and should consult formal and informal disability representative groups during all programmatic decisions.
- Highlight the exclusion of people with disabilities and any potential violation of rights and due process through advocacy towards service providers, authorities, and donors. Advocate for adapted humanitarian responses, including mobile service provision.
- Setup a network of assistance through trusted community members to provide door-to-door services.
- Continuously strive to adhere to best practices and standards as outlined in guidelines that promote inclusive humanitarian action (such as Sphere standards, protection mainstreaming guidelines, Humanitarian Inclusion Standards) during all phases of intervention and seek the technical support from international or local mainstreaming actors and representative groups to translate action planning into concrete interventions.
- All humanitarian staff should be sensitized on rights-based approaches to disability and have access to basic training on inclusion and accessibility in order to better modify the services they offer to equally include people with disabilities.

Promote accessibility and inclusion inside the PoC site

- Ensure that all service providers use the international definition of disability, have the tools necessary to properly identify people with disabilities, and have access to information collected on people with disabilities in the site.
- Support the capturing of disaggregated disability information on beneficiaries, including by facilitating the access of protection actors during registration/verification exercises to assess different protection needs, such as through the use of the Washington Group Short Set of Questions.
- Strengthen formal and informal representative groups, through structural support and through active consultation in decision-making mechanisms, such as joined assessments and humanitarian planning. Two-way communication between humanitarian actors and people with disabilities should also be promoted through these groups.
- At least one focal point per sector of intervention should be trained on right-based programming, including on the issues surrounding disability mainstreaming.
- People with disabilities should have equal employment opportunities, promoting the self-worth, the resilience, and the particular expertise they have.
- Consult people with disabilities throughout all phases of the program cycle in order to take their experiences into consideration and properly address the challenges they might face.
- Conduct regular barriers and facilitators assessments, together with people with disabilities, to better understand the challenges they face and to address these challenges accordingly.
- Promote safe and accessible infrastructure by ensuring that all new construction works follow the international standards of accessibility and further work to modify an increased number of the existing facilities to the universal accessibility standards.

Promote access to information about services

- Train camp management, focal points, and key community members on accessible communication methods, and identify focal points trained in sign language in order to involve them to reduce communication barriers.
- Provide information in accessible formats at information desks, at distribution sites and in safe spaces.
- Provide directories of information and mobile services in protection reporting mechanisms and in other services that are available.
- Make information accessible at information desks, at distribution sites, and at safe spaces, and through directories of information/mobile services in protection reporting mechanisms and in other services that are available.

Increase community participation and representation

- Conduct disability awareness raising campaigns and trainings for both humanitarian actors and PoC site community members together with representative groups, in order to reduce violence and discrimination while promoting the rights of people with disabilities and looking at impairments in a positive way.
- People with disabilities should be represented in the camp management coordination and should be supported to form an active disability network. The camp management should be provided a chair at the meetings of the disability network in order to share the networks’ concerns and recommendations with NGOs, and to provide feedback to the network on the concerns those within the network raise.

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2 As set out in the Convention on the Rights of Persons with Dis-abilities (CRPD).
3 According to Sphere Standards at least 10 per cent of all infrastructures should follow accessible design.
• Strengthen community networking mechanisms, such as the Community Disabled Committee (CDC) and other representative structures, and systematically consult them during all steps of service provision. Develop CDC subcommittees within each sector to reach more people with disabilities.

Make health services accessible
• Advocate for sufficient and accessible rehabilitation services, including the provision of assistive devices for people with injuries and functional limitations, and ensure assistive devices can be fixed in a secure area when needed.
• Develop health policies and an action plan for health staff to deliver and monitor inclusive health service provision.
• Invite disability focal points during staff trainings (e.g. parents, community members, Disabled Persons Organizations - DPOs) to reduce negative attitudes surrounding people with disabilities.
• Improve data collection systems at health centers to include the disaggregation of patient data by disability type as well as include disability data in referral tools.
• Facilitate access to health services through accessible infrastructure, and through mobile service provision, outreach clinics, provision of transportation fees or an accessible transportation system, and through general support for family members or caregivers of people with disabilities.
• Adapt recreational and psychosocial support activities to be inclusive of people with disabilities and provide alternative mental health activities such as MHPSS support groups.
• Involve the CDC in all health awareness messaging.
• Provide accessible communication materials on health issues, including on MHPSS and HIV/VCT services.
• Equip counselors with communication skills to better counsel people with disabilities for MHPSS-related problems, as well as before, during, and after HIV testing.
• Train health staff on early detection and prevention programs and disability care (including on serving the needs of people with disabilities who are HIV positive), and on the particular health risks faced by people with disabilities.
• Continue using personal testimonies to reduce stigma surrounding HIV.

Make housing conditions safe and accessible
• Ensure that people with functional limitations have appropriate assistance to install and repair their shelter.
• Provide (and monitor the use of) inner-locking mechanisms, a bed, additional blankets, and items based on identified needs (e.g. solar lamps or torches for safety).
• Avoid housing people with disabilities with strangers, or with other people with disabilities.
• People with disabilities should be proportionately represented in shelter committees and in camp management committees.
• Perform an assessment to better identify the shelter needs of people with disabilities and to understand the challenges they face in accessing shelter.

Make WASH facilities accessible
• Modify existing WASH facilities with grab bars, ramps, lifted toilet seats, fixed handrails, and tactile marking, etc. Provide inner-locks, sufficient lighting, and protection screens at all facilities.
• Coordinate with health actors to adapt hygiene kit contents (for example by providing assistive devices and adapted sanitation items such as a commode chair or bedpan) and to promote the
integration of disability sensitive hygiene messages into WASH activities.
• Ensure that all accessible latrines adhere to the universal accessibility standards for WASH in emergencies.⁴
• Involve people with disabilities in the WASH committees and in all assessment exercises.

Make distributions of food and non-food items accessible
• People with disabilities should not share items (such as radios and torches) with other community members, but rather they should be provided with their own items for use. This ensures that the person with a disability has the use of these items whenever they need them
• Set-up door-to-door services, and protection and peer-support networks, to promote safe access to NFIs and food items.
• Improve priority lanes at distribution points for people who have mobility impairments, and systematically monitor the risks of theft to people with disabilities. Make wheelbarrows available at all distribution sites to support the transportation of heavy loads as well as provide water containers adapted to be carried by people with mobility impairments.

Promote protection
• Protection actors should monitor violations against people with disabilities and other vulnerable groups, through disability sensitive monitoring systems and through assessment of disability-specific protection threats.
• Make people with disabilities visible in protection assessments, including GBV assessments (disaggregate data at a minimum of age, gender and disability), and conduct dedicated exercises to understand the specific protection risks that people with disabilities face.
• Actively inform people with disabilities, and their representative groups, where and when to report protection incidents and how to get feedback on complaints.
• Inform people with disabilities about their rights as part of awareness campaigns.
• Address situations of abandonment, deprivation, isolation, robbery, and physical and verbal violence against people with disabilities through adequate protection guidelines and operational procedures
• Train protection staff in disability protection issues, and train people with disabilities and their caregivers in self-protection.
• Make safe spaces accessible and provide adapted protection kits for people with disabilities. Additional efforts should be made to reach out to people who are not able to attend those spaces and offer alternative solutions.
• Increase safe movement inside the site by consulting people with disabilities as to where the safest locations would be, and at what times, for them to receive services. Also consult people with disabilities on what safety mechanisms are needed to be put in place (for example, installing more lightening around key infrastructures and installing inner-locking doors to all shelters and sanitation facilities) in coordination with shelter and WASH actors.
• Implement accessible and inclusive campaigns and community engagement to reduce child protection risks and GBV.
• Improve the inter-cluster information sharing mechanisms to ensure that all service providers are aware of the needs of people with disabilities.

It is hoped that the recommendations resulting from this assessment, which brought to light a number of

important issues facing people with disabilities living in the Bentiu PoC site, provide a basis for humanitarian actors to improve the accessibility of their services so that all may benefit from the protection this site provides civilians.
Introduction

Following months of political turmoil, violence broke out in Juba, the capital of South Sudan, on December 15th, 2013, and quickly spread to several other states. Within months, thousands of people were killed or wounded in the violence, directly affecting and disrupting livelihoods, markets, infrastructure, and basic services. The economic, political, and security situation deteriorated further with a renewed outbreak of violence in Juba in July 2016. In the aftermath of the recent crisis, sporadic unrest and fighting are reported in different states.

Due to the ongoing conflict, OCHA estimates a total of 1.9 million people are displaced in host communities, collective centres, PoC sites, and other camp-like settings across South Sudan. The United Nations High Commissioner for Refugees (UNHCR) further indicates some 1.81 million people have fled to neighboring countries. IOM’s biometric registrations across the country, as of December 2017, captured a caseload of 362,755 internally displaced persons (IDPs) across 35 locations. In addition to biometric registration, IOM is undertaking regular head counts in PoC sites, including Bentiu PoC site which is home to 114,245 IDPs (IOM DTM, December 2017). These people have fled their homes across South Sudan to seek shelter and safety within the PoC site offering: protection, WASH, shelter/NFI, health, nutrition, education, and livelihood services.

Disability in South Sudan

Over 30 years of political turmoil in South Sudan has led to a high number of its population being at risk of injuries and temporary or long-term impairments by war, mines, and unexploded ordinance, or by the effects of war such as poverty, insufficient access to essential services, lack of protection, and displacement. The last census conducted in 2008, estimated that 5 per cent, or 424,000 out of 8.28 million people in South Sudan, live with a disability (with a variation from 3 per cent to 8 per cent per state). However with on-going conflict since 2009, and with the outbreaks of violence throughout the country in both 2013 and 2016, it is estimated that the rate of people with disabilities is likely to coincide with the global estimates of 15 per cent of people living with disabilities worldwide. Therefore it is possible that the numbers of people living with a disability in South Sudan is much higher at 1,242,000 out of 8.28 million people.

South Sudan is yet to ratify the UN Convention on the Rights of Persons with Disabilities (CRPD), as had been done by the previous joint government of the South and the North before separation. Initial research shows that the needs of persons with disabilities are not prioritized in national plans, hence persons with disabilities experience widespread discrimination limiting their participation in community activities, and leading to less access to income generation opportunities, vocational training, and education than their peers without disabilities (Handicap International 2011, MoGCSW 2012, SSNBS 2010). Women with disabilities are especially vulnerable to wider gender and disability gaps in access to services and welfare than men or women without disabilities. For example, 92 per cent of the women in this assessment with disabilities are illiterate in comparison to 70 per cent of women without disabilities and against 67 per cent of men with disabilities and 64 per cent of men without disabilities. In general, 84 per cent of respondents with disabilities reported vulnerability to violence and abuse due to marginalization.
As humanitarian crises can exacerbate access limitations to services, people with disabilities are among the most marginalized. They often are inadvertently excluded from humanitarian assistance while being particularly exposed to targeted violence, exploitation and abuse, including sexual and gender-based violence.

**Different assessments conducted by HI reveal that service providers, including non-governmental organizations (NGOs), struggle equally to include persons with disabilities into their programming. The challenges reported include:**

- People with disabilities in the South Sudanese humanitarian response are not sufficiently visible in assessment reports and response plans.
- Disability representative groups do not participate in humanitarian coordination mechanisms.
- Humanitarian programming does not systematically consult people with disabilities about the access barriers they face or reinforce their capacities, and does not provide humanitarian relief action inclusive of people with disabilities.
- People with disabilities are confronted with unequal recruitment opportunities while humanitarian staff are not systematically trained to plan and deliver inclusive services.
- People with disabilities report they have little to no access to information and awareness about the available services provided by humanitarian actors.
- People with disabilities confront difficulties in accessing certain types of infrastructure (such as water points, food distribution areas, playing grounds, schools and health centers) and face limited livelihood opportunities responding to their capacities.
- There is limited involvement in political leadership and participative processes for people with disabilities.
- People affected by crisis are often confronted with disruption of social support networks and community structures, increased social stigma, prejudice and ignorance.

**Disability and access to services in the PoC site**

The main body responsible for the management of the Bentiu PoC site, including registration and facilitation of camp management and coordination, is the International Organization for Migration (IOM). People who arrive in the PoC site are periodically registered by IOM with information captured on age, sex, household
members, areas of origin, and special needs including disabilities, pregnancies and breastfeeding women among others. As of March 2018, IOM DTM headcount figures indicate the presence of 112,829 IDPs whereas the biometric registration database holds records of a total of 153,748 persons (72,601 male and 87,147 female) within the Bentiu PoC site. In the registration database, 14,242 (9%) are listed as having a vulnerability, and only 528 (0.3% of the total population) are listed as having a disability.

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
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<tbody>
<tr>
<td>Separated child in household</td>
<td>368</td>
</tr>
<tr>
<td>Missing child</td>
<td>7</td>
</tr>
<tr>
<td>Unaccompanied child</td>
<td>311</td>
</tr>
<tr>
<td>Malnourished</td>
<td>241</td>
</tr>
<tr>
<td>Single parent</td>
<td>264</td>
</tr>
<tr>
<td>Pregnant</td>
<td>1,517</td>
</tr>
<tr>
<td>Breastfeeding</td>
<td>10,184</td>
</tr>
<tr>
<td>Mentally disabled</td>
<td>65</td>
</tr>
<tr>
<td>Physically disabled</td>
<td>463</td>
</tr>
<tr>
<td>Serious medical condition</td>
<td>141</td>
</tr>
<tr>
<td>Special protection needs</td>
<td>681</td>
</tr>
<tr>
<td><strong>Total Vulnerabilities</strong></td>
<td><strong>14,242</strong></td>
</tr>
</tbody>
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Whereas the biometric registration database has a field to capture “special needs”, these are determined primarily based on visible vulnerabilities, on referrals by protection actors, and on self-reporting mechanisms, resulting in a strong likelihood of under-reporting. The categorization system of “special needs” also does not include the full spectrum of people with disabilities as defined by the CRPD (for example, people with sensory impairments, including those with visual or hearing impairments, and intellectual disabilities).

Within the PoC site, the available services include: WASH, Shelter/NFI, Health, Education, Food Security, Livelihood, Nutrition, and Protection. Services that particularly respond to the needs of people with disabilities include: punctual physical and functional rehabilitation services, such as the provision of mobility aids, and mental health and psychosocial support services.

This assessment built off of previous assessments conducted in Bentiu PoC site in 2016 which highlighted a number of challenges for people with disabilities, including:

- Difficulties in accessing and using available sanitation facilities such as latrines, water points and bathing areas in a dignified way due to the presence of uneven paths and steps into the facility, squat type toilets, and small toilet stalls
- Difficulties accessing token collection sites due to the absence of fast-track systems and the absence of assistance or equipment for the transportation of food or non-food items
- Health and protection centers that were not physically accessible due to steps and wooden lips in doorways
- Information collection tools that do not capture disaggregated information on the impairments of beneficiaries
- Overcrowded classrooms, making movement within classrooms challenging for children with mobility impairments
- Discrimination and stigmatization of children with disabilities in the form of name calling and other teasing, and absence of activity adaptation to meet the learning needs of children with disabilities, (peer support, alternative teaching methods, accessible information, etc).
The previous assessments concluded that these challenges are likely to be exacerbated by a lack of acceptance of people with disabilities. This lack of acceptance may act as an impediment to integration, and encourage persons with disabilities to remain hidden by their families.

The assessment conducted in December 2017 identified facilitators of access (some of which were a direct response to findings of the 2016 assessments) which assist people with disabilities in the PoC site to access services including:

- Building accessible latrines by members of the WASH Cluster
- PoC site residents serving as assistants at water points to help people get water (while at the same time protecting the points from damage by children)
- Community members helping those with disabilities to access services
- Prioritization by the Protection and Shelter/NFI Clusters for people with disabilities at food distribution sites
- The employment of several people with disabilities in the PoC site
- Wheelbarrows being provided for some people with disabilities to carry their food home
- The establishment of a community based representative group (CDC) by the Danish Refugee Council in 2015 to promote the participation and representation of people with disabilities.

These facilitators constitute a notable improvement on some of the key issues identified for people with disabilities living in Bentiu PoC site. Nevertheless, there remains scope for improvement to enhance the access to services for people with disabilities and those facing similar barriers.

**Objectives of the assessment**

This assessment is a follow-up to the previous assessments conducted in Bentiu PoC site by the HI Flying Team in May/June 2016, which focused on physical barriers for people with disabilities to education, health, WASH, food distribution and protection services. The 2017 assessment built off of the findings of the 2016 assessment and delved deeper into issues of accessibility, including attitudinal barriers prohibiting access to services for people with disabilities. Though there have been several improvements in accessibility since the 2016 assessment, more improvements are needed for full accessibility of Bentiu PoC site.

To complement these earlier assessments, and pilot the feasibility and value of joint efforts for assessing accessibility issues in the PoC, HI and IOM together conducted an assessment between the 13th and 20th of December, 2017 to identify the barriers faced by people with disabilities to easy and safe access to humanitarian assistance and other relief support in Bentiu PoC site. By highlighting the needs and challenges faced by people with disabilities, the report aims to present a set of recommendations resulting from the data collected from people with disabilities living in Bentiu PoC site, as well as from the service providers providing services in the PoC site.

**During the assessment specific attention has been put on:**

- Identifying the equal and dignified access to health services, including primary health care, voluntary counselling and treatment services, mental health and psychosocial support services
- Sanitation facilities and safe and clean drinking water
- Accessible and safe housing
- Access to non-food items related to housing and food security
- Access to information, community participation, and representation.

This assessment is meant to inform service providers and users on the actions required to promote equal and dignified inclusion of people with disabilities in humanitarian action, through providing recommendations
on how the site services and camp coordination can better address the needs of people with disabilities and the challenges they face. More details on the methodology can be found in Annex 1 and assessment challenges can be found in Annex 2.
Assessment Findings

During the assessment both community members and service providers were involved. A pre-identification for disabilities was carried out with a large group followed by an individual level survey applied on randomly selected people of this screened group. The pre-identification tool for disabilities (the Washington Group Short Set of Questions Matrix was applied on a sample of 3,079 people, including 1,407 men and boys (46%) and 1,672 (54%) women and girls. With a cut-off used for people who experience either, “a lot of difficulties,” or, “cannot perform at all” in at least one of the functional domains of the Washington Group Short Set of Questions (Annex 3), 3 per cent of the respondents of the sample reported to have a disability, 65 per cent of them being women. Most respondents were between 18 and 65 (54%) years of age or under 17 years old (45%) with a very small group of people older than 65 years (0.6%). Literacy was assessed with the individual survey sample only but it was found that the majority of people who participated in the assessment cannot read or write (70%) with small numbers being able to only read (3%) or to only write, 0.6%). Therefore the literacy rate of the population of Bentiu PoC site is estimated to be around 26 per cent. The table below provides an overview of the sociodemographic factors of the identification and individual survey sample used to analyze quantitative data.

With the current cut-off used, the number of people with disabilities is potentially underestimated. It is possible that the language barriers, together with the limited training time on disability awareness for enumerators, led to an underreporting of disabilities during this assessment.

Disaggregation of the different domains of disability was done with the large identification sample (N=3,079, of whom 83 identified with disability) as the smaller sample was insufficient to draw conclusions on the different disabilities in this assessment. Most of the people with disabilities report experiencing difficulties in multiple domains of functioning with 36 per cent (n=30) report having difficulties in seeing, 19 per cent (n=16) with difficulty hearing, 35 per cent (n=29) with difficulty moving around, 20 per cent (n=17) with

13 Low number of older people with disabilities is not typical, but potentially created due to the low number of older people in the population sample.
difficulty remembering, 25 per cent (n=21) with difficulty in self-care, and 20 per cent (n=17) had difficulties in communication.

**Access to Services: General Findings**

During the assessment several challenges were reported by both service users and service providers in equal and dignified access to health services, to hygiene and sanitation facilities, to safe and clean drinking water, to accessible and safe housing and non-food items related to housing and food security, to information about services, to rights and decision making instances, and to community participation and representation. In total, 18 per cent of all people surveyed (both with and without disabilities) reported major problems in accessing services. Access barriers were more frequently reported by respondents with disabilities (35%) in comparison to 17 per cent of respondents without disabilities. As revealed during focus group discussions, the access barriers are more severe for people with mental health problems, for unaccompanied people with disabilities (without caregivers or relatives), and for women with disabilities who face greater discrimination than others. No in-depth information has been collected on the specific situations faced by people with different types of disabilities.

“**People with disabilities are not able to use and access most services in the PoC site.**”

— Main consensus of discussion between people with disabilities in Bentiu PoC site during semi-structured interviews, December 2017
19 per cent of people with disabilities report that they find it difficult to have a good quality of life. It was revealed by 24 per cent of people with disabilities that they have no assistance to meet their needs, 19 per cent felt that there are negative attitudes towards their family due to their disability, 8 per cent reported that they think their impairment affected their family negatively, while 16 per cent preferred not to answer.

The main access barriers reported by the surveyed population (N=663) are little to no information on available services (39%), distance to services (28%), financial access barriers (18%), the absence of physical access (15%), and discrimination (13%). The population with disabilities reported to a significantly lesser extent, that services are provided on an equal basis with others (58%) compared with community members without disabilities (72%). The major difference in access of available services reported by people with disabilities are barriers due to distance (49%).

Though both people with and without disabilities reported difficulties to access the services they require with dignity, there are disparities in the areas in which people felt their dignity was not respected. The majority of community members with disabilities (68%, n=25) and without disabilities (66%, n=414) feel they can access services in a dignified way. Of those who felt their dignity was not respected, the greatest area mentioned by people with disabilities was lack of respect (24%, n=9), while those without disabilities reported this to a much lesser extent (2%, n=13). Of those without disabilities, a lack of privacy (the absence of doors to toilets or private spaces) was the most significant reason for lack of dignity at 11% (n=67). Discriminative practices while accessing services was reported proportionately by both groups at 5 per cent for people with disabilities (n=2) and at 6 per cent for people without disabilities (n=36).

The following table shows the services that are reported as, “Needed and available, but difficult to reach,” disaggregated by those with disabilities and those without disabilities. People with disabilities report greater difficulty accessing specific services (particularly food distributions, NFI distributions, education and access to medication), while people without disabilities report greater access barriers to rehabilitation services, human immunodeficiency virus (HIV) / voluntary counselling and testing (VCT) services, services provided through cash transfer modalities, and protection services. In the other six domains, access is reported with only minor differences of 1–2 per cent.

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14 Quality of life is defined here as, "an individual’s perception of their place in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (WHOQOL Group, 1994).
<table>
<thead>
<tr>
<th>Needed and available services but difficult to reach</th>
<th>With disability (n=37)</th>
<th>Without disability (n=626)</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>%</td>
<td>Total</td>
<td>%</td>
</tr>
<tr>
<td>Access to medication</td>
<td>12</td>
<td>32.43</td>
<td>161</td>
<td>25.72</td>
</tr>
<tr>
<td>Rehabilitation services</td>
<td>11</td>
<td>29.73</td>
<td>202</td>
<td>32.27</td>
</tr>
<tr>
<td>Assisted referral to other services</td>
<td>11</td>
<td>29.73</td>
<td>176</td>
<td>28.12</td>
</tr>
<tr>
<td>NFI distribution</td>
<td>11</td>
<td>29.73</td>
<td>102</td>
<td>16.29</td>
</tr>
<tr>
<td>Access to information about services</td>
<td>10</td>
<td>27.03</td>
<td>171</td>
<td>27.32</td>
</tr>
<tr>
<td>Livelihood opportunities</td>
<td>9</td>
<td>24.32</td>
<td>152</td>
<td>24.28</td>
</tr>
<tr>
<td>Mental Health and Psychosocial support</td>
<td>9</td>
<td>24.32</td>
<td>146</td>
<td>23.32</td>
</tr>
<tr>
<td>General health services</td>
<td>9</td>
<td>24.32</td>
<td>143</td>
<td>22.84</td>
</tr>
<tr>
<td>Reunification with family members/caregivers</td>
<td>8</td>
<td>21.62</td>
<td>133</td>
<td>21.25</td>
</tr>
<tr>
<td>Safe and clean water</td>
<td>7</td>
<td>18.92</td>
<td>66</td>
<td>10.54</td>
</tr>
<tr>
<td>Food distribution</td>
<td>7</td>
<td>18.92</td>
<td>22</td>
<td>3.51</td>
</tr>
<tr>
<td>HIV/VCT services</td>
<td>6</td>
<td>16.22</td>
<td>132</td>
<td>21.09</td>
</tr>
<tr>
<td>Education</td>
<td>6</td>
<td>16.22</td>
<td>68</td>
<td>10.86</td>
</tr>
<tr>
<td>Toilets and sanitation</td>
<td>6</td>
<td>16.22</td>
<td>58</td>
<td>9.27</td>
</tr>
<tr>
<td>Shelter</td>
<td>6</td>
<td>16.22</td>
<td>39</td>
<td>6.23</td>
</tr>
<tr>
<td>Services provided through cash transfer modality</td>
<td>4</td>
<td>10.81</td>
<td>121</td>
<td>19.33</td>
</tr>
<tr>
<td>Protection services</td>
<td>4</td>
<td>10.81</td>
<td>91</td>
<td>14.54</td>
</tr>
</tbody>
</table>

*Refer to methodology section on page 45
Other barriers frequently reported by service users are the distance to distribution centers, long waiting queues and limited availability of mobility aids such as wheelchairs and tricycles. At service points, people with disabilities reported not benefitting from prioritization or assistance, and are often victimized by theft.

Both service providers and service users reported during KIIs and observations that there were poor attitudes regarding people with disabilities on behalf of aid workers. During the assessment several service providers indicated that they think aid workers (not the organization the aid worker works for) assume that the numbers of people with disabilities are not high enough to serve their needs through an adaptation in service provision. During the KIIs, one service provider stated that ensuring the equal access of people with disabilities in their activities is not currently a priority in their projects while two service providers stated that the equal access of people with disabilities has not historically been a priority in their projects.

**Within humanitarian programming, service providers mentioned that little to no information on the needs of people with disabilities made it difficult to provide appropriate services for this group. Challenges include:**

- Communication barriers
- The lack of appropriate tools for identification
- The lack of available resources to adapt their services offered to people with disabilities

During the KIIs, only three out of nine consulted service providers reported to have access to a disability focal point all the time, another three reported to have access sometimes, while two reported having no access to technical resources for disability. One service provider stated that they have a focal person for MHPSS within their team but no focal person for disability in general. Of the service providers with access to a disability focal person, only one reported that this focal person is embedded within the organization, the remaining respondents indicated relying on a focal person embedded within other organizations.

> **“Although disability is not necessarily a medical concern, people with disabilities are often sent to health centers due to the lack of clarity about who is responsible for people with disabilities.”**

—Key informant interview with service provider, December 2017
Out of the 9 service providers interviewed, the majority (88%) explained that people with disabilities are included in their populations served, and all of them stated that their services were somewhat adapted for the needs of people with disabilities. These adaptations include:

- Fast tracking for NFI and registration
- Assistance to build and repair shelters
- Developing accessible WASH facilities

Despite this, only three service providers were fully aware of the rights and needs of people with disabilities, with five service providers being somewhat aware and one service provider being not aware at all. This includes 5 out of 8 (63%) key informants being unaware of the South Sudan National Disability and Inclusion Policy (NDIP) which lays out the rights of people with disabilities in South Sudan. However it was seen that six out of eight (75%) of those key informants interviewed were aware of the CRPD. Additionally, service providers reported little respect of these international and national legal rights, and an absence of concrete policies within the service providing organizations to promote the inclusion of people with disabilities and accessibility to services.

Service providers explained that measures have been taken to make services accessible to people with physical and intellectual disabilities, and to people with mental health problems. These measures include:

- Staff training on general vulnerability
- Outreach services including transport
- Adapted communication tools such as posters and radio
- Physical accessibility interventions (ramps, handrails, etc.).

However it was noted throughout the assessment that too little had been done to address the needs of people with sensory impairments such as hearing or visual impairments. Additionally, to promote the accessibility of

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15 Cluster leads from the Health (with three leads – one for general health, one for MHPSS, and one for HIV), Shelter/NFI, WASH, protection (with leads for both general protection and GBV concerns), and CCCM clusters in Bentiu PoC site were interviewed for this assessment.
16 South Sudan National disability and Inclusion Policy, South Sudan Ministry of Gender, Child, Social Welfare, 2015.
services for people with disabilities, the CDC has been established and is regularly involved in consultations on service improvement; but outside of this platform people with disabilities are not represented in other coordination and leadership forums.

**Conclusions**

While barriers to accessing services exist for a proportion of all PoC site residents, access to some available services is particularly difficult for those with disabilities, especially with regards to food and NFI distributions, shelter, water, hygiene and sanitation.

**Access barriers identified as specifically impacting people with physical and sensory disabilities include:**

- Physical access to services (such as long walking distances, inaccessible infrastructure, limited fast-tracking, and limited availability of mobility aids such as wheelchairs and tricycles)
- Little information available on the services offered
- Financial barriers
- Discriminative practices by service providers and service users
- Limited dignified and safe access to services with limited attention to the particular challenges faced by people with intellectual disabilities and mental health problems.

Service providers report some deliberate actions to better include people with disabilities in service provision, especially people with physical disabilities, such as transportation and door-to-door services and fast-tracking systems, although no strategic action plan is available within organizations to specifically reduce the access barriers or promote the rights of people with disabilities. Though some instructions are provided for humanitarian workers to better include people with disabilities on an equal basis with others, there is a need for continued disability awareness raising among service providers.

**Access to Information**

*“There is not enough information provided to inform us of the services available.”*

—Statement of service users during the Bentiu assessment, December 2017.

Among site inhabitants, 16 per cent of people with disabilities and 14 per cent of people without disabilities explained that they have no access to information. Of those who reported having access to information, the megaphone was reported to be the most common source of information (over 70 per cent of those with and without disabilities reported this), followed by boda boda talk talk and the radio (over 40 per cent of both groups reported this). It is important to keep in mind that for those with hearing impairments (19 per cent of those with disabilities, n=7) megaphones, loudspeakers, and boda boda talk talk are not accessible formats of information.

Community mobilizers are the main communication channel for both people with and without disabilities at respectively 74 per cent and 70 per cent. Additionally, block leaders also play an important role in passing information to camp inhabitants (36 per cent for people without disabilities and 32 per cent for people with

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18 Staff training was predominately (55%) completed through internal mechanisms and typically covered vulnerability in general without specific disability or inclusion information. Only a few trainings were conducted by external organizations, including HI.
Community high committees are important sources for community members without disabilities to access information (31%) while it is mentioned less by people with a disability (16%).

During the assessment, information dissemination in multiple and accessible formats such as braille, large/colorful print, pictographs, and clear contrast was identified as an area for improvement as most communication is done orally. There is also an absence of staff who know sign language, and there is limited dissemination of messages responding to the needs of people with disabilities (such as information on disability-specific services). As most of the modes of communication in Bentiu PoC site are oral, people who have difficulties hearing (19%) are at risk of having restricted access to the information they require. Visual observations and testimonies of people with disabilities revealed several physical access barriers to communication centers (such as drainage ditches) and little compliance with universal accessibility standards (including doors being too narrow with wooden lips from 2cm to 25cm in height at various centers, and the absence of handrails). In addition, attitudinal barriers, including negative language used against people with disabilities were observed, such as calling someone by their impairment rather than by their name (for example, “Hey lame man!”).

Service users expressed that complaints of people with disabilities regarding service provision are not often properly addressed or listened to, and no adaptations are done to actively reach out to people with disabilities as it is assumed that information will reach people with disabilities through their relatives. (This is possibly one of the factors contributing to low social participation.) Mobile information dissemination campaigns by community workers were observed in some sectors to overcome this, and although the CDC can promote access to information, they are not actively involved to ensure all people with disabilities get the information they require.

Service providers report some efforts to make information more accessible to people with disabilities, including the use of pictograms, radio announcements, boda boda talk talk, megaphone messaging, and translation of the information into different languages. Several actors also implement door-to-door campaigns, but they do not have the pictographic information necessary to fully facilitate access to information for those who cannot read. Information on services provided was observed to be available on posters at the PoC site health centers, however these were only printed in English. It was also indicated that some humanitarian staff have been trained on equal access to feedback mechanisms for all beneficiaries. Finally, radios have been provided to PoC site inhabitants, but people with disabilities report not having sufficient access to this resource.

**Conclusions**

Limited access to information about the services available, where to claim information about rights, and how and where to address complaints, was noted throughout the assessment as affecting people with disabilities in the PoC site. People with disabilities also face access barriers to information due to the physical condition of the information desks and communication centers, to limited door-to-door information dissemination, and to limited communication channels or inclusive communication methods used by staff. Often people with disabilities are discriminated against; they report cases of staff using nicknames for them or not being directly addressed, as people assume they lack autonomy and will receive information through their relatives. As a suggestion to reduce access barriers it is better to involve formal groups representing people with disabilities in service design, to strengthen mobile information dissemination, and to train humanitarian staff on inclusive communication methods.

**Community Participation and Representation**

Community participation and representation is available through several mechanisms. Site residents have the possibility to access community gatherings and social events, as well as to access complaint and response mechanisms at communication desks. Community representative groups have also been created to express the challenges experienced by site residents and to help identify solutions. People with various types of disabilities have equal rights to access these activities and complaint and response mechanisms, and are also represented through their community representative group, the CDC. This group meets twice a month. During this meeting, issues are raised on the needs of people with disabilities and solutions are discussed. The CDC is comprised of more than 100 members, however, there remain concerns about representativeness of the group, given that one CDC group is representing the entire PoC site of over 114,000 people.

“The voices of people with disabilities are not heard, despite the fact that disability representative groups exist. People with disabilities are not involved in meetings and any community participation. Only a few of them are employed by humanitarian actors.”

—Statement of service providers in Bentiu PoC site, December 2017

Overall, more than a third (38%) of the people with disabilities living in the PoC site report to have no community engagement, especially with regards to decision making, while another 14% indicate insufficient community engagement. These challenges are not unique to community members with disabilities, but affect them in higher proportions, as illustrated in the graph below. Almost half of the assessed sample with a disability (43%) reported to not be included in decision-making processes in comparison to one quarter of the sample without disabilities (24%). This difference is especially striking when the information is disaggregated by gender as men without disabilities report always having access to decision-making processes (50%), compared to women with disabilities who report never having access to decision-making processes (48%). Additionally, over a
third (35%) of people with disabilities and close to half (45%) of those without disabilities are not currently members of a community grouping but would like to participate in these groups if given the opportunity to do so. Finally, 40 per cent of the people with a disability reported not having access to complaint mechanisms, compared to 30 per cent of those surveyed without a disability.

The assessment revealed multiple barriers to equal access in decision-making processes experienced by people with disabilities. The majority of service providers reported a limited consultation of people with disabilities during program planning and design, due to their limited mobility (the lack of assistive devices is expressed as a major hindrance to active participation) and to the lack of data collection tools that capture the needs of people with disabilities (55 per cent of service providers stated that they do not have tools that capture disability specific information or other vulnerability factors, whereas 30 per cent reported to have tools capturing vulnerability factors but unable to capture disaggregated disability information.

People with disabilities get invited to social gatherings, but both groups (service providers and people with disabilities) report the lack of active participation and the presence of discrimination of people with disabilities during those events.

“**Person[s] with disabilities in the PoC site are always intimidated and segregated upon any social gathering.**”

—Statement of a person with a disability during a semi-structured discussion, Bentiu PoC site, Dec 2017

Additionally, the skills of people with disabilities are not often considered in the hiring practices of humanitarian workers, as only few people with disabilities are offered employment opportunities as staff or volunteers. However, it was reported as a challenge by service providers that people with disabilities often do not have the education required for some jobs and so it is hard to hire them for certain positions. It was also noted that when workers are needed, humanitarian actors go to the community high committee (CHC) to seek employees but do not go to the CDC to see if there are people qualified for the work.

Whereas service providers and service users report the CDC as a representative organization of people with disabilities, they highlight that the committee has limited capacities and influence. Regular meetings are organized to discuss the issues experienced by people with disabilities, but the CDC is reported as a one-way complaint mechanism which allows those with disabilities to express themselves, but with little feedback or dialogue with service providers on decisions taken. Furthermore the CDC was reported to be mostly male driven with little participation of women. Besides being a representative group feeding into the PoC site complaint mechanism, the CDC also mobilizes local groups, such as youth groups, to create awareness among community members on the rights of people with disabilities through drama and inclusive sporting events.
The assessment revealed limited community engagement and participation of people with disabilities, with only partial access to feedback and complaint mechanisms and limited consultation of people with disabilities and representative groups. People with disabilities report exclusion from job opportunities, social events and local governance. Concerns and suggestions raised by people with disabilities do not always reach humanitarian actors and coordination mechanisms. People with disabilities thus request more structure and influence of representative groups, equal recruitment procedures, and a better two-way communication between humanitarian actors, camp management, and people with disabilities.

“People with disabilities face access barriers to general health services, as services are far away and health workers are not able to communicate with us and understand the complications we are raising. Often we get discriminated.”

—Main consensus of discussions with people with disabilities in Bentiu PoC site, December 2017

General health services, including medication, voluntary screening and counselling/ HIV prevention/treatment/support services, and psychosocial support and mental health services are available for all people in the PoC site, in addition to punctual specific health services (including rehabilitation services). Public Health messaging includes messages on the identification and prevention of disability. 24 per cent of people with disabilities reported having medical needs, while only 14 per cent of those with needs reported having their needs addressed. Of those without disabilities, 35 per cent said they have a medical need while 26 per cent of those with needs reported having these needs addressed. Comparing the two groups it is seen that 58 per cent of those with disabilities have their medical needs addressed, while 74 per cent of those without disabilities have their medical needs addressed.

Both service providers and service users reported limited access for people with disabilities to the available health services due to:

- Long distances to the health center services
- No transportation to get to health facilities
- Inaccessible buildings (e.g. steps at the building entrance and in waiting rooms, narrow doors, no handrails or visual guidance, inadequate lighting and the lack of assistive devices available to transport those who face difficulties walking)
- Pharmacy windows being too high to be reached by a person sitting in a wheelchair
- No deliberate action being taken to ensure people with disabilities are identified and mobilized to attend health services (radio messages and door-to-door campaigns by health promoters only encourage the
population at large to attend health services and do not target people with disabilities)

- Diverse communication modes (audio messages, sign language, pictographic messages) being absent, and no staff who are trained in sign language
- Discrimination and limited prioritization for service provision combined with long waiting times
- People with disabilities being considered as, ‘a burden, less worthy and dirty’
- The current health data management system not monitoring the access of people with disabilities to health services. Registration tools are disaggregated by age and gender, but not by disability.

Although health staff report that people with disabilities are entitled to equal treatment, they also report that they find it challenging to include people with intellectual impairments or mental health problems in the services they offer.

“What makes health centers accessible is that people with disabilities come with their families who help to facilitate access for them.”

—Stated by a key informant during the assessment in December 2017.

Though not a written policy, it was also reported by service providers that people with disabilities are typically prioritized at health facilities for services.

**Rehabilitation, mental health and psychosocial support services**

Health services responding to the needs of people with disabilities, including physical rehabilitation and mental health needs, are not sufficiently covered in the PoC site. Referrals to more specialized tertiary health services, for example to MSF, are available and some puntual support has been provided in the past by actors such as HI. Of the people with disabilities, nearly a third (30%) reported that they require more specific services to ensure a good quality of life. A fifth (22%, n=8) of those with a disability surveyed (N=37) reported the need for an assistive device (mainly a cane or a walking stick), while others mentioned the need for a walking frames and wheelchairs.
Though MHPSS services were launched in Bentiu PoC site in 2013, there is still limited information available about the mental health status of people living within the site and their perception of MHPSS services. The survey showed that all people with disabilities value being able to share their concerns with others. People with disabilities mainly find their strength from their families (32%) and service providers (68%) while people without disabilities find more strength in service providers (87%). About half (49%) of the people with disabilities and a third (32%) of those without disabilities report they do not have access to MHPSS services from service providers, nor do they have access to family members to find strength.

For individuals with access to MHPSS services, the services are mostly provided through formal support groups for both people with disabilities (41%) and for those without disabilities (47%). The rate of access to counseling was lower for both groups at 8 per cent for people with disabilities and 11 per cent for people without disabilities.

Access barriers to MHPSS services varied, but in general show a large gap between people living with disabilities and those living without disabilities. The largest gap between these two groups was that in regards to distance (reported by 14 per cent of people with disabilities and 4 per cent of people without disabilities) while the smallest gap was that of health services not being locally available (reported by 14 per cent of people with disabilities and 15 per cent of people without disabilities). The absence of information (reported by 16 per cent of people with disabilities and 9 per cent of people without disabilities), and the absence of physical access (reported by 8 per cent of people with disabilities and 2 per cent of people without disabilities) were also reported with wide disparities between the two groups.

Health centers each have at least two staff trained in the Mental Health Gap Action Program (mhGAP). This is a program of WHO which aims to scale up mental health care in low to middle income countries, allowing people with disabilities to access MHPSS services and to benefit from adapted services including peer support groups organized for people with disabilities (2 peer support groups are currently present at the disability center in sector 2). It was explained by service providers that psychiatric staff have been trained to identify people with psychiatric needs, and that mobile teams are responsible: for the identification and referral of people in need of PSS services, for the sensitization of family members, and for promoting physical
access and reduction of stigma, although no specific training of these outreach workers on disability-inclusive MHPSS services was mentioned. Follow-up of people with mental health problems is performed on a regular basis by counsellors, as also reported by the service providers.

While the assessment did not further investigate the work of the mobile teams, information gathered indicates different access barriers to MHPSS services are present, such as social exclusion and few social resources of people with disabilities. Observations show limited accessibility of counseling interventions for both individual and group counseling due to small and inaccessible counselling areas, to communication barriers, to inaccessible information, and to no mobile services. Additionally, people with disabilities reported that they do not have enough information about the services offered or have no alternative modes to access MHPSS services.

**Voluntary screening and counselling/ HIV prevention/treatment/support services**

The assessment revealed that only 29 per cent of the total of those surveyed and 8 per cent of the people with disabilities surveyed were aware of HIV prevention services, and 16 per cent of the total population and 11 per cent of those with disabilities had actually tried to access these services (of which 8 per cent of people with disabilities had benefitted from the services while 10 per cent of people without disabilities had benefitted from the services).

According to service providers, comprehensive HIV and tuberculosis (TB) counselling, testing and treatment are offered through three HIV programs in Bentiu PoC site, focusing on pregnant and lactating women as well as the general population. However data on people who are tested or who are HIV positive is not currently disaggregated by disability, but only by age and sex. Existing HIV/VCT treatment programs are reported not to include mobile outreach modalities to enable people with disabilities, or those with mobility challenges, to get tested for HIV. HIV prevention campaigns are disseminated through the radio and information is available in written formats, but no specific programs address the additional risks and access barriers faced by people with disabilities. Health staff report that they are challenged to communicate with people with disabilities, thus not being able to counteract stigma and not being able to encourage individuals with disabilities to get tested. Stigma was reported to be the biggest factor preventing people from getting tested and also reported to be the reason behind many communication materials on HIV getting destroyed in public places. Service providers also reported that no specific training on HIV and disability is available for humanitarian staff, nor are there any special arrangements available for people with disabilities living with HIV.
Several actions were undertaken to reduce the stigmatization and judgment towards people living with HIV, including the development of testimonies by people living with HIV as well as the implementation of weekly radio shows that promote awareness messaging on HIV and TB. These testimonies have already resulted in an increase of people getting tested for HIV. Those initiatives include all people affected by or at risk of HIV, including: people with disabilities, vulnerable populations, sex workers, gay, transsexual or bisexual people, children born to HIV infected mothers, and people who engage in casual sex. There is also planned to be a comprehensive assessment of people living with HIV in Bentiu PoC site in 2018 with disability planned to be included in this assessment.

The presence of health centers in all sectors (except for sector 5) with opening hours flexible enough to meet the needs of patients, in addition to the existing mobile identification, referral and prevention campaigns for the general population, have helped to facilitate access to the health centers despite the challenges mentioned earlier. Some health centers attempt to provide accessible information about the services they offer through sign posting and through the availability of written information. Most of the health services for patients are provided in private locations (private counseling rooms), ensuring the confidentiality and protection of patients. Individual and peer counselling sessions are also provided separately for both male and female patients, with some activities provided specifically for people with disabilities.

Following advocacy by HI within the Health Cluster, in 2018 for the first time the Health Cluster has developed standard indicators for disability for Health Cluster partners to report against.

**Conclusion**

People with disabilities report challenges to maintain a healthy life and to access the available health services. Health services responding to the particular needs of people with disabilities, such as physical rehabilitation services, do not fully address the existing needs in the site and despite there being a health center per sector (except for sector 5), access barriers persist due to distance, discrimination, and due to the way the facilities are constructed. People with disabilities do not always have information on the health services offered and how to access these services and so may be provided with health services that do not fully correspond to their needs. Limited modification is done to accommodate people with disabilities in primary health, MHPSS, and HIV/VCT services, such as with door-to-door services, accessible information, caregiver support, orientation and referral to specialized health services. People with disabilities mainly find their strength through their family support and they request increased access to rehabilitation care and adapted psychosocial support services.

**Accessible and safe housing**

The Protection Cluster is responsible for identifying the shelter needs of people with disabilities in the site and for adapting the Shelter Cluster supply items accordingly.

*“People with disabilities are the first to be affected when shelters need to be shared, as they risk to be expelled. They are challenged as they do not get any assistance to build or renovate their shelter.”*

—Main consensus of discussion between service providers in Bentiu PoC site, December 2017

Half of the people with disabilities surveyed report to be satisfied with their shelter condition (49%) while those without disabilities report being satisfied with their shelter at a greater rate of 59 per cent.
The majority of people with disabilities reported not receiving any type of support to improve the condition of their shelter (79%). They also reported that they had difficulties in accessing available reconstruction materials as reported by 62 per cent of people with disabilities (and 46 per cent of people without disabilities). Discussion among people with disabilities revealed that some people with disabilities have to share their shelter with households other than their own, or they have been pushed out of their shelter, or their bed or their mattress has been taken away by family members, so they end up sleeping on the ground or in the outside area of a compound. The shelter environment is not accessible, as shelter areas are dense with narrow roads and pathways between shelters which are often slippery and uneven (due to delays/ lack of maintainence of water drainage systems). Shelters are not fully accessible nor do they accommodate the needs of people with disabilities due to insufficient circulation space, and narrow doors often made of blankets or plastic). In fact, 43 per cent of the people with disabilities report a lot, or some, difficulties moving around in their shelter, whereas only 21 per cent of those without disabilities report difficulty moving around in their shelter. No rehabilitation services of shelters are provided according to people with disabilities, though there is a strong request for the availability of repair materials.

Service providers report that they are not aware of universal shelter accessibility standards or methods to accommodate people with disabilities (the current solution is attaching two shelters together to increase circulation space).

Additionally, shelters do not fully protect inhabitants from the rain and wind, specifically impacting people who have difficulties to move around and stay warm. Shelters also do not protect against protection threats, as they do not have inner-locking mechanisms (and sometimes lack doors as residents tend to repurpose doors for other uses) and do not have sufficient lighting surrounding the site. It was noted that lighting is a challenge to provide in the site as residents tend to remove the lights for their own purposes. Shelter safety was reported as a concern by 41 per cent of people with disabilities in comparison with 26 per cent of people without disabilities, including incidents of theft of food from inside the shelter.

In looking at shelter safety by gender, it was reported that women without disabilities (76%) felt safer in their shelters than women with disabilities (56%), while men with disabilities (66.67%) felt safer in their shelters than men without disabilities (65.24)

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To increase shelter safety, people with disabilities reported that providing lighting would be the greatest factor that could be improved (14%) along with changing shelter locations (8%), installing a protection screen (5%), and providing inner locking mechanisms (5%). Those without disabilities also stated that providing lighting (14%), changing the shelter locations (5%), installing protection screens (9%), and providing inner locking mechanisms (8%) could help improve shelter safety.

Service providers report that camp coordination ensures that all people with disabilities are installed in the center of the blocks to allow them to easily access main facilities; but according to people with disabilities, this is not done in a systematic way. Also according to service providers, problems are solved on a case-by-case basis and as much as possible assistance is provided to older people and people with disabilities to construct and repair their shelter if they are without family support. Community leaders are also involved to identify those in need of shelter and report them to IOM for problem solving. It was not possible to undertake direct observations on the assistance provided to people with disabilities regarding shelter construction/repair as part of this assessment.

<table>
<thead>
<tr>
<th>Improving Shelter Safety</th>
<th>People with disabilities</th>
<th>People without disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lighting</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>Protection screen</td>
<td>5%</td>
<td>9%</td>
</tr>
<tr>
<td>Interlocking mechanisms</td>
<td>5%</td>
<td>8%</td>
</tr>
<tr>
<td>Change shelter location</td>
<td>8%</td>
<td>8%</td>
</tr>
</tbody>
</table>

**Conclusion**

The housing conditions in Bentiu PoC site do not respect universal accessibility standards and there is scope for improvement for accommodating people with disabilities, or other people who face difficulties to move around. The density of shelters, the insufficient drainage systems, and the dispersion of main services makes access challenging for people who have mobility difficulties. 43 per cent of the people with disabilities report a lot, or some, difficulties to move around in their shelter. People with disabilities are not systematically provided assistance to install and repair their shelters or benefit from alternative solutions (such as connecting two shelters together). The quality and safety of the shelters does not protect people with disabilities sufficiently against theft, violence, and physical elements such as rain, wind, and cold. It is also noted that significant challenges including PoC site size and theft of shelter materials (such as doors and lights) make providing appropriate shelters difficult.

**Access to safe and clean WASH facilities**

“There are no accessible toilets for people with disabilities in the sites, toilets are squeezed and have a poor drainage system. People using wheelchairs or those with visual impairments are particularly challenged during the rainy season as toilets get dirty and roads slippery”

—Statement of service providers in Bentiu PoC site, December 2017
“Getting water is hard, as there are no water containers available for us to transfer the water. In addition, people with disabilities are challenged to use sanitation facilities. They are not clean, so people with disabilities cannot use them in a dignified way, and they are not accessible for people using wheelchairs.”

—Main consensus of discussion between people with disabilities in Bentiu PoC site, December 2017

49 per cent of people with disabilities report they do not have access to enough safe and clean water (in comparison to 28 per cent of those living without a disability) with barriers related to little economic resources (8%), lack of physical access (8%), the lack of information (11%) and distance (19%) being cited as the greatest reasons for this. Improving the access to safe drinking water should be promoted, according to people with disabilities, by relocating water taps closer to the places of residence (49%) and increasing the physical accessibility of the taps (38%).

41 per cent of people with disabilities report they do not have access to sanitation facilities, (in comparison to 16 per cent of those living without a disability) mainly due to the large distance to facilities (19%), to poor facility hygiene (8%), to the absence of information on services (5%), to the difficulty of physical access to facilities (5%) and to poor facility safety (5%). Notably, only 17 per cent of men with disabilities report having access to sanitation facilities, compared to 28 per cent of women with disabilities, while over 80 per cent of men and women without disabilities have access to sanitation facilities. It was also discussed during the semi-structured interviews that people with disabilities do not like using water points as they are often mocked or intimidated when they seek to use these services.


23 It is important to note that the size of the Bentiu PoC site is static, without the possibility of expansion, and so this limits the ability of shelter actors to provide appropriate shelter size for certain beneficiaries as well as prevents the ability of shelter actors to widen the pathways between shelters.
There are no specific items (such as commode chairs or bed-pans) or private facilities for people with disabilities available in the site. As few inner/outer lights are provided at sanitation facilities, people with disabilities report facing difficulties to easily and safely access and use the latrines, especially during night time (some locks are provided, but both locks and doors are reported to get stolen).

During observations of water points, laundry stations and latrines (in Sectors 1, 3, and 4) it was observed that the minimum international accessibility criteria for emergencies was not met.

Only one accessible latrine was identified in sector 3 block 7 (though the latrine was observed to be too small inside for a wheelchair to maneuver and it was missing grab rails for mobility assistance, the door to the latrine was also observed to be too narrow for a wheelchair to pass through), though accessible latrines are being built at the health facilities in sectors 3 and 4 in addition to at least one accessible latrine planned to be built in each block of the PoC site near the shelters for people with disabilities. Nevertheless, access issues will remain a concern with latrines that are located at a distance that remains challenging for people with mobility impairments, and those with visual impairments to reach. Other existing latrines do not achieve universal accessibility standards to allow people with mobility aids to use the facilities with the issues identified including: no handrail or ramps, narrow doors and stalls which contain lips to cross over, no easy-maneuverable handles or no handles at all on doors, no tactile marking, no inner lightening thereby increasing the risk of trip hazards, no grab bars or raised toilet seats (only squatting latrines were observed), and uneven and slippery floors causing trip hazards.

Bathing areas and laundry points revealed access barriers including raised wooden platforms and lips, hindering people with mobility impairments from moving within the space. Grab bars were also observed to be absent from the inside of the shower stalls, though doors were reported to be sufficiently wide enough for wheelchair access. Laundry areas were either absent or contained little to no accessibility improvements. It was noted that laundry areas were challenging for service providers to maintain in general as protection concerns prevent people from using the established laundry points.

Water points and wells are located closer to residency areas, with water handles that are easily maneuverable and at an accessible height, and with a non-slip floor. On the other hand, the water points do not have accessible entrances (no ramps or handrails), or tactile signage, and are often crowded. People with disabilities reported the absence of adapted water containers for people with disabilities to carry water from water points to their homes.

People with disabilities must rely on others to help them access WASH services and if they have no one to
help them, problems may occur. It was observed that people with disabilities had a difficult time accessing WASH services with dignity. As many of the WASH facilities were observed to generally be dirty and unclean, people with disabilities, especially those who must crawl on the ground, are deterred from using them. Instead, people with disabilities use the area outside the facility for their WASH needs, where they are exposed increasing their vulnerability and protection risks. The open defecation practices also lead to conflict with other site inhabitants.

Service providers report limited space in the PoC site to create accessible latrines, since insufficient attention was paid to facility accessibility during initial design. However, resources are now being mobilized to better consider the protection needs of people while using the WASH services they require as well as to implement a referral system to meet people’s WASH needs.

People with disabilities indicate that to improve the access to WASH facilities better information about the services should be provided (35%), more sanitation facilities should be built (24%), the physical accessibility of existing facilities increased (22%), special items provided for adapting the services to the needs (16%) and the cleanliness of facilities improved (16%). Additionally, people with disabilities requested more community ownership over the maintenance of WASH facilities.

Hygiene promotion guidelines are in place for the PoC site, and people with disabilities are included to ensure the sensitivity of hygiene messages with respect to culture, gender, age, and disability.

It is worth noting that after these same findings of inaccessible services (especially physical barriers preventing people with disabilities from using WASH facilities) were made in 2016, efforts began to improve the accessibility of WASH facilities in Bentiu PoC site resulting in the current construction of accessible WASH facilities.

**Conclusion**

49 per cent of people with disabilities report they do not have sufficient access to drinking water and 41 per cent report not having access to sanitation facilities, including latrines, shower stations, and laundry stations. Within the PoC site, efforts need to be increased to ensure people with disabilities can access safe and clean water, and access sanitation and hygiene facilities. People with disabilities mainly rely on relatives to help them benefit from WASH services and they are obliged to use difficult-to-access, often dirty facilities, which do not align with protection mainstreaming standards and increase the risk of protection threats, especially during night time.

Efforts are being undertaken to increase the number of accessible latrines, although initial models do not fully align with the universal accessibility standards. To promote accessible design of facilities it is necessary to involve people with disabilities during the design, monitoring and evaluation of barriers and facilitators of access, as well as to increase the link with health actors to promote access to technical aids.

**Access to distributions of food and non-food items**

“*Services are provided equally, but humanitarian organizations should consult people with disabilities before any distribution. People with disabilities are getting food but are challenged due to violence and theft at distributions, and are always discriminated on basis of their impairment.*”

—Statement of people with disabilities in Bentiu POC, December 2017
“During food distributions ‘people with specific needs’ struggle due to the tensions during distributions, and the lack of special queues meant for them. They get passed by and once they receive their ration they struggle to get it home.”

—Statement of service providers in Bentiu PoC site, December 2017

The survey revealed several challenges reported by people with disabilities in accessing NFIs including the high distance to distribution sites (22%) and the lack of physical access (19%).

During focus group discussions as well as within the survey, people with disabilities reported severe challenges in the safe and dignified access to NFI distributions. Observations at distribution points show that those sites are physically accessible and service providers reported that people with disabilities often get prioritized if resources are scarce. Service providers and service users both reported that mobile services or transportation assistance is available through casual workers. However, as also reported in 2016, people with disabilities and elderly people explained that these casual workers often steal food or materials or demand a price (or some of the items) for helping the person - making it challenging for those without family support to reliably access the services. Even for those with family support, sometimes family members take the rations of the person with a disability for their own use. Furthermore, at the distribution points people with disabilities feel confronted by tensions and overcrowding, and are exposed to robbery and theft (especially reported by people with visual impairments during the focus group discussions) and repeated discrimination. Some also highlight the absence of availability of adapted food or nutrition services.

Whereas wheelbarrows have been made available to transport food, they are not available to transport wood or charcoal. (Some people with disabilities report that the wheelbarrows have also been used to transport people with disabilities.) People with disabilities fear to collect wood outside of the PoC site and are challenged to access sufficient fuel, to grind and cook their food, or to transport wood or charcoal. As a result of this, people
with disabilities rely heavily on family members and friends for food preparation.

Service providers have no post-distribution mechanism to monitor the access of people with disabilities to NFI and food items and report to have little understanding on how NFI kits could be adapted to better fit the needs of people with diverse impairments. Service providers possibly underreport the exclusion of people with disabilities as many people with disabilities remain absent from distribution points (due to lack of mobility), which may effect particularly those who cannot rely on other household members to attend distributions which are usually targeted at the household level.

Efforts to increase the access of people with disabilities to NFIs and distributions include prioritization of people with disabilities to receive blankets and other limited goods, and fast-tracking vulnerable people in special queues during general distributions. To ensure the safety of distributions, all distributions are done during daylight hours, community safety networks are established, and additional assistance and community safety awareness and protection kits are provided.

To increase the safety of people while accessing services, the protection cluster is also involved to ensure that people with disabilities receive the distributed items at the time of distribution.

**Conclusion**

About a third of people with disabilities reported challenges in the safe and dignified access to NFI distributions, including difficulties reaching distribution sites, tensions and overcrowding at the distribution sites, mockery, and difficulties to get rations home as people with disabilities report experiencing violence and robbery of items. It was also noted that special queues for people with disabilities, prioritization for limited items, as well as people present to help those with mobility challenges facilitated the access to distributions for people with disabilities. Efforts to facilitate access could also include improved assistance for transportation or door-to-door services.

**Protection**

*“We feel safer in the PoC site. However, we have been disturbed by thieves at night.”*

—Statement of service users in Bentiu PoC site, December 2017

The general security of Bentiu PoC site is being guaranteed by the United Nations Mission in South Sudan (UNMISS). Furthermore, there are quarterly protection assessments conducted by protection partners/cluster leads to identify protection threats, services offered, access barriers and leads on the services available, to then adapt protection monitoring indicators accordingly. A needs assessment on protection issues was reported to have been conducted in September 2017 and issues identified were raised with the Protection Cluster and referred to the appropriate partner. It was reported by service providers that information from the Protection Cluster is relied on by organizations to respond to the identified protection concerns of all those within the PoC site, and is the main source of information for service providers on the needs of people with disabilities in the site.

Child protection services include prevention of child abuse through the establishment of parent groups, through awareness on prevention messaging, and through provision of child friendly spaces in each sector providing educational and recreational activities. In the child friendly space in Sector 2 it was observed that
serving the needs of children with disabilities was challenging as the area was too small for recreational activities and the door did not meet the universal accessibility standard for width. It was also reported that no child with a disability had been served at the facility.

Protection centers are available in each sector to receive and process complaints and to provide information on the services offered. These centers link service users with service providers, provide referrals for services, as well as resolve problems occurring within the PoC site. For example, if an issue is brought to the protection desk that cannot be easily resolved, it is then brought to the cluster level and a solution is found among all cluster partners. The protection desk also receives people with disabilities identified during field monitoring by IOM, MSF, and Concern Worldwide and referred by the Danish Refugee Council (DRC) for further protection services.

Legal services do not exist within the site so any conflict resolutions needed are typically provided through community based resolution mechanisms.

One women center was observed where protection, psychosocial support, community cohesion and education services for women and girls take place. The psychosocial support offered includes counseling services for women, case management, non-specialized MHPSS services, prevention activities, training/awareness on GBV and referrals to the International Rescue Committee (IRC) and MSF.

Protection threats were found to be very similar for people both with and without disabilities with little percentage variance between the two groups reported. These concerns include: physical violation (reported by 49 per cent of those with disabilities and 45 per cent of those without a disability), bribery (11 per cent of people with disabilities and 4 per cent of people without disabilities), and coercion (3 per cent of people with disabilities and 2 per cent of people without disabilities). Additional threats identified for both groups include (gender based) verbal and physical violence (mainly outside the PoC site, when fetching charcoal, at distribution sites and within the shelters), early marriage, with people with disabilities being also abandoned by their family or being relocated by their family from an initial shelter to another location.
These threats increase due to generalized violence and banditry, to inaccessible reporting mechanisms and inadequate measures to address perpetrators, and to few protection mechanisms installed at distribution sites.

It was also reported by service providers during the semi-structured discussions that people with disabilities are often targets of robbery and have a higher rate of being raped, beaten, harassed and intimidated within the PoC site due to their disability, especially when they are alone.

At night, site residents report higher protection risks due to poor lightening of the main site infrastructure and little access to protection kits or to training on self-protection.

Those threats were reported to hinder safe access to the services available for a quarter (25%) of people interviewed, with people with disabilities reporting slightly less hindered access (18%) than those without disabilities (26%).

**People with disabilities face several challenges to access the available protection services, including:**

- Information about the protection mechanisms in place that are not in adapted formats such as pictographs, large print, or audio
- Physically inaccessible protection desks
- Safe spaces and activities which are not adapted to accommodate people with disabilities

According to protection actors, no assessments have been conducted to identify the protection threats faced specifically by people with disabilities and monitoring systems are only disaggregated by age and sex without tracking the prevalence of incidents involving people with disabilities. Protection messaging does not actively reach out to people with disabilities, or their representative groups, and does not include disability rights messaging. Service providers also reported that actors do not have technical resources, including standards or monitoring tools, to promote the inclusion of people with disabilities within the planning and design of the protection response, although protection partners consider disability mainstreaming as an important cross-cutting issue.

Vulnerability criteria was mentioned by service providers as needing to be defined by sector, as the current criteria was set by protection partners but is not sector specific. This has led to issues with service providers not knowing if they are providing the correct service to individuals.

**Conclusion**

Protection issues are of paramount concern for people with disabilities. Protection threats that people with disabilities are exposed to include: violence, robbery, denial of rights, deprivation from service, isolation, and abandonment. They also struggle to access available protection services due to barriers involving discrimination, physical accessibility, and communication. Specific interventions need to be identified to better understand the protection issues facing people with disabilities, in order to protect them against these threats.
Conclusions

As has been demonstrated throughout this assessment, people with disabilities face additional challenges to those without disabilities, in meeting their basic needs in Bentiu PoC site. Barriers ranging from discrimination and little information on services and absence of physical accessibility are compounded by a lack of knowledge on the prevalence and the needs of people with disabilities among aid workers, as well as by an absence of disability representation in leadership positions and sectoral committees. However, facilitators to inclusion such as special queues during food distributions, the employment of people with disabilities, and the construction of accessible latrines, are providing momentum for aid workers to take people with disabilities into consideration when providing services. It is hoped that this assessment provides relevant insights into the needs and rights of people with disabilities to access basic services and that the recommendations outlined at the beginning of the report are helpful to humanitarian actors in making their services accessible to people with disabilities.
The assessment took place over a month and a half period, commencing with document review and initial research design (November 2017), followed by development of data collection tools, preparation for implementation, enumerator training and data collection in December 2017, and concluding with data analysis and report preparation in the first quarter of 2018.

The data collection methodology combined qualitative and quantitative data collection methods, including individual surveys, key informant interviews, semi-structured discussions and service observations.

The house to house individual survey was conducted to gather information on the living conditions, and on the needs and access to available services, of community members. The survey was developed to identify socio-demographic factors, to identify barriers and facilitators of access to mainstream services, and to collect information on the access of people with disabilities to the disability related health and nutrition services they require. Individuals were found in randomly selected households with various household statuses. A pre-identification of disability was done with all household members (above 5 years old) in addition to the collection of socio-demographic household information.

Key informant interviews were conducted to gather information on barriers and facilitators to inclusion and accessibility, and on key challenges and good practices expressed by service providers working in the site at field and coordination level.

Service provision observations collected information on the barriers evident, reported, or suspected in and around the services offered.

Semi-structured discussions with both service users and service providers were used to go deeper into certain issues and to explore the possibilities for people with disabilities in Bentiu PoC site.

- Service users include people with disabilities, their parents, caregivers or guardians and representative groups, including the CDC.
- Service providers include field staff and senior management of United Nation agencies and non-governmental organizations providing services in the site, in addition to the humanitarian and camp coordinators.
<table>
<thead>
<tr>
<th>Method</th>
<th>Specification</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification of people with disabilities</td>
<td>3,079 assessments</td>
<td>All household members above 5 years old, selected through computer-generated sampling of households in each sector of the site. People with and without disabilities living in the five sectors of Bentiu PoC site above 14 years old. Individuals were selected at random within every household.</td>
</tr>
<tr>
<td>Individual surveys</td>
<td>663 individual surveys with people with and without disabilities</td>
<td></td>
</tr>
<tr>
<td>Service observations</td>
<td>22 (direct) observations</td>
<td>Community health centers providing primary health care, voluntary counselling and treatment services, HIV, mental health and psychosocial support services. Sanitation facilities including public and individual latrines, showers, laundry and water points. Shelters. Distribution points and information centres. Community gathering points, including protection centres and women and child friendly spaces.</td>
</tr>
<tr>
<td>Key informant interviews</td>
<td>9 key interviews with service providers and coordinators</td>
<td>Nine individual service providers providing health, MHPSS, HIV, shelter/ NFI, WASH, protection, and camp coordination services.</td>
</tr>
<tr>
<td>Semi-structured discussions</td>
<td>5 discussions with service users with disabilities</td>
<td>Service providers providing health, MHPSS, HIV, Shelter/ NFI, WASH, protection and CCCM services. Service users with disabilities including their representatives, living in the 5 geographical sectors of the site.</td>
</tr>
</tbody>
</table>

<table>
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<th>Cluster Represented</th>
<th>Service Providers targeted for semi-structured interview discussion</th>
</tr>
</thead>
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<tr>
<td></td>
<td>Sector 1</td>
</tr>
<tr>
<td>Shelter/NFI</td>
<td>0</td>
</tr>
<tr>
<td>Health</td>
<td>3</td>
</tr>
<tr>
<td>CCCM</td>
<td>3</td>
</tr>
<tr>
<td>WASH</td>
<td>4</td>
</tr>
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<td>Protection</td>
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<tr>
<td>Nutrition</td>
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<td>Total</td>
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<table>
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<tr>
<th>Sex Representation</th>
<th>Service users targeted for semi-structures interview discussion</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Sector 1</td>
</tr>
<tr>
<td>Females</td>
<td>14</td>
</tr>
<tr>
<td>Males</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
</tr>
</tbody>
</table>

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Annex 2: Assessment Challenges

Several challenges were experienced during this pilot assessment, including:

- The assessment was conducted within a short timeframe between November and December 2017, limiting opportunities for contextualization and testing of tools in order to ensure their accuracy and relevancy.
- Participation of people with disabilities and their representative groups in the planning and implementation of the assessment was limited to HI staff who were providing support to monitor the quality of intervention and to guide the assessment team.
- Enumerators had no previous experience in conducting disability-related assessments. Thus a specific two-day training was held for enumerators prior to the assessment.
- The survey and Washington Group Short Set of Questions were not translated prior to the exercise. Enumerators translated questions during the survey to the local language, potentially leading to discrepancies in how questions were phrased and understood. This may potentially have led to biased identification of people with disabilities and/or non-identification of some with invisible impairments, such as people with intellectual and psychosocial disabilities or mental health problems.
- The assessment did not include an in-depth assessment of protection concerns faced by people with disabilities, reducing the depth of information available on access barriers to services due to the safety and protection threats faced by people with disabilities. Sensitive information may not have been revealed, due to cultural barriers and an absence of methods that involve confidential data collection. The limitation has been mitigated through the sensitization of the team on protection principles.
- Few female enumerators means that female respondents may not have felt as comfortable providing information to male enumerators. Due to cultural barriers only one female enumerator was mobilized among a total of 30 enumerators.

People with disabilities have been identified and mobilized through the use of the United Nations’ Washington Group on Disability Statistics Short Set of Questions, based on the International Classification of Functioning, Disability and Health, (ICF). The model is a classification of health and health-related domains including a list of environmental factors (World Health Organization - WHO, 2002).

Throughout the assessment the equal participation of people with different types of disabilities was sought. To ensure this, a two-day specific training on disability, inclusion, and disability data disaggregation was provided to IOM DTM enumerators and HI staff which provided a general sensitization of enumerators on the definition and identification of people with disabilities. Households were identified through a random computer generated sampling as survey participants, and separate semi-structured discussions were organized for people with disabilities and their representative groups in each sector.

In order to reduce cultural barriers and to ensure participants felt free to offer their ideas, it was attempted to organize two semi-structured discussion groups with men only, and two semi-structured discussion groups with women only. An additional discussion group was supposed to be comprised of both men and women. Despite this, men and women were present at all discussion groups but in varying numbers. This accounts for the disparity in numbers of men and women present at each semi-structured discussion group. Maximal efforts were done to mobilize both male and female enumerators and to integrate gender and age sensitive questions throughout all tools.
Annex 3: Washington Group Short Set of Questions on Disability

1. Do you have difficulty seeing, even if wearing glasses?
   a. No - no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?
   a. No - no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

3. Do you have difficulty walking or climbing steps?
   a. No - no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

4. Do you have difficulty remembering or concentrating?
   a. No - no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

5. Do you have difficulty with self-care such as washing all over or dressing?
   a. No - no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
   a. No - no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all
This report is the result of a collective effort among all those involved in the Joint Assessment activities conducted in Bentiu PoC site in December 2017. HI and IOM would like to acknowledge the contributions from all members of the Assessment Team: from the International Organization for Migration - Michael Lumanyi, and from Humanity and Inclusion - Henry Swaka, James Ochan, Alex Modoyi, Lioto Samuel, and Kelly Thayer. This assessment would not have been made possible without the support of the Displacement Tracking Matrix (DTM) team at IOM: Debora Gonzalez, Zerihun Zewdie, Philip Tangermann, and Kaoi Nakasa. Thanks is also due to the Humanity and Inclusion Mental Health, Inclusion, Protection, HIV, and Washington Disability Statistic Group technical advisors who reviewed and commented on all tools and assessment findings. A specific thanks is due to Lena Schmidt, the Humanity and Inclusion Senior Psychologist, for analyzing the quantitative data and providing insight on the statistical analysis. Sien Andries, the Humanity and Inclusion Inclusive Humanitarian Action Technical Advisor, is also thanked for her contribution in designing the assessment tools and commenting on the assessment findings.

The members and coordinators of the WASH, NFI, Health, CCCM, and Protection Clusters are also greatly appreciated as they set aside time to talk to the assessment team and to participate in focus group discussions and in key informant interviews. The staff of Concern Worldwide, DRC, IRC, IOM, WHO, UNHCR are also thanked for their support and assistance in facilitating this assessment as well as for escorting the assessment team through the PoC site to make observations of the services provided. The wealth of information received from these activities greatly contributed to the accuracy of the information in this report.

Of course this assessment would not have been possible without the hard work of the 30 IOM enumerators living within the PoC site. HI and IOM are deeply thankful for the work of the enumerators who adapted quickly to the subject and who interviewed those living within the PoC site.

Finally, it is with the sincerest thanks that HI and IOM would like to acknowledge the PoC site residents, both with and without disabilities, who attended the focus group discussions held in each sector, as well as those residents who allowed the enumerators into their homes to be interviewed for this assessment and thus enabled the assessment and the formulation of recommendations on how to improve the accessibility of Bentiu PoC site.

This assessment was made possible through funding received from ECHO and from the Canadian government.