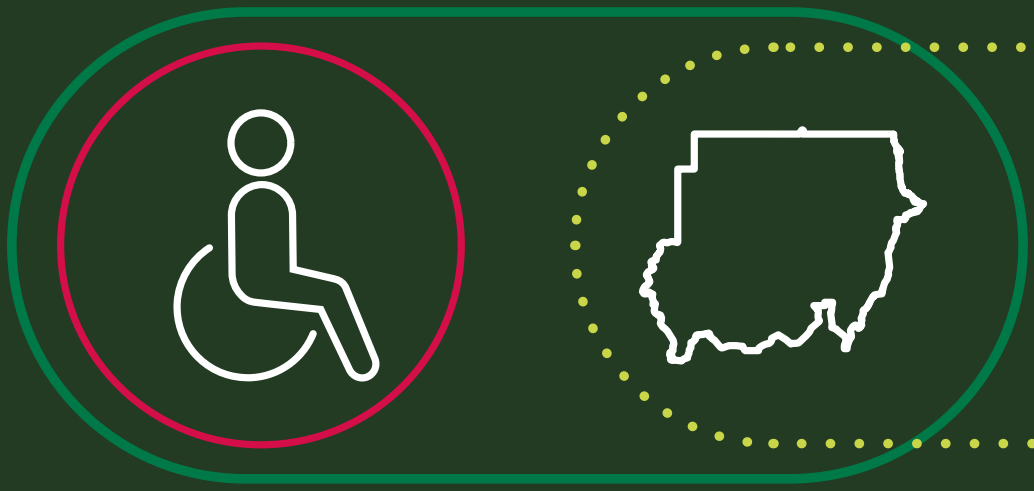

BARRIERS TO INCLUSION - SUDAN 2021

WASH HUMANITARIAN PROGRAMME

Landscape Analysis of Barriers to inclusion faced by people with disabilities and older people in WASH humanitarian programming in Zalengi and Nertiti Localities, Central Darfur State of Sudan

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About us

The Research Team

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Muslim Aid (MA)

Muslim Aid is an international faith-based development and humanitarian relief organisation, which has served vulnerable communities across 70 countries since 1985.

MA is committed to serving humanity and working towards a world where inequality and suffering are removed through the empowerment of people and communities, and a world with leadership and systems that value humanity and compassion over individual gain. The MA team is working towards this vision through its wide-ranging programmatic work in four thematic areas including Humanitarian/ Emergency Response, Education, Livelihoods, and Healthcare; with cross-cutting themes, including WASH, Gender, Inclusion, Disaster Risk Reduction (DRR), and advocacy and campaigning. Visit **https://www.muslimaid.org/** to find out more.

Source: Muslim Aid

Elrha

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This research is funded by Elrha's Humanitarian Innovation Fund (HIF) programme, a grant making facility which improves outcomes for affected people by humanitarian crises by identifying, nurturing and sharing more effective, innovative and scalable solutions. Elrha's HIF is funded by aid from the Foreign Commonwealth, and Development Office (FCDO).

Acknowledgments

Acknowledgments

This research project was a successful collaboration between an INGO, National NGO, DPO, and an academic institution. It was this collaboration that was able to produce, hopefully, a piece of research that has a practical impact on the work of implementors, nationally in Sudan, and globally.

This study also aims to highlight areas where further research can be done to understand the complex set of barriers faced by older people and people with disabilities in WASH programming. The MA team and leadership would like to extend its gratitude to Elrha and UK Aid for funding valuable research in this area.

This study faced several hurdles along the way, including but not limited to the COVID-19 pandemic, which delayed the work and created numerous operational challenges. Completing this study was only possible in these challenging conditions due to the diligence, flexibility, and hard work of the project team, and our partners including Coventry University, SORR, and AAALK. MA would also like to extend a special thank you to the advisory committee for the project, which provided insights and support through the process of research. Additionally, the team would like to thank the Ministry of Health and Central Darfur government, as well as the National and Central Darfur WASH clusters for facilitating this study and ensuring its success.

Most important of all, the MA team would like to thank all the research participants. These participants gave their valuable time and shared insights. We hope that this piece of work contributes towards organisations better serving people with disabilities and older people.

Recommended Referencing

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Abbreviations

ADCAP	Age and Disability Capacity Programme
ADL	Activities of Daily Living
AFMM	African Finance Ministers' Meeting
BSR	Organisation of Sustainable Business Experts
CBM	Christian Blind Mission
CRPD	Convention of the Rights of People with Disability
DPO	Disabled People's Oerganisation
FGD	Focus Group Discussion
GWC	Global WASH Cluster
HIF	Humanitarian Innovation Fund
IDPs	Internally Displaced Persons
IASC	Inter-Agency Standing Committee
MA	Muslim Aid
PAR	Participatory Action Research
RAM-OP	Rapid Assessment Method for Older People
SDGs	Sustainable Development Goals
SIDA	Swedish International Development Cooperation Agency
SORR	Sudan Organisation for Relief and Recovery
UK	United Kingdom
UN	United Nations
UNCRPD	United Nation's Convention of the Rights of People with Disability
UNDESA	United Nation's Department of Economic and Social Affairs
UNFPA	United Nation's Population Fund
UNHCR	United Nations Refugee Agency
UNICEF	United Nation's Children Fund
UNOCHA	United Nations Office for the Coordination of Humanitarian Affairs
UN-WDPAC	United Nation's -Water Decade Programme on Advocacy and Communication
USAID	United States Agency for International Development
WASH	Water, Sanitation and Hygiene
WHO	World Health Organisation
WRC	Women's Refugee Commission
WV	World Vision

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Executive Summary

In 2010 the United Nations' General Assembly explicitly recognised water and sanitation as human rights that are "essential for the full enjoyment of life and human rights" (UNICEF, 2016, 1). Gender equality has emerged as a core issue within the human rights context of the UN Convention on Rights of Persons with Disability (UNCRPD).

A core principle of the UNCRPD is equality between women and men with disabilities. The recognition of the need for an intersectional approach to disability and gender is not only identified as important in international law, but more and more policy makers are now beginning to understand how the intersection of disability and gender can create additional barriers and inequalities, particularly for women and girls with disabilities (CBM, 2017).

Whilst much progress has been made with respect to implementing Water, Sanitation and Hygiene (WASH) programming, there are certain groups of people and settings which have received less attention, namely older people and people with disabilities and in particular those living in humanitarian settings (WaterAid, 2013; Richard & Kiani, 2019). It is these neglected groups and settings that this research will focus on.

Aim

The aim of this research was to develop an in-depth understanding of the barriers faced by older people and people with disabilities in inclusive WASH programming in internally displaced humanitarian (IDP) settings in Central Darfur State in Sudan.

It focussed on technical/environmental, institutional/organisational as well as attitudinal barriers. It explored how these barriers limited the participation of older people and people with disabilities in inclusive WASH programming.

The Research Location

Central Darfur in Sudan was selected as the location of this study as it had a high prevalence of people living with disabilities. The number of persons with disabilities in the state was estimated to be 80,767, (National Council of Persons with Disabilities, 2019) with 50% of households supporting a family member living with a disability.

The State Council of Persons with Disabilities had been inactive in Central Darfur due to the political change since 2019 and the Covid-19 pandemic. Therefore, Disabled People's Organisations (DPOs) and people with disabilities lacked guidance and directions to activate the UNCRPD and the Sudan Disability Act.

A few organisations were present in the region and included: the Sudanese National Union of Physical Disabled (SNUPD), the Sudanese National Union of the Deaf, and the Sudanese National Union of the Blind. There were no DPOs for people with cognitive disabilities.

Two IDP camps were selected for this research, one near the state capital of Zalengi (Himidiya Camp) and one remote rural camp in Nertiti locality (Shimali Camp). The population of Himidiya Camp was estimated to be over 60,000 whilst in Shimali Camp the population was estimated to be in excess of 34,000. Both camps were established in 2003. Humanitarian agencies have

constructed WASH facilities in the camps in consultation with the Sudanese Government. Due to the protracted security situation these camps are classified as being in the 'WASH Gap', being neither defined as in the humanitarian or development WASH phases as defined by UNHCR.

Research Approach, Methodology and Methods

The project adopted a rights-based approach using the Social Model of WASH Inclusion. This model promotes an all-encompassing approach to WASH by accepting that older people and people with disabilities are just one of many 'different' groups within society. It accepts that difference is a normal part of every society and focusses on identifying and removing barriers that prevent inclusion.

The research employed a Participatory Action Research (PAR) methodology, which is highly effective in generating insights into sensitive issues such as WASH among hard-to-reach groups, for instance older people and people with disabilities. It is particularly useful where stigma and marginalisation makes traditional research methods difficult to implement.

The study used six quantitative and qualitative participatory research tools as follows:

1. **The Adapted Rapid Assessment Method for Older People (RAM-OP) [Modules: WASH, Disability, Activities of Daily Living]: Individual Survey Tool.**
2. **Accessibility and Safety Facility Audit: Group Activity**
3. **Social Model of WASH Inclusion: Group Activity**
4. **Peer-to-Peer Conversations: Individual Interviews**
5. **Mapping International Standards of WASH Inclusion: Focus Group Discussion (FGD)**
6. **Semi-Structured Interviews with older people, people with disabilities, community members and members of Disabled People's Organisations: Individual Interviews.**

Following the granting of Ethical Approval by Coventry University, and due to Covid-19 regulations, a weeklong online research training workshop was held with Muslim Aid staff in London and Sudan. The aim of the research was presented, and the research tools were introduced, discussed and piloted. All documentation including Participant Information Sheets, Informed Consent Forms and Researcher Tool Guides were translated into Arabic.

The online training was then cascaded down by the Sudan National Research Coordinator to those who would be facilitating data collection in Central Darfur. Local researchers were selected by Disabled People's Organisations (DPOs) and Muslim Aid's local partner Sudan Organization for Relief and Recovery (SORR). Thirty-seven (18 females; 19 males) local researchers were recruited including 16 people with disabilities (10 with mobility challenges (6 males and 4 females) and 6 with sensory impairments (3 males and 3 females). In addition, 18 people were recruited as note takers, and one transcriber/translator, and one sign language translator were employed. All were trained in undertaking ethical research.

The field work took place between 17th February and 4th April 2021. Additional data was collected from 30 August to 14 September 2021 to verify and supplement information gathered in the first round of data collection. Ethical processes and Covid-19 biosecurity was observed by all those involved in data collection.

Sampling

In total 652 people, all aged 18 and over and who could give informed consent, participated in the research (326 in each research location). The sampling frame paid particular attention to intersectionality including age, gender and type of disability(ies). Details can be found in Chapter Three.

Findings

The results were analysed thematically by each research tool and are presented in Chapter Four. These were then amalgamated and analysed using the Social Model of WASH Inclusion framework to produce findings from the research (Chapter Five). Four main themes were identified:

1. Characteristics and needs of users. Including type and severity of disability as well as age and gender.

There was no data available on the types and severity of disability in the two IDP camps that participated in this research. The team therefore had to do a rapid survey of the situation using three modules from the RAM-OP Tool (see Chapters Three and Four). The results indicated that 26% of participants self-reported as having mobility disability (73% of whom reported the disability to be moderate to severe). Fifty-six percent of participants reported living with sensory disabilities (80% moderate to severe). Eighteen percent reported they had cognitive disabilities (89% moderate to severe). Forty percent of participants were living with multiple disabilities and therefore had complex WASH needs. The prevalence of multiple disabilities was highest in older people and individuals with cognitive disabilities.

It is important that the complexity of the disability situation of a population in a particular situation to be screened. This should include type(s) of disability as well as the severity of the disability. The proportion of multiple disabilities is also pertinent. This is particularly important when the humanitarian circumstances progress from an emergency to a development situation as was the situation in the IDP camps involved in this research.

The results and findings of this research clearly demonstrate that age, gender and the type and severity of disability are interlocked and cannot be easily separated. These combined characteristics result in specific WASH needs that very often are not accommodated in standardised responses to humanitarian crisis. If real inclusion of older people and people with disabilities into WASH Programming is to be achieved and UNCRPD to be implemented, then the intersection of age, gender and disability type and severity must be considered together.

2. WASH Facilities. The availability, accessibility and useability of latrines/ toilets and water points by older people and people with disabilities.

80% of the participants in the RAM-OP survey indicated that they did not have access to improved non-shared facilities. This was heavily skewed by the data from the rural Nertiti location at 92%. In the group activities though, the participants stated that they had access to improved shared latrines; these were usually located in public facilities such as health or community centres. The same was the case for safe drinking water, with public hand-pump boreholes and taps being accessed at locations such as youth and women's centres. All participants complained that shared latrines/toilets and safe water points were often located some distance from residential areas and were not well maintained.

The main complaint concerning the accessibility of WASH facilities by older people and people with disabilities was the access path or road and the immediate environmental surroundings. Participants at both research locations reported that uneven potholed, narrow paths limited the use of a walking frame or wheelchair and were often strewn with rubbish and stones that hindered access to latrines/toilets and water points. They also complained that the paths often had vegetation over hanging them and were often wet and slippery due to poor drainage near the facilities and especially during the rainy season. This was mentioned by many participants but in particular those with a visual disability. This was the case at both latrines/toilets and water points. A number of women's focus groups mentioned safety issues associated with using WASH facilities after dark and felt that if there was solar powered lighting along the path and at the facilities, this would give them the confidence to use the facilities in the evening.

Most of the usability issues raised by the participants concerned the design of WASH structures. In particular participants criticised the number of steps and their depth at both latrines/toilets and water points. They suggested these should be replaced with gently sloping ramps that were wide enough for a wheelchair or walking frame and that handrails be installed to assist people with mobility as well as visual difficulties. Participants proposed that latrine/toilet cubicles should be bigger and adding a seat and handles would make a huge difference. Replacing hand-pumps with taps would enable the elderly and frail to use them. The provision of seating was mentioned so people could rest whilst waiting to use the facilities. This was particularly requested at water points where people often have to queue for some time to fill their water containers. In addition, participants suggested that providing hygiene services and solar lighting would give some people the confidence to use the facilities, in particular females. It would seem that some relatively simple changes in the design of these facilities would enable more older people and people with disabilities to use the facilities.

3. Social factors that are a barrier to WASH inclusion, including attitudes, stigma and discrimination, family support and resources.

Most participants commented on an apparent lack of acceptance of people with disabilities within their community and a negative social attitude in particular towards older people with disabilities. These social attitudes were perceived by the participants as a major barrier to WASH inclusive programming. People with disabilities were particularly upset by, and critical of, the derogatory terminology used to describe them within their communities. Negative social attitudes concerning older people with disabilities resulted in stigma and discrimination, which was then translated into a lack of individual self-esteem. The combination of stigma, discrimination and low self-esteem were put forward by participants as important reasons for the lack of participation in WASH Programming by older people with disabilities. This was particularly articulated by female participants.

The vast majority of participants both men and women reported that older people and people with disabilities receive almost all their support from their families. Most participants explained that the amount of help and support that a family could give to an older person or somebody with a disability depended on the type and severity of the disability and the resources available to the family. All agreed that older people and people with disabilities were provided with essential services such as food, water and personal hygiene care by their families. However, the family's ability to provide disability aids, such as hearing aids, spectacles and walking frames was compromised by poverty.

Older people and people with disabilities that had no family received less support and were thus very vulnerable and were reliant on community charity and help.

4. Institutional barriers to WASH inclusion. This covered building standards/ guidance, consultation, management and resources.

It did not appear that any building standards or guidance were in place in the two IDP camps with respect to latrines/toilets or water points. This research asked participants to make recommendations as to what improvements could be made to enable them to more easily use these facilities. Whilst the type and severity of disability was a fundamental consideration, a number of suggestions were made that would enable a range of older people and people with disabilities to more easily use such facilities.

In neither IDP camp did there appear to be any consultation mechanism in place to include older people and people with disabilities in decisions concerning the location and design of WASH facilities. Many participants stated that they were not invited to such meetings and if they were, they often could not attend due to financial constraints, in particular the cost of transport. This was particularly the case for people with mobility disabilities. Men with sensory disabilities on the other hand did report attending such public meetings, although deaf people reported having difficulty in communicating during the meetings. Women, particularly younger women with a disability, reported restricted attendance at public meetings, usually because their parents refused to allow them to attend citing personal security as the issue. Thus, age, gender and type and severity of disability were all factors that determined if older people and people with disabilities were invited to public meetings and if they were able to participate. This means that many older people and people with disabilities felt disempowered with respect to inclusive WASH programming.

A dearth of financial resources, tools and trained staff to maintain, repair, replace or build new WASH facilities was mentioned frequently, as was poor local management with respect to daily management and hygiene of WASH facilities. Participants repeatedly requested the provision of disability technical support such as hearing aids, spectacles and mobility aids to allow people to become more independent and their disability mitigated. Also participants persistently raised the need for vocational training for people with disabilities to provide them with income generating skills and to provide livelihood opportunities for them and their families, thus improving their self-esteem.

Recommendations

Older people and people with disabilities should be at the centre of WASH programming. However, they are often treated as homogeneous groups by policy makers and those providing WASH programming. This is clearly not the case as this research demonstrates. This study suggests that using an intersectional lens which includes age, gender as well as type and severity of disability can facilitate more effective inclusive WASH planning and implementation. We recommend:

- The use of some of the research tools used in this research, such as RAM-OP and Accessibility and Safety Facility Audits, to help provide crude baseline data on age, gender, as well as type and severity of disabilities. This will enable effective and much more targeted strategies to be developed and operationalised.

- Stakeholders should work together with local communities to develop appropriate building standards and guidance to ensure WASH facilities are as inclusive as possible, and that communities are more aware of the needs and human rights of older people and people with disabilities. Such consultation should be formalised into programming from an early stage.
- Set up local WASH management committees with representation from older people and people with disabilities of various ages and genders to maintain and ensure hygiene of shared WASH facilities.
- Training, construction and hygiene tools and other resources to be made available so that local communities can effectively manage the daily functioning of WASH facilities. In particular to ensure paths and roads are well maintained, are of a good width to provide access for wheelchair users, are clear of potholes and obstacles, with hand rails where appropriate and benches for people to rest to ensure inclusive public WASH is prioritised.
- Providers of WASH facilities and programming should be trained in UNCRPD and national legislation (eg Sudan Disability Act) and work together with local communities to tackle the stigma and discrimination faced by older people and people with disabilities in IDP camps and to provide affordable disability aids. We recommend:
- The provision (free or at reasonable cost) technical help such as hearing aids, spectacles, mobility aids, incontinence pads and commode chairs for those who need them, to give them more independence and improve their self- esteem.
- Offering vocational training for people with disabilities to provide them with income generating skills and support livelihood opportunities for them and their families.
- Stakeholders should sponsor and participate in national, local and community-based campaigns to raise awareness of the human rights of older people and people with disabilities with a special focus on inclusive WASH programming.
- Programmes to be put in place to tackle the stigma and discrimination faced by older people and people with disabilities in IDP camps. This should include challenging the use of derogatory terminology.
- Help should be put in place specifically for older people and people with disabilities who do not have a family support network and as such are highly vulnerable. These people need to be specifically targeted by WASH programming.
- Support is needed for the few organisations that are present in the IDP camps that work with older people and people with disabilities. In particular facilitating the setting up of DPOs to advocate for and support people with cognitive disabilities.
- Assistance and training for families who are caring for older people and people with disabilities to ensure these vulnerable people are treated with as much dignity and respect as is possible, to ensure their human rights are protected and honoured.

Conclusion

The Social Model of WASH Inclusion needs to be revised to put older people and people with disabilities at the centre of WASH inclusive programming. These groups of people need to be consulted, included and their experiences and views listened to. The complex requirements of older people and people with disabilities should be recognised and formalised in WASH programming. This can be done by encouraging men and women who are living with a disability and/or are over 60 years of age to participate in consultative and planning meetings so their experiences of WASH, the barriers they encounter and their proposed solutions to such challenges can be heard and incorporated into WASH programming to make it as inclusive as is possible. The solution is not just a technical one, although this is important, but social and institutional barriers to WASH inclusion also need addressing if the UNCRPD are to become a reality and the Sustainable Development Goals achieved.

1. Introduction

1.1 Water, Sanitation and Hygiene (WASH)

According to the United Nations, the lack of safe water, sanitation and hygiene constitutes one of the world's most urgent issues to resolve (WHO & UNICEF, 2014, 2021).

Globally it is estimated that in 2020, 25% of people do not have access to safely managed drinking water, 3.6 billion people lack access to safely managed sanitation, and 2.3 billion lack basic hygiene services including soap and water at home (WHO & UNICEF, 2021). It is estimated that 673 million people still practice open defaecation (WHO, 2019a, b). Globally at least 2 billion people use a drinking water source contaminated by faeces (WHO, 2019a, b). Figure 1 taken from the Sphere Handbook (Sphere Association, 2018) clearly demonstrates the linkages between unsafe drinking water, poor sanitation and public health risks such as diarrhoea, cholera, dysentery, typhoid, hepatitis A and polio.

Credit: Elie Gardner/RI - A mini-water yard inside Zamzam Camp, Darfur, Sudan.

Inadequate sanitation and unsafe water are estimated to be the cause of 829,000 global diarrhoeal deaths a year (297,000 in children under 5 years) and is a major factor in several neglected tropical diseases such as intestinal worms, schistosomiasis and trachoma (WHO 2019a, b; GWC, 2020). According to GWC (2020) poor water and sanitation conditions in humanitarian contexts account for nearly 40% of diarrhoeal deaths amongst those living in camps and the figure rises to 80% in children under the age of two years. Hence, reducing child mortality, improving health in a sustainable way and meeting the Sustainable Development Goals (SDGs) requires urgent improved water related services and sanitation (UNW-DPAC, 2015). The Covid-19 pandemic has amplified the need for good hygiene, including the regular washing of hands with soap and water.

Those working to find solutions to these fundamental issues have adopted the abbreviation 'WASH'. The term WASH first appeared in USAID projects back in 1981 and featured in the USAID's project "Water and Sanitation for Health" in 1988 (USAID 1988). From the early 2000s onwards international organisations such as the Water Supply and Sanitation Collaborative Council and International Water and Sanitation Centre started to actively advocate for improvements in sanitation and safe water supply using WASH as an umbrella term for water, sanitation and hygiene (Jong, 2003). International development actors have since adopted WASH as an acronym for water, sanitation and hygiene (WHO, 2005).

According to UNICEF, 'WASH is the collective term for Water, Sanitation and Hygiene. Due to their interdependent nature, these three core issues are grouped together to represent a growing sector' (UNICEF, 2016). While often applied separately in the field, they are all linked. For instance, 'without toilets, water sources become contaminated; without clean water, basic hygiene practices are not possible' (UNICEF, 2016). So as the Inter-Agency Standing Committee (IASC) declare 'WASH is more than 'just' water. It addresses hygiene, water supply, sanitation (excreta management and solid waste management) and vector control. It also relies on a range of expertise from a variety of fields including engineering, public health, communications and behaviour change.' (IASC, 2019, 177).

WASH is therefore regarded as a fundamental building block to both human and economic development, as well as environmental sustainability. Table 1 summarises the key components of WASH.

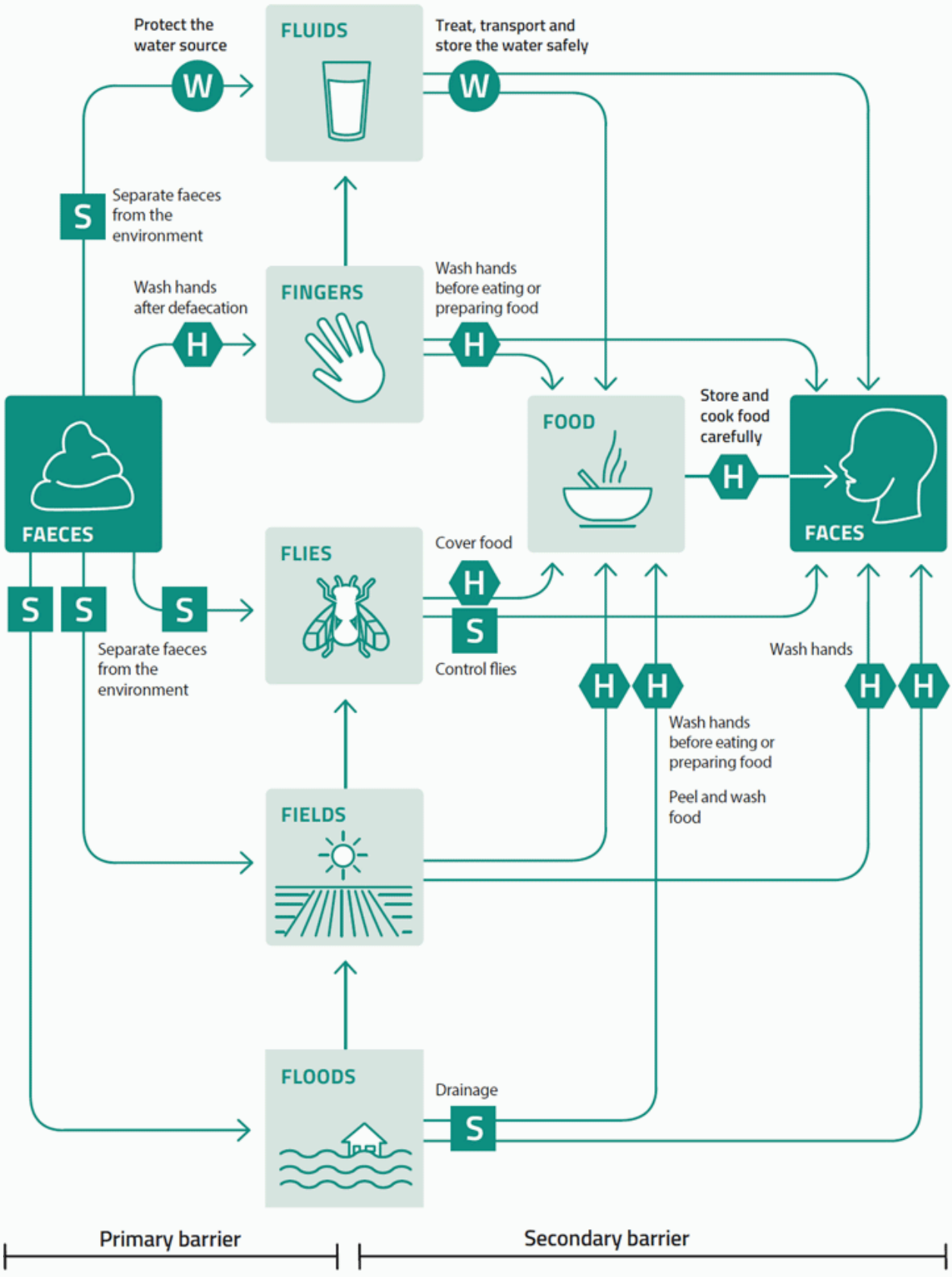
Table 1: Components of WASH. (Adapted from IASC 2019, 179)

Water Supply	The provision of safe water for personal and household needs. Water may be supplied by public utilities, formal or informal commercial organisations, community-based organisations or individuals. Management arrangements also may vary according to the context. The minimum quantity of safe water required ranges from 5-50 litres per person per day depending on context.
Sanitation	The provision of facilities and services for the safe disposal of human faeces and urine and their processing. This includes menstrual hygiene and management of incontinence. It also includes the maintenance of hygienic conditions through services such as rubbish collection, wastewater disposal and drainage. The safe disposal of human (and animal) excreta is a key way of breaking the faecal-oral disease transmission cycle.
Hygiene	The practice of keeping people and public facilities and their environments clean, especially in order to prevent illness or the spread of disease. Environmental controls may remove or reduce the physical spaces where vectors of disease can easily breed and/or can reduce vector-human contact. The promotion of behaviour and community engagement and action to reduce the risk of the spread of disease is an important element. Hygiene promotion (including menstrual and incontinence management) which is adapted to local culture and context regarded as vital to the success of WASH.

However not all elements of WASH receive the same attention and investment. In a report published by Bastable & Russell in 2013, there were three key areas of WASH promotion that were identified as requiring attention. These were excreta disposal (highlighted as being the most neglected part of WASH), followed by hygiene promotion and community mobilisation. A follow up gap analysis of WASH in humanitarian response published in 2021 (Lantagne et al, 2021) presented the gaps in WASH identified in focus group discussions with people affected by crisis. The sanitation gap was identified as the most serious gap (35%) together with water (35%) followed by hygiene (21%). Within the hygiene gap participants highlighted a need for hygiene tools, kits and products.

Providing safe drinking water has been one of the most successful elements of WASH. But as Figure 1 demonstrates, all elements of WASH are interconnected and shows that just providing safe water will not reduce the disease burden and mortality associated with poor WASH programming.

Credit: UNICEF Sari Omer



NOTE: The diagram is a summary of pathways; other associated routes may be important. Drinking water may be contaminated by a dirty water container, for example, or food may be infected by dirty cooking utensils. © WEDC

Figure 1: The 5 Fs: faeces, fluids, fingers, flies, food. (Source: Sphere Association, 2018, 143)

1.2 WASH and Older People and People with Disabilities

In 2010 the UN General Assembly explicitly recognised water and sanitation as human rights that are "essential for the full enjoyment of life and human rights" (UNICEF, 2016, 1). However, whilst much progress has been made with respect to implementing WASH programming, there are certain groups of people and settings which have received less attention, namely older people and people with disabilities and in particular those living in humanitarian settings (WaterAid, 2013; Richard & Kiani, 2019). It is these neglected groups and settings that this research will focus on.

It is estimated that 15% of the world's population have a disability equating to over 1 billion people (IASC, 2019; UNOCHA, 2021). More than 46 percent of older people (defined as over 60 years by UNFPA & HelpAge International, 2012. and the definition used in this research) are living with disabilities, including more than 25 million experiencing moderate to severe disabilities (UN Department of Economics and Social Affairs 2020; UNOCHA, 2021). One in ten children have a disability, with one in twenty women likely to experience disability during their lives (IASC, 2019). Christian Blind Mission (CBM) (2017) estimate that 20% of the poorest people living in developing countries have a disability with more than 80% of all people with a disability living in developing countries. Therefore, there is an estimated one billion people in the world living with disabilities, 800,000 of whom live in developing countries. Their inclusion in WASH provision is therefore crucial if their Human Rights are to be protected (WHO & World Bank, 2011). UNICEF (2019a) estimates that globally, 110 million people living with disabilities do not have access to improved WASH services.

Although there is no single definition of disability (Mitra, 2006), the UN Convention on the Rights of Persons with Disabilities (CRPD) recognises that 'disability is an evolving concept' (UNCRPD, 2006,1) and proposes an inclusive definition of persons with disabilities as follows: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (Convention on the Rights of Persons with Disabilities, art. 1) (UNCRPD 2006, 4; CBM 2017, 16; UN 2019, 37). This is the definition that was applied in this research project.

Put simply, disability can be defined as the relationship between a person's impairment and their environment. CBM (2017) express this as an equation shown in Figure 2. This illustrates that impairment alone does not lead to disability if there is a completely inclusive and accessible environment. As CBM state, 'Ultimately, the way in which people perceive and experience disability in day-to-day life is far more complex than a simple definition or equation. It is also highly influenced by cultural beliefs; for example, in some cultures, disability is erroneously viewed as a curse or the influence of a bad spirit.' (CBM 2017, 16). Thus an 'accessible environment' is part of inclusive WASH programming and will alter a disability into an impairment.

Figure 2: The difference between disability and impairment. (CBM 2017, 16)

Impairment + barrier = disability

or better:

Impairment + accessible environment = inclusion

Whilst there are many different experiences of disability, there is an agreed understanding of what disability means in terms of universal human rights that are enshrined in the UNCRPD (2006). The Convention of the Rights of People with Disability (CRPD) recognises people with disabilities to be active subjects, capable of claiming their rights and making decisions about their lives based on their free and informed consent (CBM 2017). These are applicable to WASH interventions. The general principles of the Convention are laid out in Article 3 and include:

I. **Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;**

II. **Non-discrimination;**

III. **Full and effective participation and inclusion in society;**

IV. **Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;**

V. **Equality of opportunity;**

VI. **Accessibility;**

VII. **Equality between men and women;**

VIII. **Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.** (CBM 2017, 18-19)

All of these are relevant and should be central to the planning, designing and implementation of WASH interventions. Access to safe water, sanitation and hygiene facilities is a fundamental human right and is essential to any humanitarian response. However, many people with disabilities do not have access to these basic rights. The reasons for this are unique to each circumstance, including the physical environment in which a person with disability lives, the relationship they have with other members of their household, their economic and social status, their access to assistive equipment, the functional impact of the person's impairment, and the water, sanitation and hygiene resources and facilities available within their community (WV & CBM, 2018). These issues are amplified in humanitarian contexts.

1.3 Gender and Disability

Gender equality has emerged as a core issue within the human rights context of the UNCRPD. A core principle of the UNCRPD is equality between women and men with disabilities.

The recognition of the need for an intersectional approach to disability and gender is not only identified as important in international law, but more and more policy makers are now beginning to understand how the intersection of disability and gender can create additional barriers and inequalities, particularly for women and girls with disabilities (CBM, 2017). The UNCRPD takes a gender mainstreaming approach focused on ensuring equality between women and men with disabilities with specific measures to empower and advance the rights of women with disabilities (CBM, 2017).

According to CBM (2017) understanding how disability and gender intersect is key to identifying and dismantling root causes of discrimination for women, men, girls and boys with disabilities and also other marginalised groups. As CBM (2017) states, it is essential to use a gender lens 'to

recognise, understand and address the different lived experiences of women and men, girls and boys with different impairments in the very diverse communities and contexts.' (CBM, 2017, 88). Equally age should also be a consideration, as when combined with gender and disability can result in severe marginalisation and neglect as well as discrimination, not just for the individual but also their carers and family. This is particularly pertinent to WASH and especially in humanitarian situations.

1.4 WASH in Humanitarian Settings

In 2021, on-going and new crises including the effects of the Covid-19 pandemic left 235 million people in need of international humanitarian assistance (UNOCHA, 2021), an increase of over 40% on 2020 almost entirely due to Covid-19. Of these 235 million UNOCHA (2021) state that the most vulnerable 160 million lived in 56 countries.

The majority of these people continuing to comprise internally displaced people fleeing conflict, violence and natural disasters with many living in protracted displacement situations. In 2020 the number of people forced into displacement exceeded 82 million with approximately two-thirds of these people being internally displaced (UNHCR, 2020). Of the forcibly displaced people in 2020 it was estimated that 20 million were living with a disability (Women's Refugee Commission (WRC), 2020).

In contexts of conflict, displacement and humanitarian emergencies, disabilities increase due to conflict or disaster-related impairments and lack of access to services (Handicap International, 2015). Yet 'despite being significant population groups, people with disabilities and older people are often invisible in humanitarian action' (Akerkar & Bhardwaj 2018, 10), where one-size-fits all approaches are dominant as: 'Factors such as health risks, injuries and chronic illness are behind increased disability rates among older people.' In addition, older people are facing additional ageing attitudes from humanitarian actors where humanitarian operations tend to adopt a one-size-fits-all approach in their emergency responses, hence older people's needs are often overlooked in humanitarian interventions (Slim 2018; Age International & HelpAge International 2016).

The Sphere Handbook (Sphere Association, 2018) details the Sphere WASH Standards for humanitarian settings and are shown in Figure 3. The Sphere Handbook states that: 'the main objective of WASH programmes in disasters is to reduce the transmission of faecal-oral diseases and exposure to disease-bearing vectors through the promotion of:

- **Good hygiene practices**
- **The provision of safe drinking water**
- **The reduction of environmental health risks**
- **The conditions that allow people to live with good health, dignity, comfort and security.** (Sphere Association, 2018)

In 2019 Richard & Kiani (2019) published a rapid review focussing on inclusive WASH interventions in humanitarian contexts. The review revealed a general appreciation concerning inclusive awareness and efforts towards inclusive WASH interventions in humanitarian contexts, but concluded that 'In general, literature on inclusion of older people is scarcer than that for those with a disability.' (Richard & Kiani, 2019, 19). They continued: 'More interventions focused on inclusion of disability, and considerably less focused on age inclusion. This highlights that a siloed approach to inclusion

is often taken: interventions focus either on disability, gender or age without integrating these intersecting factors in a holistic approach.' (Richard & Kiani 2019, 25). For example, Richard & Kiani (2019) could find no information or any interventions addressing menstrual health management for girls and women with disabilities living in humanitarian settings. They concluded: 'Though dimensions of good practices were noted, important gaps in equitable and inclusive WASH provision were identified, where people with disabilities and older people continue to face barriers in realising their right to access WASH.' (Richard & Kiani, 2019, 55).

Credit: UNICEF/UN075399/Kealey - Access to safe drinking water means Angelina and her children, and others in the community, won't be sickened by waterborne disease.

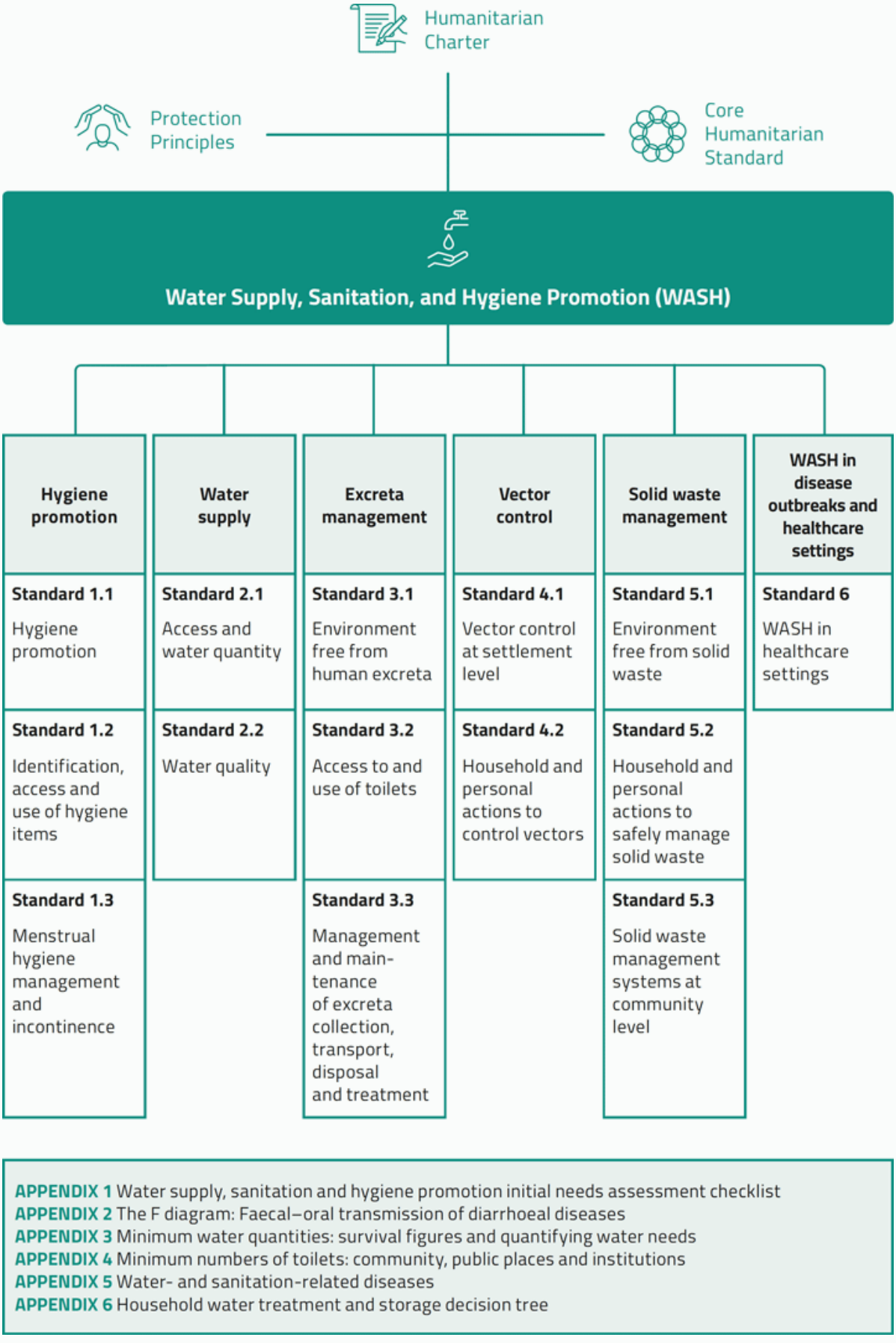


Figure 3: Sphere WASH Standards (Source: Sphere Handbook, 2018, 90)

Until recently there has been a clear distinction between WASH interventions undertaken from a humanitarian perspective, namely focusing on short term, emergency issues, and those focusing on longer-term development needs (Parkinson 2009; Save the Children 2019; GWC, 2020). Tillet et al (2020) refer to humanitarian and development WASH programming as 'silos' and have produced a Humanitarian-Development Divide/Nexus. This distinction appears irrational as many emergency situations become prolonged and protracted humanitarian contexts and sustainable development focussed WASH initiatives are required. Tillet et al (2020) state ''Conventional' humanitarian responses and funding are increasingly not fit to address the needs of protracted crisis' (page 12). UNICEF (2019) explain: 'Preventing WASH systems from deterioration and collapse in protracted crisis must be a major priority of humanitarian responses – and closely connected to sustainable development policies.' (page 17).

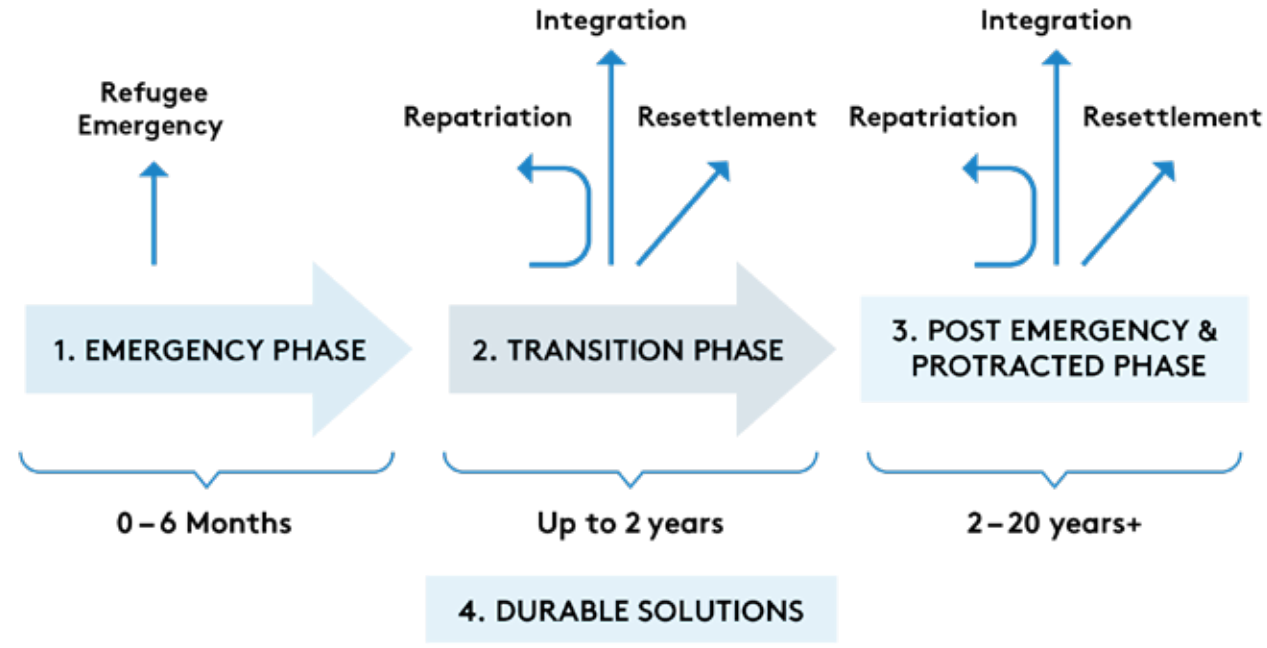
This leaves many people living in humanitarian situations in what has been termed a 'humanitarian WASH gap'. This is a situation where facilities and services have been provided as short-term emergency measures and are very often unsuitable for longer term development contexts. However globally there is currently a move to expand the range of WASH services from the emergency humanitarian phase (< 6 month), transitional phase (6 month to 2 years) and post emergency and protracted phase (2-20 years) (Save the Children, 2019; UNHCR, 2020b; GWC, 2020). (See figure 4 below). Whilst this is to be applauded there is a growing recognition of the need to devise strategies that link these phases in a more effective and efficient manner (Save the Children, 2019; UNICEF, 2019) and break down the silos between humanitarian and development WASH programming (GWC, 2020). The Global WASH Cluster (GWC) Road Map 2020- 2025 (2020), recognises this disjuncture and states the Road Map 'will be focussed on saving lives, reaching better public and environmental health outcomes and building synergies between acute and complex emergencies, human crises and long term development.' (GWC, 2020, 6). In order to achieve this GWC claims 'we will link humanitarian and development WASH programming through new and innovative approaches aimed at overcoming the 'siloed' and 'business as usual' approach.' (GWC, 2020, 16). They plan to achieve this by:

1. **Reinforcing linkages between humanitarian and development WASH actors.**
2. **Calling for a Human Rights Approach that leaves no one behind.**
3. **Accelerating climate change adaptations in delivering services and assistance.**
4. **Embedding water scarcity and responsible water resource management into project design and implementation.**
5. **Integrating environmentally sound durable and sustainable solutions using appropriate technology.** (GWC, 2020, 24).

Save the Children (2019) proposes a sustainable WASH Model which focuses not only on the technical but also the institutional, socio-cultural, financial and environmental aspects of WASH interventions which may go some way in dealing with the issue.

Addressing the humanitarian WASH gap is a priority if the Sustainable Development Goals (SDGs) are to be achieved. As a Save the Children Report (2019) concludes: 'A more systematic approach is needed to understand how to bridge the humanitarian and development divide from both the health and social outcome perspective.' (p.22).

Figure 4: Overview of UNHCR WASH Priorities by Phase (source: UNHCR, 2020, 8)



- ☐ Immediate Lifesaving Interventions
- ☐ Communal WASH Facilities
- ☐ Higher Immediate Cost

- ☐ Intergration with National Systems
- ☐ Household WASH Facilities
- ☐ Low long Term Operational Costs

Emergency Phase WASH Priorities:

- ☐ Saving lives/reducing transmission of diseases of public health importance
- ☐ Provide immediate access to basic WASH services
- ☐ Identification of suitable refugee hosting sites
- ☐ Close monitoring of WASH service provision and rates of scale up
- ☐ Full refugee participation in the design and provision of WASH services to reduce protection risks

Transition Phase WASH Priorities:

- ☐ Transition to cost efficient services with reduced reliance on fuel, energy, chemicals and expertise
- ☐ Support to national WASH authorities and WASH service providers
- ☐ Capacity building of refugee community based organisations
- ☐ Transition to household toilets and bathing facilities
- ☐ Monotiring of WASH services
- ☐ Reduce WASH protection risks

Post Emergency & Protracted Phase WASH Priorities:

- ☐ Service provision to National WASH Strategies, Policies and Standards
- ☐ Handover of responsibility for WASH service provision to refugee community based organisations and national WASH authorities and service providers
- ☐ Revenue collection if refugee livelihood opportunities exist (fees collected to cover the costs of WASH services)
- ☐ Monotiring of WASH services
- ☐ Reduce WASH protection risks

1.5 Older People and People with Disabilities in Humanitarian settings

A 2015 survey published by Handicap International (2015) found that while WASH was identified as a priority by 62% of people with disabilities in humanitarian contexts who were interviewed, only 30% reported having full access.

Further, only 36% of WASH humanitarian actors responded that basic WASH services were accessible. Social, attitudinal, environmental and institutional barriers to participation and access to humanitarian assistance, put people with disabilities and older people at higher risk of exclusion (Stough, et al 2015).

Understanding that disability, age and gender, among other identities (e.g. ethnicity, refugee status) are universal determinants that are interrelated and have an impact on the realisation of rights, it is important to consider how the combination of these factors impact on people's needs and exposure to risks and capacities, especially in humanitarian contexts in particular the right to WASH. Real life examples from the perspective of people with disabilities and older people in humanitarian settings are given in Figure 5.

Credit:© WaterAid/James Kiyimba - Olupot, Abibico village, Uganda.

Figure 5: Common barriers to access WASH for people with disabilities and older people (Richard & Kiani, 2019, 20)

Common barriers to access WASH for people with disabilities and older people	
Services are not adapted or accessible	• Lack of specific items (e.g. commode chairs or bedpans, water containers) or private facilities • Latrines, bathing areas and water points are not accessible (not meeting universal design standards) • Distance to access water and sanitation • Water points and sanitation facilities located at a distance and/or difficult to access due to poor accessibility of roadway
Financial barriers / Service too expensive	• Mainly related to insufficient, unavailable or inaccessible safe water, requiring beneficiaries to purchase water posing additional financial burden on their household.
Lack of safety	• Lack of lighting at sanitation facilities makes it challenging to access especially at night • No locks on latrine doors
Lack of information on services	• Information not available and/or accessible
Negative attitudes / stigma / discrimination	• Being intimidated or mocked when using services

IASC (2019) has analysed the issues and has identified three key barriers with respect to access and inclusion of people with disabilities and older people in accessing WASH in humanitarian settings (see Figure 6). It classifies the barriers into three categories: environmental, which includes accessibility of facilities and information; attitudinal, namely negative attitudes and stigma and; institutional, when sector standards and guidelines are not implemented, due to a range of factors which might include limited budgets and lack of technical capacity. These three barriers to inclusive WASH interventions result in increased risk to vulnerable people such as those people living with disability or older people.

The Age and Disability Capacity Programme (ADCAP) (2018) has identified three standards that apply to older people and people living with disabilities with respect to access to WASH in humanitarian settings. These are:

WASH Inclusion Standard 1:

Older people and people with disabilities have their WASH-related capacities and needs identified and monitored:

1.1. Adapt WASH assessment and monitoring tools to collect information on the capacities and needs of older people and people with disabilities.

1.2. Include older people and people with disabilities in WASH assessments and monitoring activities. (ADCAP, 2018, 123).

WASH Inclusion Standard 2:

Older people and people with disabilities have safe and dignified access to water supplies, sanitation facilities, and hygiene promotion activities:

2.1. Design, construct and adapt accessible water supply and sanitation facilities.

2.2. Review and adapt distribution methods and supplies to provide safe and equitable access for older people and people with disabilities.

2.3. Sensitise the community, staff and partners on the right of older people and people with disabilities to access WASH activities and services.

2.4. Build the capacities of staff and partners to make WASH services, facilities and programmes inclusive of older people and people with disabilities. (ADCAP, 2018, 127)

WASH Inclusion Standard 3:

Older people and people with disabilities participate in WASH activities:

3.1. Strengthen the WASH-related capacities of older people and people with disabilities.

3.2. Support the participation of older people and people with disabilities in WASH programmes and related decision-making. (ADCAP, 2018, 135)

The Sphere Association (2018) reminds us that the right to water and sanitation is part of the Universal Rights essential for human survival and dignity and that state and non-state actors have responsibilities to fulfil this Right. The Sphere Handbook (Sphere Association, 2018) emphasises that this Right includes:

- **Access to a sufficient, safe and affordable water supply for personal and domestic use.**
- **Access to private, safe and clean sanitation facilities.**

Figure 6: IASC WASH Inclusion International Standards (Source: Adapted from: IASC, 2019)

WASH Inclusion Barriers	WASH Inclusion International Standards
Environmental Barriers	1. WASH facilities or supplies such as latrines/toilets, water sources, hygiene kits and water containers should be accessible to older people and people with disabilities. 2. Signage and information regarding WASH services, facilities and programmes should be accessible to older people and people with disabilities. 3. Accessible WASH facilities should be located to be convenient for older people and people with disabilities.
Attitudinal Barriers	1. Eliminate negative attitudes and stigma against older people and people with disabilities. 2. WASH actors and organisations to have knowledge and awareness on how to effectively communicate with older people and people with disabilities to ensure their inclusion in WASH programming. 3. Older people and people with disabilities should be actively involved in WASH programming and decision making. 4. Promote the participation of older people and people with disabilities in formal and informal mechanisms and processes concerning WASH programming.
Institutional Barriers	1. Improve/increase technical capacity to promote the inclusion of older people and people with disabilities in WASH. 2. Sector standards, guidelines and policies should include the requirements of older people and people with disabilities. 3. Budgets to include funding to ensure accessible latrines/toilets and other WASH facilities and supplies. 4. Ensure building codes and supply chains include accessibility and universal design. 5. Need for accurate data on the requirements of older people and people with disabilities with respect to inclusive WASH programming. 6. Mainstream the protection and safeguarding measures across all WASH interventions, in particular recognising the gendered aspects of some protection and safeguarding risks. 7. Key stakeholders should advocate and promote inclusive WASH services.

1.6 WASH Inclusion Standards

In the contexts of humanitarian emergencies, access to water and sanitation can be affected, which can lead to increased morbidity and deaths, and lack of hygiene can contribute to various infectious diseases (Sphere Association, 2018). In these situations, people with disabilities and older people are disproportionally affected due to not having adequate access to water and sanitation (WHO & World Bank 2011). Therefore, the provision of safe water, adequate sanitation and improved hygienic conditions is relevant. In particular, WASH provision is needed in humanitarian contexts because illnesses and deaths can be exacerbated due to the vulnerability of people with disabilities and older people as well as the fragile nature of emergency and humanitarian situations.

In order to achieve this, the Inter-Agency Standing Committee (IASC 2019) has published a series of guidelines that build on existing and more general standards and guidelines. These are designed to ensure that all phases of humanitarian actions (preparedness, response and recovery) are disability inclusive. These are the first guidelines for humanitarian settings that have been developed with and by people with disabilities, their representative organisations and traditional humanitarian stakeholders. According to IASC (2019) the guidelines 'ensure persons with disabilities have equal rights and opportunities to access WASH programmes and services, remove barriers, promote comprehensive inclusion and effective participation.' (p 181). As IASC (2019) state, WASH interventions should mainstream people with disabilities:

- **'WASH programmes and interventions are designed and adapted to ensure that they are inclusive of and accessible to everyone, including persons with disabilities.'** (p.181)

But at the same time interventions might also need to target people with disabilities:

- **'WASH programmes accommodate the individual requirements of persons with disability, for additional water, incontinence kits, toilet chairs, skin care lotions, etc.'** (p. 181)

Implementing these guidelines should enable persons with disabilities to become actors in the humanitarian response and will place them at the centre of humanitarian actions.

These guidelines are likely to become the gold standard in terms of disability inclusion in WASH interventions in humanitarian settings.

1.7 Aim of the research

The aim of this research was to develop an in-depth understanding of the barriers faced by older people and people with disabilities in inclusive WASH programming in internally displaced humanitarian settings. It focussed on technical/environmental, institutional/organisational as well as attitudinal barriers. It explored how these barriers were perceived and limited the participation of older people and people with disabilities in inclusive WASH programming.

The project was underpinned by a rights-based approach using the Social Model of WASH Inclusion. It employed a Participatory Action Research (PAR) methodology and used quantitative and qualitative participatory research tools to understand different types of barriers faced by older people and people with disabilities in WASH programming. It paid particular attention to intersectionality including age, gender and type of disability(ies).

The research took place in two Internally Displaced Persons (IDP) camps in Central Darfur, Sudan.

2. Context of WASH in Sudan
(including IDP camps and Central Darfur)

2.1 WASH in Sudan

In 2020, WHO and UNICEF (2021) report that 60% of Sudanese households had access to basic drinking water (53% in rural areas compared to 74% in urban areas), with 37% having access to safely managed sanitation services.

The same report estimates that 24% of people defaecate in the open, with the figure being 36% in rural areas compared to 2% in urban areas. It also states that only 13% of people have access to basic hygiene services, including soap and water in their homes. Thus, the disparities identified in the MICS 2014 survey (UNICEF 2016a; AFMM, 2020) between different states and between urban and rural settlements perpetuate.

Table 2 compares WASH access data from Sudan with the averages from sub-Saharan Africa and the Least Developed Countries. It is difficult to compare the data concerning access to safely managed water in Sudan with other regions, as the Sudanese data for this category is not available, instead access to basic drinking water is recorded. With respect to safely managed sanitation services Sudan appears to have a higher proportion of the population having access compared to the averages of sub-Saharan Africa and Least Developed Countries. However, it has a much higher proportion of people who defaecate in the open. Access to basic hygiene services are also well below the average for sub-Saharan Africa and Least Developed Countries. The data for rural areas is consistently poorer than for urban areas. Unfortunately, more granular data is not available for older people and people with disabilities.

Table 2: Proportion (%) of population having access to safely managed drinking water and sanitation, open defaecation and access to basic hygiene services in 2020: Sudan compared to other global regions. (Compiled from WHO & UNICEF, 2021).

Country/ Region	Safely Managed Drinking Water			Safely Managed Sanitation Services			Open Defaecation			Access to Basic Hygiene Services		
	Total	Rural	Urban	Total	Rural	Urban	Total	Rural	Urban	Total	Rural	Urban
Sudan*	60	53	74	37	24	60	24	36	2	13	-	-
Sub-Saharan Africa	30	13	54	21	19	23	18	27	5	26	18	37
Least Developed Countries	37	28	55	26	25	27	16	22	4	37	31	47
World	74	60	86	54	44	62	6	13	<1	71	60	-

* 'Access to basic drinking water'. No data for access to 'safely managed drinking water'. | - No data

Differences in access to WASH services are not just geographical. The same report (WHO & UNICEF, 2021) demonstrates that access to WASH is also associated with wealth.

Table 3 reveals the difference in WASH access by the wealthiest quintile of the population compared to the poorest quintile. The data shows very clearly that poverty is a significant barrier to access to WASH programming.

Table 3: Sudan: Inequalities in access to WASH by wealth quintiles. (Compiled from WHO & UNICEF, 2021. Data from 2014).

Access to WASH by wealth quintile	Percentage of total population (%)
Basic Drinking Water	
Poorest quintile	36
Richest quintile	96
Basic Sanitation	
Poorest quintile	7
Richest quintile	78
Open Defaecation	
Poorest quintile	54
Richest quintile	<1
Basic Hygiene	
Poorest quintile	16
Richest quintile	49

The Sudanese Government pledged in 2020 to ensure that by 2030 that all the people living in Sudan would have access to sustainably managed water and sanitation (AFMM, 2020). In particular 'Achieve – by 2030-universal and equitable access to safe and affordable drinking water for all. Achieve – by 2030- access to adequate and equitable sanitation and hygiene for all and end open defecation.' (AFMM, 2020, 2-3). The pledge also mentions providing gender and disabled people sensitive access to domestic basic water supplies and household basic sanitation facilities. However the Sudan Government does recognise there are challenges and limitations in delivering these pledges, of particular note is the 'Absence of WASH Policy' and 'Lack of an overall effective WASH coordination mechanism.' (AFMM, 2020, 3). As well financial constraints.

Credit: UNICEFSouthSudan/Hill - Rose Peter and one of her neighbors are sitting in front of the water kiosk, waiting for the water project to be ready and for the water to be turned on.

2.2 Water

The Government of Sudan conceptualises the provision of drinking water as a three-step ladder with water that is piped into a dwelling, plot or yard being regarded as the safest source and at the top of the ladder (37% of households). This is followed by other improved sources of water usually shared (31% of households) with unimproved drinking water being at the bottom of the ladder with 32% of households using such water for drinking (Government of Sudan, 2017, 124).

The two main water sources in Sudan are groundwater and surface water including from the Blue and White River Niles, as well as irrigation channels. In rural areas rainwater is also collected in earth dams or hafirs and some households also use rainwater harvesting. Some areas of Sudan rely on groundwater abstracted from hand dug wells and boreholes, with hand pumps, motorised pumps or by hand using a bucket and rope. Spring water is also utilised in some areas of Sudan. Particular challenges for water safety related to groundwater include:

- **High levels of fluoride, nitrates / nitrites and sometimes sulphates.**
- **Contamination of hand dug wells that are not protected.**
- **Resistance of some communities, particularly in pastoral areas to cover and protect hand dug wells, because queuing for water from a hand pump is more time consuming for abstracting water for livestock than using separate buckets.**
- **Maintenance of abstraction systems such as hand pumps and motorised pumps.**
- **Decreasing water tables due to climate change or due to over-abstraction against the capacity of the borehole.**
- **Pollution of groundwater sources from septic tanks and pit latrines.**
- **Some boreholes not having tanks and hence water is pumped into a pond lined with a plastic sheet. In Sudan disposing of sludge on the ground surface in ponds is also not prohibited, and it is one of the main hazards not only to groundwater but also to human health** (Government of Sudan 2017b).

Hazards from drinking water may come from naturally occurring chemicals in the water or from external pollutants. These may occur due to natural fluctuations in weather conditions; inadequate protection, siting, design and construction; inadequate management or operation and maintenance; or inadequate community engagement, communication and/or enforcement (Government of Sudan 2017b). In different areas of Sudan, problems are related to health risks, challenges for treatment or acceptance by consumers with many refusing to use water that has been chlorinated. According to the Government of Sudan (2017b) Fluorides, Nitrates, Chlorides, Total Dissolved Solids, Sulphates, metals, pesticides, insecticides, fertilisers, or petroleum products are the principal chemical pollutants, whilst microbiological or biological hazards include a range of bacteria, viruses and protozoa, as well as algae. Examples of health-based risks include Cholera, Giardia, Shigella, Typhoid, Hepatitis A and E and Fluorosis (Government of Sudan 2017b).

In 2017, the Government of Sudan published the Sudan Drinking Water Safety Strategic Framework led by the Ministry of Water Resources, Irrigation and Electricity with the Federal Ministry of Health. The aim of the framework is to provide strategic direction to the scaling up of access to safe drinking water across Sudan. This will be through providing drinking water systems that are appropriately designed which effectively protect the drinking water at all times to minimise faecal contamination and elevated levels of toxic chemicals; and through ensuring that treatment processes are effective and sustainable (Government of Sudan 2017b).

2.3 Sanitation and Hygiene

The Government of Sudan conceptualises the provision of sanitation as a four-step ladder. At the top is improved sanitation available in a dwelling, plot or yard (33% of households). Next step down is improved sanitation facilities that are shared, often public facilities (8% of households), next is unimproved sanitation facilities (30% of households) and at the bottom of the ladder are households which have no access to sanitation facilities and defaecate in the open (29% of households) (Government of Sudan 2017a, 124). This means that nearly a third of households in Sudan, equivalent to over 10 million people, practice open defaecation. Sudan has the highest prevalence of open defaecation in the Middle East and North Africa region, posing a grave public health risk to transmission of diseases such as cholera.

Sudan is a signatory to key global actions and commitments on sanitation and hygiene such as the AfricaSan and Sanitation and Water for All; the eThekwini and Ngor Declarations. However, as the data above shows there has been a wide gap between political commitment to and the provision of sanitation coverage. One of the reasons has been that sanitation has received low prioritization in WASH strategies so far, with most of the funding and resources being allocated towards provision of water resources. Second, on the whole, the sector funding for sanitation has been low, both among donor funding and investments made by the government. Thirdly, there are several bottlenecks at the institutional level with inadequate capacity to roll out and implement community led sanitation approaches, weak coordination and lack of harmonization among different actors engaged in sanitation. Another reason has been the greater attention given to humanitarian contexts than development, with most of the donor funding being directed towards addressing emergency situations which is a growing concern in Sudan (Government of Sudan 2016).

According to a Government of Sudan report (2016) access to improved sanitation and hygiene information increases the time that is spent in school and work, due to less time off due to sickness,

looking after the sick or in order to manage a woman or girl's menstrual period and it reduces the workload burden, particularly on women and girls. It can also 'improve dignity and reduce shame and embarrassment associated with open defecation and the management of menstrual hygiene; and it contributes to increased cognitive function and concentration in school for both girls and boys. It can also contribute to reducing vulnerabilities to violence particularly for adolescent girls, women and children through reducing the need to practice open defecation or using unsafe facilities, which can lead to opportunities for harassment or assault. Accessible facilities can contribute to ensuring health, dignity and quality of life for people with disabilities and mobility limitations.' (Government of Sudan 2016, 23). The Government of Sudan has introduced 10 steps to be implemented in order to assess, plan and implement hygiene promotion. These are summarised in Table 3.

Table 3: Hygiene Promotion Assessment, Planning and Implementation Steps

(Source: Government of Sudan 2017a: 9-10)

Steps	Issues
Step 1 - Assessment Conduct rapid assessment to identify risk practices and get an initial idea of what the community knows, does, and understands about water, sanitation, and hygiene.	• What is the current WASH situation? • Which specific practices allow diarrheal microbes/other diseases to be transmitted? Which practices are the most harmful? • Identify needs of vulnerable groups
Step 2 - Initial consultation Consult women, men, and children on contents of hygiene kit & possible locations and designs of latrines and bathing facilities for safety, privacy and usability	• What specific hygiene needs do men, women, and children have e.g. sanitary towels, razors, potties?
Step 3 - Planning Select practice(s) and hardware for intervention (define objectives and indicators)	• Which risk practices are most widespread? • Which will have the biggest impact on public health? • Which risk practices are alterable? • What can be done to enable alteration of risky practice?
Step 4 - Target Audience Define target audiences (this may be all the affected community with priority focus on those who care for young children) and identify stakeholders	• Who employs these practices? • Who influences the people who employ these practices? E.g. teachers, community leaders, Traditional Birth Attendants etc.

Step 5 - Priority methods • Define initial mode of intervention • Determine initial key messages and channels of communication • Determine advocacy and training needs for stakeholders	• What mass media methods are available? E.g. 60% of people have radios but they are often used only by men • What methods do the target audiences trust? E.g. traditional healer, discussions at women's group meetings • Where/how, can men and women be accessed? E.g. distribution queue, water point
Step 6 - Recruit and train Recruit/identify and start to train fieldworkers and establish outreach system	• What capacity (systems, skills, and approaches) already exists in government/national NGOs?
Step 7 - Implementation Begin implementation and continue assessing situation	• Distribute hygiene kits • Emphasis initially on providing information and use of mass media e.g. radio spots, campaigns, and home visits by volunteers • Organize group meetings/interviews and discussions with key informants and stakeholders to initiate a more interactive approach.
Step 8 - Ongoing assessment • Develop baseline • Understand motivational factors/ refine key messages	• Obtain quantitative data where feasible. • Carry out systematic collection of qualitative data using participatory methods (coordinate with others and be careful not to overwhelm communities with over questioning) • What motivates those who currently use safe practices? • What are the advantages of the safe practices? • What differences in need and priorities are there for vulnerable groups?
Step 9 - Monitor	• Are hygiene kits being used/are people satisfied with them? • Are toilets being used/are people satisfied with them?

	• Do men and women feel safe when accessing facilities? • Are people washing their hands? • Is drinking water in the home free from contamination?
Step 10 - Implementation • Refine communication plan • Rapidly adapt intervention according to outcome of monitoring • Continue training • Continue monitoring	• Emphasis more on interactive methods e.g. group discussions using mapping, three pile sorting etc. • Identify and train (with engineers) longer term structures e.g. committees

Source: Muslim Aid – Data Collectors in Central Darfur

2.4 Legal Instruments

It is estimated that 52 laws in Sudan make reference to drinking water and sanitation. A number of key laws, acts, regulations and standards have relevance to drinking water safety with the most important ones being: Environmental Health Law, 2009; Water Resources Code, 1995; Environmental Conservation (Protection) Act, 2001; Local Government Laws, 2003 and 2016; Regulations on Drinking Water Safety Control, 2014; Regulations of License of the Exploitation of Groundwater, 2014; and the Sudanese Drinking Water Quality Standards, 2016 (Government of Sudan 2017b). The strategies and policies with most direct relevance to drinking water safety include the Environmental Health Strategic Plan, 2015-16 and the Water, Sanitation and Hygiene (WASH) Sector Strategic Plan, 2012-16. There are currently no Sudan specifications for drinking water related equipment and chemicals, so sometimes international or British Standards are referred to, particularly for construction. Chlorination guidelines are being updated. (Government of Sudan 2017b)

Credit: UNICEF - Happy young girl carrying water on her head

With respect to sanitation the Sudan National Sanitation and Hygiene Strategic Framework was published in 2016 (Government of Sudan 2016). A review is underway of the policies and laws for Sudan with relevance to WASH. The WASH Sector Strategic Plan, 2012-2016 highlights particular issues for pollution such as the increase in population pressure along the Nile and the lack of sewerage/agriculture drainage water treatment and as a result water related health risks are increasing. It highlights that 'safe water handling and reuse' is part of community-based hygiene and sanitation promotion and this one of the six components of the rural sanitation and hygiene approach. The urban sanitation approach focuses on the role of the water corporations and highlights the old infrastructure and poorly functioning water treatment systems (Government of Sudan 2017).

The main Government of Sudan legal Instruments for WASH are:

- **Sudan National Sanitation and Hygiene Strategic Framework** (Government of Sudan 2016)
- **Drinking Water Safety in Sudan** (Government of Sudan 2017)
- **Emergency Technical Guidelines for Sudan** (Government of Sudan 2017a)
- **Sudan Drinking Water Safety Strategic Framework** (Government of Sudan 2017b)

According to a Government of Sudan report published in 2016, there has never been an approved water, sanitation and hygiene policy in Sudan, although WASH Strategic Plans exist at national and state levels (Government of Sudan 2016, 16). What is clear that drinking water safety takes precedence over sanitation and hygiene and that the three are not treated as connected.

2.5 WASH, People with Disabilities, Older People and other vulnerable groups in Sudan

Through the Persons with Disabilities Act of 2017 (Government of Sudan 2017c), Emergency Technical Guidelines (Government of Sudan 2017a) and the Sudan National Sanitation and Hygiene Strategic Framework (Government of Sudan 2016), women and adolescent girls, elderly, children, people living with disabilities and HIV/AIDS are considered as vulnerable groups that need particular attention in WASH programming.

According to the 2008 census, the number of disabled persons in Sudan was 1.854 million or 4.8 per cent of the total population, of these 52.3% were males and 47.7% were female (Government of Sudan nd). However, according to the Swedish International Development Cooperation Agency (SIDA) report (2014), 'considering that global estimates of people with disabilities range from 10-15 per cent, and the likelihood of under reporting, this figure is probably more than double.' The Government of Sudan estimates that 67% of people with disabilities live in rural regions, 26% live in urban settings with the remainder being nomads (Government of Sudan nd). The four provinces with the highest numbers of people with disabilities are: South Darfur (176,844); North Kordofan (169,462); Jazeera (159,258); and North Darfur (104,254) (Government of Sudan nd.). Most stakeholder organisations agree that the numbers of people with disabilities in Sudan is probably underestimated and suggest they are more likely to be two or three times higher than reported.

Since the implementation of the 2009 Convention on the Rights of Persons with Disabilities in Sudan, the government claims it has made progress towards adopting a human rights-based, rather than medical approach to disability. Some of the new developments included the enactment of the amended Persons with Disabilities Act of 2017, replacing the previous Persons with Disabilities Act of 2009 (UN Human Rights 2018). The Persons with Disabilities Act of 2017 addresses issues related to people with disabilities such as equality and non-discrimination, women with disabilities, children with disabilities, awareness raising, accessibility, right to life, situations of risk and humanitarian emergencies. It also gives equal recognition of persons with disabilities before the law, living independently and being included in the community, education, employment among others (Government of Sudan, 2017c). However, the Act does not mention WASH specifically.

Gender, equity and vulnerability are issues that the Government of Sudan recognise may affect adequate access to safe water supplies:

- **People who are chronically ill, older people, children and new-borns are particularly vulnerable to the risks from drinking unsafe water supplies, which can lead to disease or death.**
- **If anyone, but women and girls in particular, do not feel safe collecting water at specific water points it may lead them to look for alternative sources including those that may be less safe.**
- **If safe water supplies break down, or are not provided on a constant basis, this means that women and girls may have to walk to more remote locations to collect water from open sources, putting them at increased risks of violence.**
- **Women and girls who are most likely to be the people who collect water, may have the least say over how a water supply is designed, water points sited, and the systems managed or how household money is spent including on water storage or household water treatment equipment or chemicals.**

- People who have a disability or mobility limitations, such as older people, may find it difficult to reach and queue for water supplies, particularly if there are long queues, or face difficulty using a hand pump. In Zamzam camp the Health and WASH Committees said that family members help people who may be vulnerable and cannot afford to pay for drinking water as the community is close-knit and they take care of their relatives, but the problem is with transportation when the near-by water source is out of action. The poorest people may not be able to buy soap and household water treatment equipment or consumables.
- It is not clear how much consideration has been made in the methodologies for communication and engagement with people who are particularly vulnerable, marginalised or disadvantaged to ensure they are involved in and benefit from safe drinking water activities. (Government of Sudan, 2017, 55)

Source: Muslim Aid

2.6 WASH in humanitarian contexts in Sudan

Credit: Tom Gardner/TNH - A meeting takes place between residents of Zamzam camp for the internally displaced in North Darfur.

Sudan faces multiple humanitarian emergencies of varying kinds, including conflicts, refugee influxes, internally displaced persons (IDPs), disease outbreaks, floods and droughts, as well as the Covid-19 pandemic.

A country situation report for 2020 (UNOCHA, 2021a) estimates that 9.8 million people in Sudan were severely food insecure in 2020 with 8.9m targeted for assistance. The Report explains: 'human needs continue to grow across the country, driven by localised armed clashes, intercommunal violence, displacement, climatic shocks and hazards, disease outbreaks that disrupted the livelihoods and aggravated food insecurity, malnutrition and protection risks.' (UNOCHA, 2021a.). UNOCHA (2021a) estimates that there were 1.1 million refugees and 3.03 million internally displaced people in Sudan in 2020, with 45% of refugees and over 50% of internally displaced people being food insecure. UNHCR (2020a) assists 307,288 refugees in 17 sites in the country. Of these 21% have access to basic water service levels and 20% have access to basic sanitation levels. On average, UNHCR assisted refugees to access 15 litres of water a day, with 30 people sharing a toilet.

The area of Sudan with the largest population affected by humanitarian emergencies is the Darfur Region, following conflict related displacements occurring in North, Central and Eastern Darfur (Government of Sudan 2016). The Humanitarian Needs Overview for Sudan (2020) estimates 55% of IDPs are children, 37% are adults with 8% being older people. The situation is complex with combinations of protracted and new emergencies in rural and urban contexts, compounded by severe floods, political instability and conflict as well as the Covid-19 pandemic. In addition, there are security challenges in accessing some areas, particularly in Central Darfur.

Many of the WASH activities undertaken in Sudan at present are focussed on the humanitarian context, which is volatile, complex, fluid and in increasing numbers of cases protracted. Contexts vary from IDPs living in camps to those living in rural areas, to those who have been present for a number of decades, but still with new arrivals. There are also refugees, returnees and host communities, each of which require variations in WASH solutions. A supply driven approach for WASH tends to be utilised in humanitarian contexts and a demand driven approach used in longer term more stable contexts; which causes some challenges when transitioning between the two (Government of Sudan 2016, 28).

Other examples of challenges faced by WASH interventions in humanitarian settings include: the lack of consistency of the different approaches used by different agencies (such as subsidy or the level of payment made to hygiene promoters); the security situation; limited space in some camps; the fact that some IDPs have animals which live with the household. There are also challenges related to the operation and maintenance of communal sanitation facilities; as well as the sustainability of solid waste management operations (Government of Sudan 2016, 28).

Through its emergency technical guidelines for WASH, the Government of Sudan and its humanitarian partners recognise that 'access to safe water and sanitation is a fundamental human right and is essential to any humanitarian response' (Government of Sudan 2017a). Moreover, the 'provision of water is a critical element of any emergency response and as part of a wider water, sanitation and hygiene programme and it is fundamental for survival in the earliest stage of a disaster. People affected by disaster, especially women and children, are more vulnerable to diseases related to poor sanitation and water supply and poor hygiene' (Government of Sudan 2017a).

However, there are specific issues associated with humanitarian contexts in Sudan. Particular difficulties include:

- **Changing numbers of displaced populations, including refugees, leading to water systems that are being used to supply much larger numbers of people than they were designed for, leading to people to look for alternative sources.**
- **Poorly maintained water supply systems from the development context, leading to risks for contamination and spread of communicable diseases such as Cholera.**
- **High density of populations living in camp contexts may lead to pit latrines being placed near to water points or water storage tanks.**
- **Inadequate access to chemicals for sustaining water treatment, at all times, but particularly during infectious disease outbreaks.**
- **If people feel the water points are not safe to visit in conflict situations this may lead them to seek and use less safe water supplies.**
- **Access to water supplies for on-going monitoring and water treatment in conflict areas.** (Government of Sudan, 2017, 54)

A number of regional governments have their own response plans. The Regional Refugee Response Plan, Jan – Dec 2017 for South Sudan (which includes South Sudanese refugees living in Sudan) mentions aspects related to water safety briefly:

- **The response will continue to improve safe water supply access, with emphasis on water quality monitoring and maintenance, and the provision of WASH-related core items to all refugee households.**

- **The provision of basic sanitation services at all refugee sites will be ensured, including improvements in the provision of wastewater disposal, solid waste and sludge collection and refuse disposal. Intensified hygiene promotion at refugee sites will also be pursued, including hand washing and latrine usage, safe water handling and storage and water conservation, with special attention paid to the hygiene needs of children at risk of malnutrition"** (Government of Sudan 2017, 73).

However, there are still a number of key issues related to the WASH sector in Sudan that need attention. Four main issues have been identified by UNICEF (nd):

- **Frequent emergencies, conflicts/displacements make planning for long-term improvements difficult**
- **Sanitation continues to be a low national political and budgetary priority**
- **Data gaps hinder prioritization of resources**
- **Inadequate institutional arrangements and capacities of sector stakeholders**

These issues are aimed at the development context in Sudan, but as many refugee and IDP camps have been operating for almost 20 years, these problems are also relevant to the humanitarian context in Central Darfur State which is the focus of this research.

Source: Muslim Aid - Water collection point Central Darfur.

Source: Muslim Aid - Data collection team travelling to meet with participants

2.7 Central Darfur State

Central Darfur State was established in 2012 with Zalengi as the capital. Central Darfur State has borders with North Darfur in the north, South Darfur in the east, and West Darfur in northwest, and Chad in the west and Central African Republic in the south.

The population of Central Darfur is estimated at 2.5 million people according state-level population survey conducted in 2017. The State is divided into 9 administrative divisions known as localities; Azum, Bindisi, Golo, Mukjar, Nertiti, Rokero , Um Dukhun, Wadi Salih and Zalengi. According to UNHCR Central Darfur State hosts 422,877 internally displaced persons and 10,151 refugees. According to The Sudanese Humanitarian Needs Overview (2020) Central Darfur is home to the third largest population of IDPs in the country after South Darfur and North Darfur.

The main livelihoods pursued by the people in Central Darfur include a combination of agricultural production, raising livestock, small business enterprises and wage labour. Agricultural activities and livestock raising have been affected by the conflict because people were displaced from their traditional production areas. Over 80% of households in Central Darfur depend on women and girls to collect water, the highest proportion in the country (AFMM, 2020).

The number of persons with disabilities in Central Darfur State is estimated to be 80,767, (National Council of Persons with Disabilities, 2019). In a survey conducted by the Danish Refugee Council (2021) in Central Darfur revealed that 50% of households had a family member living with a disability. This indicates high prevalence of disabilities within communities in Central Darfur State. The State Council of Persons with Disabilities has been inactive due to the political change since 2019. Therefore, Disabled People's Organisations (DPOs) and people with disabilities lack guidance and directions to activate the UN Convention on the Rights of Persons with Disabilities and the Sudan Disability Act. A few organisations are present in the region and include: the Sudanese National Union of Physical Disabled (SNUPD), the Sudanese National Union of the Deaf, and the Sudanese National Union of the Blind. There are no DPOs for people with cognitive disabilities.

2.8 IDP Camps selected for the research: Nertiti and Zalengi

Two IDP camps were selected for this research, one near the state capital of Zalengi (Himidiya Camp) and one remote rural camp in Nertiti locality (Shimali Camp).

The population of Himidiya Camp was estimated to be over 60,000 whilst in Shimali Camp the population was estimated to be in excess of 34,000. The major movements to these IDP camps occurred between 2003 and 2013 and were the result of hostilities and violence in their home villages. Both camps are very crowded without adequate space for the construction of kitchen, toilet and hygiene facilities. It is very common for more than one family to share a house with extended family members.

Humanitarian agencies have constructed WASH facilities in the camps in consultation with the Sudanese Government. Water points were located in open spaces near residential areas or within a school, health or community compound. Many water points lacked fencing and there was little evidence of security or maintenance of these facilities (see figures 7 and 9).

Figure 7: Water point at Nertiti (Source: Muslim Aid)

Initially, communal latrines were constructed but were gradually being replaced with household/family latrines. This replacement process is intended to ensure that households/families are responsible for the hygiene, security and maintenance of their own latrines. The replacement process has been slow with humanitarian agencies providing slabs and skilled labour with the families providing the unskilled labour for the construction process (See Figures 8, 10 & 11).

Figure 8: Latrines in Zalengi (Source: Muslim Aid)

Household/family latrines are poorly designed (there appeared to be no standard blueprint) and are often a pit with a low fence and may not have a door. They are usually located at the back of the family compound. Some collapse during the rains and others are not safe to use due to poor construction and security. Thus, many families have no latrine and share with neighbours or resort to open defaecation.

Security at communal water points and latrines were reported to be an issue, especially for women and girls, as they have no lighting at night (see Figures 7 & 9).

Figure 9: Water point in Zalengi (Source: Muslim Aid)

Figure 10 & 11: Latrines at health centre in Nertiti (Source: Muslim Aid)

3. The Social Model of WASH Inclusion, Methodology, and Research Tools

3.1 Social Model of Inclusion

In order to investigate the aim of this research (see above), the team adopted a rights-based approach (based on UNCRPD) which aims to mainstream older people and people with disabilities into WASH interventions in humanitarian settings.

The research used the Social Model of WASH Inclusion as its conceptual framework (IASC, 2019, 179). The Social Model of WASH Inclusion focuses on the elimination of barriers that prevent the effective participation of marginalised people in society. The model was developed by the disability movement but can be applied to other people and groups, such as older people, who face exclusion from WASH facilities and programming (Jones et al, nd; WaterAid, 2010). The model identifies three major barriers to WASH inclusion:

1. **Environmental** (physical, accessibility of infrastructure and facilities, communication issues.)

   This includes **barriers in the natural environment** such as rough paths, long distances, steep riverbanks, and muddy springs. Barriers in the built environment include steps, narrow entrances, slippery floors, high concrete platforms, and visual hygiene education messages that are inaccessible to people with impaired vision.

2. **Attitudinal** (negative views of people by others in society, including social norms and internalised attitudes).

   This includes the barriers put in place by **cultural and social norms**, which can produce community prejudice, pity, isolation, overprotection, stigma, misinformation and shame the families of older people and people with disabilities. These cultural and social norms can affect the **internalised attitudes** of older people and people with disabilities.

3. **Institutional/organisational (**systematic exclusion or neglect in social, legal, educational, religious, political and development institutions and organisations).

   These barriers include lack of policies and strategies, knowledge, skills, information, and consultation mechanisms. (WaterAid, 2010, 25).

The Social Model of WASH Inclusion is based on the principles of equity, namely the principal of fairness, and inclusion, which is the process of ensuring that all people are able to participate fully (WaterAid, 2010).

The Social Model of WASH Inclusiveness promotes an all-encompassing approach to WASH by accepting that older people and people with disabilities are just one of many 'different' groups within society. It accepts that difference is a normal part of every society and focusses on identifying and removing barriers that prevent inclusion. This is in contrast to the Medical Approach that tends to segregate people perceived as 'different' with a focus on curing/rehabilitating/normalising the 'different' person or group before they can join 'normal' society. And also the Charity Approach, which perceives 'different' groups as helpless, unfortunate, dependent and suffering and are thus seen as needing pity and charity (Jones et al, nd).

The Social Model of WASH Inclusion is thus a positive, participatory and empowering approach, which is based on human rights. It is one that should embolden both individuals and communities ensuring that older people and people with disabilities are consulted and have an input into WASH planning and implementation.

3.2 Methodology

The research was conducted within the Participatory Action Research (PAR) paradigm, which is highly compatible with, and compliments the Social Model of WASH Inclusion that was the framework which underpinned this research.

PAR is a paradigm that advocates collaborative research, education and action used to gather information to use for change on social or environmental issues. It involves people who are concerned about, or affected by, an issue taking a leading role in producing and using knowledge about it. PAR focuses on social change that promotes democracy and challenges inequality; is context-specific, often targeted on the needs of a particular group; is an iterative cycle of research, action and reflection; and often seeks to 'liberate' participants to have a greater awareness of their situation in order to take action.

PAR brings out the views of local people: their reality, their challenges, and their understanding of problems and solutions. Their ideas may prove to be quite distinct from those in charge of formulating the policies that affect their lives. PAR can therefore produce surprising insights for policy, and may challenge the assumptions on which policy frameworks are based.

PAR is a family of approaches, methods, attitudes, behaviours and relationships, which enable and empower people to share, analyse and enhance their knowledge of their life and conditions and to plan, act, monitor, evaluate and reflect. PAR recognises that individuals within any community being researched are themselves competent agents and capable of participating in research at a number of levels, including as researchers. It aims to move away from the 'extractive' model of social science research and to empower people to affect positive change by participating in research on and with their own communities.

PAR is highly effective in generating insights into sensitive issues such as WASH among hard to reach groups, for instance older people and people with disabilities, where stigma and marginalisation makes traditional research methods difficult to implement.

3.3 Research Tools

PAR uses a range of different participatory methods and tools, both qualitative and quantitative. This research used a range of complementary tools to elicit information associated with inclusive WASH programming with special reference to older people and people with disabilities. It paid particular attention to intersectionality including age, gender and type of disability and investigated the environmental, attitudinal, and institutional/organisational barriers preventing older people and people with disabilities accessing WASH programming.

Five research tools were used in the research as follows:

1. **The Adapted Rapid Assessment Method for Older People (RAM-OP): Survey Tool**
2. **Accessibility and Safety Facility Audit: Group Activity**
3. **Social Model of WASH Inclusion: Group Activity**
4. **Peer-to-Peer Conversations**
5. **Mapping International Standards of WASH Inclusion: Focus Group Discussion**
6. **Semi-Structured Interviews with community members and members of Disabled People's Organisations**

Credit: Muslim Aid - Focus group discussion in Central Darfur.

3.3.1 The Adapted Rapid Assessment Method for Older People (RAM-OP): Survey Tool

The Rapid Assessment Method for Older People (RAM-OP) is a tool devised to help humanitarian and development workers to gather information on older people.

Developed by HelpAge International in collaboration with Valid International and Brixton Health, with funding from the Humanitarian Innovation Fund (HIF), RAM-OP explores older people's nutrition and health status, their capacity to undertake activities of daily living, their access to water and sanitation and other essential services. Using the UN definition of older people means the tool will usually be applied to people aged 60 years and older.

RAM-OP surveys collect and report data for a broad range of indicators relevant to older people, including:

- **Demography and situation**
- **Health and health-seeking behaviour**
- **Food intake**
- **Sources of income**
- **Presence of severe food insecurity**
- **Water, sanitation and hygiene (wash)**
- **Activities of daily living**
- **Anthropometry and screening coverage**
- **Mental health and well-being**
- **Visual impairment**
- **Dementia**
- **Disability**

The RAM-OP tool set has a modular design. Each module covers one of the indicators from the list given above using a dedicated set of questions and measurements in the form of a survey questionnaire. Whenever possible, RAM-OP uses standard and validated indicators and questions. The Manual explaining how to apply RAM-OP can be found here: **www.helpage.org/RAM-OP.**

For this project we used the following modules of the RAM-OP tool: **Disability; Activities of Daily Living; and WASH.** We applied the tool to older people (people >60 years) and to people with cognitive, sensory and mobility disabilities aged over 18 years. An equal number of men and women were included in the survey.

Having undertaken screening for gender, age and type of disability (self reported) and followed Ethical Processes, including getting Informed Consent, each eligible participant answered the questionnaires for the following three RAM-OP Modules: Disability, Daily Living Activities and WASH.

The RAM-OP survey provided baseline information on the disability, activities of daily living and access to WASH facilities of older people and people over the age of 18 years living with a disability in the two internally displaced persons settlements where the research took place.

The RAM-OP tool was applied to older people (people >60 years) and to people with cognitive, sensory and mobility disabilities aged over 18 years. The team aimed to include an equal number of men and women in the survey. A total of 372 people were included in the sample and the

demographics of the sample are shown in Table 4. This sample was then used to invite participants to become involved in the other elements of the research detailed below.

Data was analysed using the methodology provided by the manual explaining how to apply RAM-OP which can be found at: www.helpage.org/RAM-OP.

Table 4: Sampling Frame for RAM-OP Tool[1]

Method	Participants	Age group	Zalengi		Nertiti		Combined total for both localities
			Male	Female	Male	Female	
RAM-OP (adapted)	Older People without disability	>60 years	37	33	28	30	**128**
	Cognitive disability	>18 years	21	22	17	16	**76**
	Mobility disability	>18 years	15	21	23	22	**81**
	Sensory disability	>18 years	19	27	20	21	**87**
Total			**92**	**103**	**88**	**89**	**372**

3.3.2 Accessibility and Safety Facility Audit: Group Activity

Most WASH facilities have traditionally been designed for the 'average' person. As such large numbers of 'non-average' people such as older people and people with disabilities are excluded from normal WASH services and facilities.

This accessibility and safety facility audit activity was designed to assess the barriers to use by older people as well as by people with different types of disability. It used the WEDC/WaterAid Accessibility and Safety Audit Tools designed to assess access to latrines and water points by people with disabilities. These have been adapted from the following sources:

- Jones, H (2012) Accessibility Audit: Water Point. WEDC, Loughborough University, UK https://wedc-knowledge.lboro.ac.uk/collections/equity-inclusion
- Jones, H (2012a) Accessibility Audit: Latrine. WEDC, Loughborough University, UK https://wedc-knowledge.lboro.ac.uk/collections/equity-inclusion

There are no international technical specifications for WASH facilities that are suitable for older people and people with disabilities. However, the following report does make some useful suggestions and these were incorporated into the WEDC/WaterAid Accessibility and Safety Audit Tools.

[1] The targeted sample was 384 participants across the two locations. The field team was able to achieve the 372 participants in the field based on the numbers provided above across the different groups. For the ADL and the disability modules of the survey, participant's data points had to be removed due to incomplete responses.

- Jones, H & Reed, R, (2005), Water and Sanitation for disabled people and other vulnerable groups: designing services to improve accessibility. WEDC, UK. https://wedc-knowledge.lboro.ac.uk/details.html?id=16357.

The WEDC/WaterAid Accessibility and Safety Audit Tools were adapted into a group activity and were undertaken as a group with a local researcher acting as facilitator and note taker. Each group undertook two facility audits:

- A water point similar to the one participants usually used.
- A latrine or toilet facility similar to the one the participants usually used.

The purpose of this activity was to:

1. **Find out if older people and people with disabilities were able to use the facility independently and/or with a helper.**
2. **Identify which features made it easy to use and which features made it difficult to use by older people and people with disabilities.**
3. **To find out if there are any safety concerns associated with using the facility.**
4. **Make suggestions concerning changes and improvements to the facility or its surroundings to improve accessibility and to reduce any safety risks identified.**

The Accessibility and Safety Facility Audit was conducted as a series of group activities with community members who met specific gender, age and disability criteria. The audit was undertaken in Nertiti and Zalengi. In each location six groups undertook the audit. Each group conducted two facility audits: a latrine/toilet and a water point audit. In total 57 people participated in the Accessibility and Safety Audit Group Activity. The sampling frame is shown in Table 5.

Data was analysed using a thematic analysis approach using availability, accessibility, and usability of the facilities as the analytical framework.

Table 5: Sampling frame for the Accessibility and Safety Audit Group Activity.

Method	Participants	Age group	Zalengi		Nertiti		Combined total for both localities
			Male	Female	Male	Female	
Group Facility Audit of latrine and water point	Older People without disability	> 60	5	5	4	6	**20**
	People with disabilities	18-59 years	3	7	3	5	**18**
	Old people with disabilities	> 60	4	5	5	5	**19**
Totals			**12**	**17**	**12**	**16**	**57**

3.3.3 Social Model of WASH Inclusion: Group Activity

The Social Model of WASH Inclusion Activity was based on the Social Model of Exclusion/Inclusion and associated activities developed by WEDC and WaterAid and published in:

- Jones, H, Gosling, L, Jansz, S & Flynn, E.(n.d.) Equity and Inclusion in WASH provision – using the social model of exclusion. WEDC, WaterAid. Loughborough University, UK. https://WEDC-Knowledge.Lboro.ac.uk/collections/equity-inclusion.

This is a model that promotes an inclusive approach to WASH by accepting that older people and people with disabilities are just one of many 'different' groups within society. It accepts that difference is a normal part of every society and focusses on identifying and removing barriers that prevent inclusion. This is in contrast to the Medical Approach which tends to segregate people perceived as 'different' with a focus on curing/rehabilitating/normalising the 'different' person or group before they can join 'normal' society and the Charity Approach which perceives 'different' groups as helpless, unfortunate, dependent and suffering and are thus seen as needing pity and charity. The Social Model of WASH Inclusion is thus a positive, participatory and empowering approach.

The group activity comprised two elements:

1. **Element 1: The purpose of the first group activity was to explore the barriers to inclusive WASH programming:**
   a. **The group ranked the barriers and explained their reasons for the ranking.**
   b. **The group classified the barriers using the Barriers to Inclusion Framework:**
      - **Natural Environment**
      - **Infrastructure**
      - **Policy/institutional**
      - **Social/cultural/attitudinal**
      - **Individual**

2. **Element 2: The second activity enabled the group to suggest and explore solutions to the barriers, and prioritise those that urgently needed to be addressed based on the Social Model of Inclusion. The Group made recommendations to improve the inclusion of older people and people with disabilities in WASH programming.**

Those participants who took part in the Social Model of Inclusion Group Activity consisted of adult participants of different ages, genders and types of disabilities. In total 98 people participated in this activity. The sampling frame and demographic characteristics of the participants are shown in Table 6.

Data was analysed by identifying themes under the framework of barriers and obstacles to WASH inclusion.

Table 6: Sampling Frame for the Social Model of Inclusion Group Activity.

Method	Participants	Age group	Zalengi		Nertiti		Combined total for both localities
			Male	Female	Male	Female	
Social Model of WASH inclusivity group Activity	Older People	>60 years	5	5	5	5	**20**
	People with disability	18-59 years	4	6	5	5	**20**
		>60 years	5	5	5	5	**20**
	Caregivers	>18 years	4	5	3	7	**19**
	Community Member	>18 years	4	5	5	5	**19**
Total			**22**	**26**	**23**	**27**	**98**

3.3.4 Peer-to-Peer Conversations

Peer-to-Peer Conversation is a participatory method in which people with lived experience of issues of mutual interest talk to each other in the form of a conversation (can be face-to-face or virtual).

It involves a trained Peer Researcher having a conversation with a person with whom they share certain characteristics and/or experiences and with whom they have an established relationship of trust eg friends and siblings. The topics covered in Peer-to-Peer Conversations tend to be sensitive, embarrassing or taboo, but using Peer-to-Peer Conversations allows the participant a safe situation to share their narrative and views. Peer-to-Peer Conversations are steered by a Conversation Guide. The Peer-to-Peer Conversation Guide for this project was adapted from in-depth interview schedules used in:

- White, S, Kuper, H, Rimu-Phiri, A, Holm, R & Biran, A, (2016), A qualitative study of barriers to accessing water, sanitation and hygiene for disabled people in Malawi. PLOS One: 11(5), e0155043. Doi:10.1371/journal.pone.0155043.

Peer-to-Peer Conversations were used principally to generate insights into internalised barriers as well as the impact of social norms and community attitudes faced by older people and people with disabilities on access to and use of WASH programming.

Peer-to-Peer Conversations involved 51 participants and included a mix of age, gender and types of disability. The sampling frame and demographic characteristics of the participants are shown in Table 8. Note peer researchers were not able to recruit any participants with cognitive disabilities. Thus this particular group of people with disabilities are not represented in the sample.

Data was analysed using thematic analysis.

Table 7: Sampling Frame for Peer-to-Peer Conversations.

Method	Participants	Age group	Zalengi		Nertiti		Combined total for both localities
			Male	Female	Male	Female	
Type of disability: participants must be >18 years No disability: participants must be >60 years	Cognitive disability	>18 years	0	0	0	0	**0**
	Sensory disability	>18 years	4	4	4	4	**16**
	Mobility disability	>18 years	3	4	4	4	**15**
	No disability	>60 years	5	5	5	5	**20**
Total			**12**	**13**	**13**	**13**	**51**

3.3.5 Mapping International Standards of WASH Inclusion: Focus Group Discussion

Focus Group Discussions (FGDs) are a popular method used within PAR. They are often used to illuminate gaps between policy, stakeholder actions and perceptions of stakeholder activities by beneficiaries.

In the focus groups International Standards of WASH inclusion were discussed and mapped against the situation in the locations where the research was taking place. The themes and topics discussed by the groups were derived from the following sources:

- IASC, (2019), Guidelines: Inclusion of persons with disabilities in humanitarian action. Chapter 18: Water, sanitation and hygiene. https://interagencystandingcommittee.org/isac-task-team-inclusion-persons-disabilitirs-humanitarian-action/documents/launch-isac-guidelines.
- ADCAP, (2018), Humanitarian inclusion standards for older people and people with disabilities. Chapter: Water, sanitation and hygiene inclusion standards. https://reliefweb.int/sites/reliefweb.int/files/resources/Humanitarian_inclusion_standards_for_older_people_and_people_with_disabilities.
- Sphere Association, (2018), The Sphere Handbook. Chapter: Essential concepts in water supply, sanitation and hygiene promotion. https://handbook.spherestandards.org/en/sphere#ch006_002.

The purpose of the focus group discussions with groups comprising community members and Disabled People's Organisations (DPOs) was to:

- **Identify gaps in International Standards in WASH inclusion in the sampled region.**
- **Make suggestions as to how WASH inclusion can be improved.**
- **Discuss any obstacles to remedying the situation.**
- **Put forward recommendations to progress WASH Inclusion in their locality.**

Focus Group Discussions included participants who were community members as well as people representing or members of DPOs. The participants had not been involved in other elements of the research and thus were expected to give a community perspective on WASH programming in their respective communities as well as having some policy and implementation influence. In total 48 people participated in eight focus group discussions (four in each research locality). The sampling frame and demographic characteristics of the participants are shown in Table 10.

Data was analysed using a thematic approach based on gaps and possible solutions to WASH inclusion of international standards and their application in the two research localities.

Table 8: Sampling Frame for Focus Group Discussions on International Standards of WASH Inclusion

Method	Participants	Age group	Zalengi		Nertiti		Combined total for both localities
			Male	Female	Male	Female	
Focus Group Discussion of WASH facilities against International Standards with emphasis on Water, Sanitation, Hygiene and Public Health messages	Disabled Persons Organisation (DPO)	>18 years	6	6	6	6	24
	Community Members	>18 years	6	6	5	7	24
Total			**12**	**12**	**11**	**13**	**48**

3.3.6 Semi-Structured Interviews with community members and members of Disabled People's Organisations

Semi-structured interviews are guided conversations in which only the topic(s) are predetermined and questions and insights arise as a result of the discussion. Semi-structured interviews allow for new questions to emerge during the interview as a result of the information the participant provides.

The local researcher/facilitator had an interview guide consisting of the themes to be explored, but was not constrained by a formal set of pre-set questions. This meant the researcher/facilitator could ask questions in various ways as appropriate for the participants and to probe more deeply on topics or specific issues specific to each participant. Thus semi-structured interviews gave the researcher/facilitator the freedom and flexibility to tailor their questions to the specific context and situation and to the people they were interviewing (Appel et al, 2012).

Individual semi-structured interviews explored community attitudes, cultural perceptions and social norms affecting older people, people with disability and access to and use of WASH programming.

Semi-structured interviews were undertaken with community members and representatives/ members of Disability People's Organisations, as well as older people and people with disabilities.

In total 28 people participated in the semi-structured interviews. The sampling frame and demographic characteristics of the participants are shown in Table 11.

Data was analysed using a deductive thematic analysis approach.

Table 9: Sampling Frame for Semi-Structured Interviews

Method	Participants	Age group	Zalengi		Nertiti		Combined total for both localities
			Male	Female	Male	Female	
Semi-Structured Interviews	Older People	>60 years	1	1	1	1	4
	People with disability	18-59 years	1	1	2	0	4
		>60 years	1	1	0	2	4
	Caregivers	>18 years	2	2	2	2	8
	Community Members	>18 years	2	2	2	2	8
Totals			**7**	**7**	**7**	**7**	**28**

3.4 Collecting primary research data/information

Following the granting of Ethical Approval by Coventry University Ethics Committee (Certificate Number: P116037) a weeklong online workshop was held with Muslim Aid staff in London and Sudan including the Sudan National Research Coordinator. The purpose of the research was presented and the research tools were introduced, discussed and piloted. All documentation including Participant Information Sheets, Informed Consent Forms and Researcher Tool Guides were translated into Arabic. Throughout the workshop the need to adhere to ethical research principles was stressed and procedures explained.

This training was then cascaded down by the Sudan National Research Coordinator to those who would be facilitating data collection in Central Darfur. Local researchers were selected by Disabled People's Organisations (DPOs) and Muslim Aid's local partner Sudan Organization for Relief and Recovery (SORR). Thirty-seven (18 females; 19 males) local researchers were recruited including 16 people with disabilities (10 with mobility challenges (6 males and 4 females) and 6 with sensory impairments (3 males and 3 females). No researchers with cognitive disabilities were recruited). Local researchers were selected from the IDPs in the camps because they spoke the local language and were likely to be trusted and accepted by participants. Local researchers were trained on undertaking ethical research, ethical procedures and the research tools they used. In addition, 18 people were recruited as note takers, and one transcriber/ translator, and one sign language translator were employed. All were trained in undertaking ethical research.

Data was collected in two IDP camps: Himidyia Camp in Zalengi locality; and Shimali Camp in Nertiti locality. These two camps were selected as study sites because they host large populations of IDPs (Himidyia Camp 60,000 and Shimali Camp 34,000 persons). The field work involving the

orientation of community leaders, training of local researchers and data collection took place between 17th February and 4th April 2021. Additional data was collected from 30 August to 14 September 2021 to verify and supplement information gathered in the first round of data collection. Covid-19 bio-security was observed by all those involved in data collection.

Source: Muslim Aid - Group activities for the study in Central Darfur

Chapter 4: Results by Tool/Activity

4.1 Introduction

This chapter presents the main results from each of the six research tools and activities used in the research. In each section the tool or activity is briefly summarised and the results summarised by main theme. These will be discussed in the following chapter.

4.2 RAM-OP

The Rapid Assessment Method for Older People (RAM-OP) was used to gather baseline information on older people and people with disabilities in the two research locations, Nertiti and Zalengi.

For this project the following three modules of the RAM-OP tool were used: **Disability; Activities of Daily Living (ADL); and WASH**. Each module used a dedicated set of simple questions and measurements in the form of a survey questionnaire. Whenever possible, RAM-OP uses standard and validated indicators and questions.

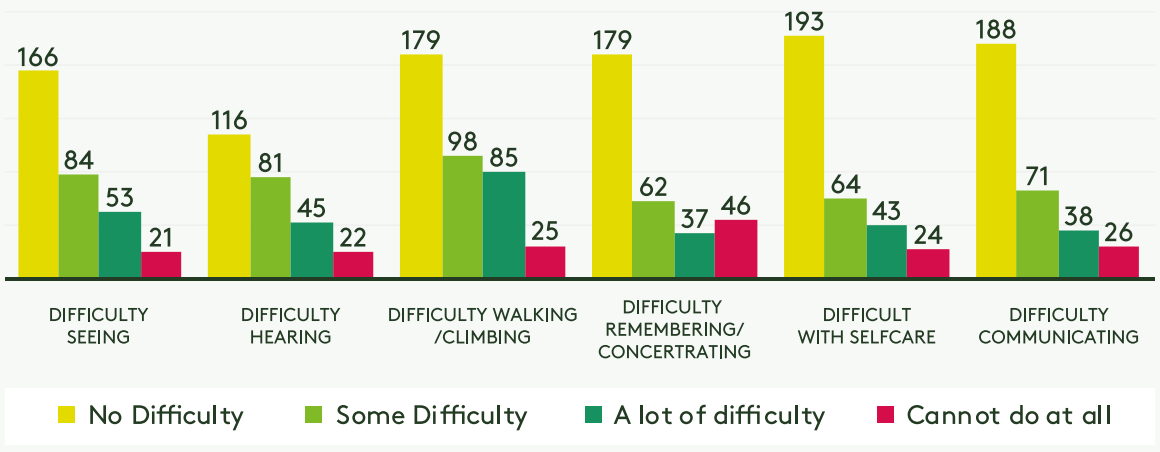
4.2.1 Results

In this section key results of this survey will be presented per module (Disability, ADL, WASH). This will be broken down further by location, type of disability, and gender.

Module 1: Disability

For the Disability module of the tool, participants were asked to respond to six questions about the level of difficulty they faced in different domains of disability including seeing, hearing, walking/climbing, remembering/concentrating, self-care, and communicating. This module is based on the Washington Group Short Test. Figure 12 provides a summary of the responses received for each of these questions.

Figure 12: Disability Module Response Frequencies to Questions

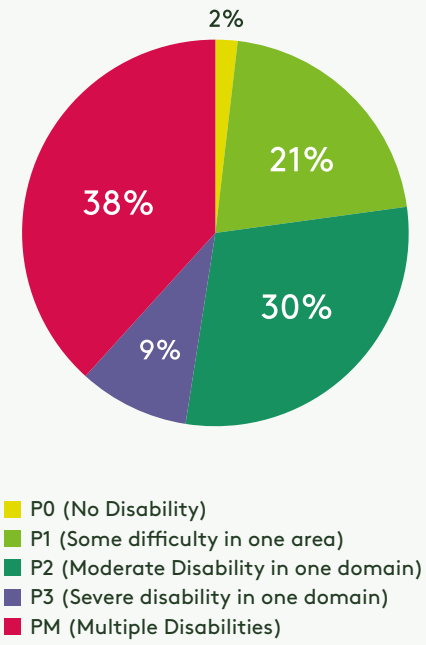


An average of 48% of respondents in each of the six questions responded stating that they had at least 'some level of difficulty', 'a lot of difficulty', or 'cannot do at all'. What is noteworthy is that 24% of the participants responded stating they had 'a lot of difficulty' or 'cannot do at all', in all six domains. In other words, a quarter of participants self-reported as experiencing all types of disability. This suggests that the disability burden of the sampled group was high and thus presents specific challenges for WASH inclusion.

Based on the responses provided in these six disability domains, participants were assigned a prevalence disability code (see Figure 13). This placed participants in one of four categories, based on the self-reported severity of their disability. Overall, the disability module identified that 2% of participants reported 'no disability' or 'some difficulty' (P0, P1), however 77% of the participants surveyed reported 'moderate' to 'severe' disability (P2, P3) in one disability domain.

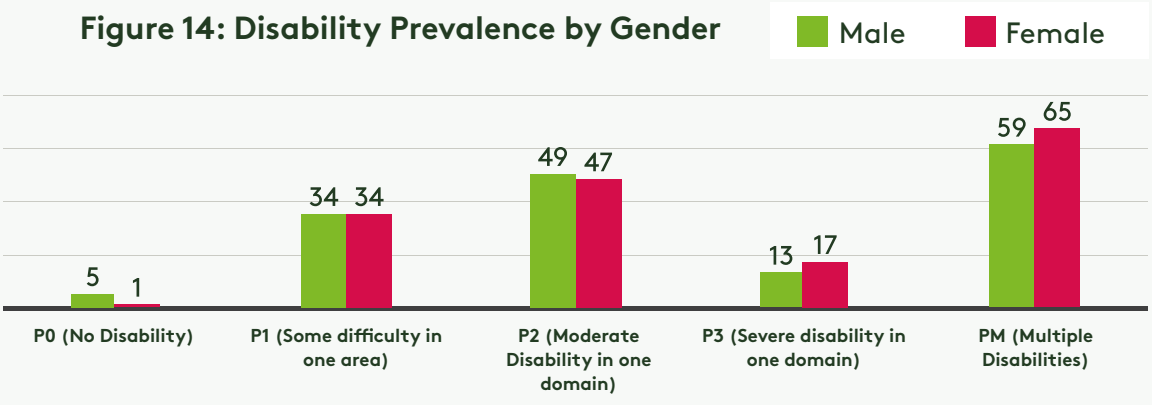
Additionally, 38% of the surveyed participants had multiple disabilities (PM). This indicated that not only is there a high level of self-reporting of disability, but also that their disability is regarded by participants as moderate to severe. This presents a challenge for WASH inclusion, as not only are levels of disability highly varied and complex, but the severity of the disabilities participants are living with was significant.

Figure 13: Disability Prevalence Code



In both Nertiti and Zalengi, 77% of the participants surveyed had moderate to severe disability in one or more domains (P2, P3, PM). In Nertiti, a higher percentage of the participants had moderate disability in at least one domain compared to Zalengi (38% Nertiti, 22% Zalengi). While in Zalengi, a significantly larger percentage of the participants were noted to have multiple disabilities (46% Zalengi, 31% Nertiti).

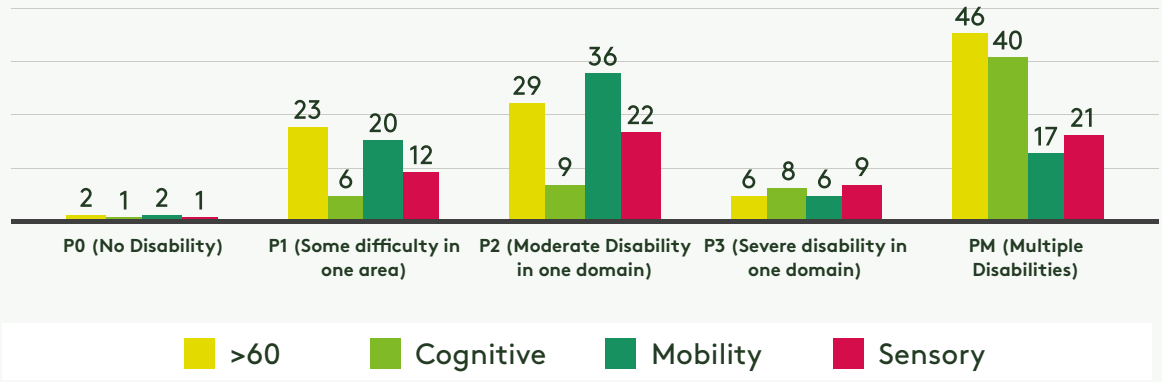
Figure 14: Disability Prevalence by Gender



The overall disability prevalence by gender is shown in Figure 14. No significant difference by gender was recorded for disability prevalence. Female participants were noted to have a slightly higher level of moderate to severe disabilities (79% female, 77% male). This translated to slightly higher levels of severe disability (10% female, 8% male) and multiple disabilities (40% female, 37% male).

In Zalengi this trend is more pronounced with 83% of female participants experiencing moderate to severe disability and multiple disability (P2, P3, PM), while only 71% of male participants experienced moderate to severe disability and multiple disability. In Nertiti, male participants experienced a higher percentage of moderate to severe disability and multiple disability (80% male, 74% female). In Zalengi, the difference between female and male participants experiencing severe disability and multiple disabilities was more pronounced.

Figure 15: Disability Prevalence – Disability Type



The overall disability prevalence by disability type is represented in Figure 15. In the participant identification process, the team identified participants that self-identified as predominantly in one of 3 disability domains including cognitive, mobility, and sensory. Additionally, older people (aged over 60 years of age) were categorised as a separate domain.

Overall, participants with cognitive disabilities were noted to have the highest percentage of moderate to severe disability and multiple disability at 89% (P2, P3, PM) compared to other disability domains and older people (80% sensory, 73% mobility, 71% older people). Participants with cognitive disabilities and older people had the highest percentage of multiple disabilities (63% cognitive, 40% older people). Participants with sensory disabilities experienced severe difficulty in at least one domain at a higher level than other domains at 14%. In Nertiti and Zalengi the trends noted are replicated. In Nertiti, the percentage of participants with sensory disabilities experiencing severe disabilities was more pronounced at 16%.

Module 2: Activities of Daily Living (ADL)

For the ADL module of the tool, participants were asked to respond to six questions about whether they needed help in six daily activities. Additionally, a seventh question was included in the survey to determine if participants had someone assisting them in daily living activities. Figure 16 provides a summary of the responses provided by the 339 participants.

Figure 16: ADL - Response Frequencies

On average 66% of the participants responded that they needed no help with these various daily activities. Seventy percent of the respondents said they did not have anyone to assist them in daily activities, while 30% stated that they did. These responses indicate a high-level of independence in the surveyed participants. This corresponds with the analysis done using the Katz index below. The response frequencies trend is more pronounced in Nertiti with 78% on average responding no, and only 22% responding yes.

The responses provided in the first six survey questions were summed to form the Katz Index of ADL (Figure 18). This score indicates the level of dependency of each participant (independent, moderate dependency, and severe dependency). Question 7, along with the Katz index were used to identify unmet needs of the participants (Figure 17).

Figure 17: Level Unmet Needs

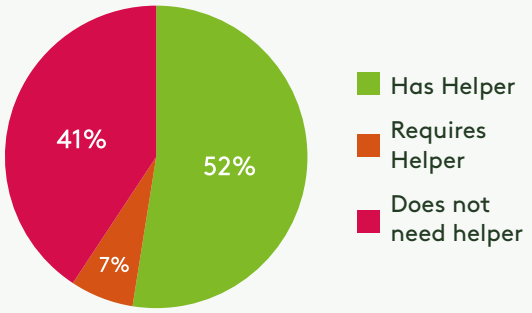
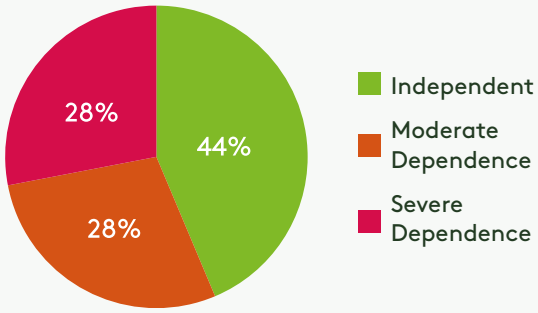


Figure 18: Katz Index (dependency)



As noted in Figures 17 and 18, about 56% of the participants indicated that they had moderate or severe dependence. Fifty-nine percent of respondents were recoded as either having helpers or requiring helpers. This 3 percent difference is likely due to independent participants also having assistance from family members in daily activities of living. In Zalengi, levels of moderate (29%) and severe dependence were significantly higher than in Nertiti (moderate 28%, severe 15%). This also translated to a much lower level of participants in Nertiti stating that they required helpers (1%), compared to 12% in Zalengi.

Figure 19: Katz Index by Gender

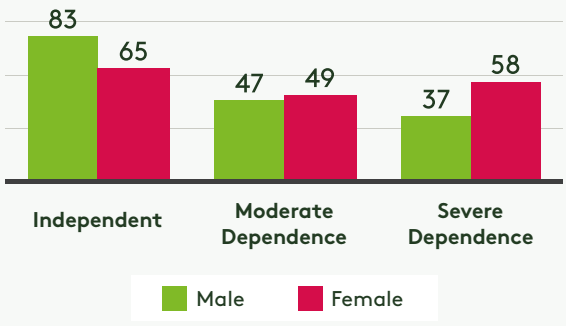
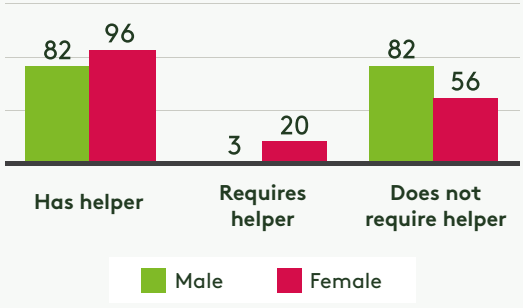


Figure 20: Level of Unmet Needs by Gender



Figures 19 and 20 break down the Katz Index and Level of Unmet Need, by gender. These figures clearly indicate higher levels of moderate and severe dependencies for female participants, with a stark rise in severe dependency. Additionally, female participants were also predominantly the ones that had responded that they required helpers. This gap indicates that female respondents (older females and females with disabilities) were likely have difficulty getting help when needed. In Zalengi, in line with the overall indicator findings, female participants had a higher level of moderate (33%) and severe dependency (47%) compared to males (25% moderate, and 31% severe). In Nertiti, male participants had a higher level of moderate dependency.

Figure 21: Katz Index by Disability Type

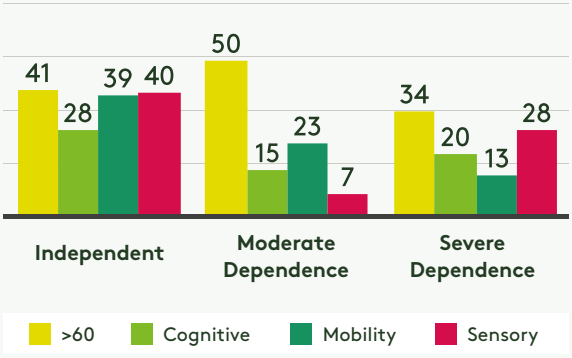
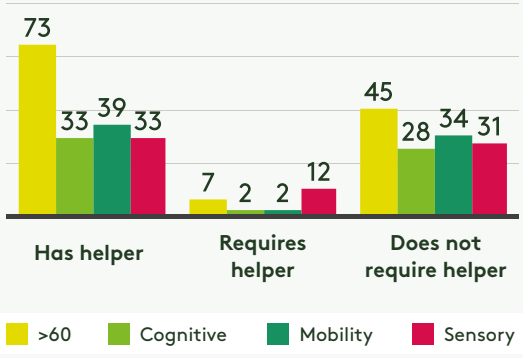


Figure 22: Level of Unmet Needs by Disability Type



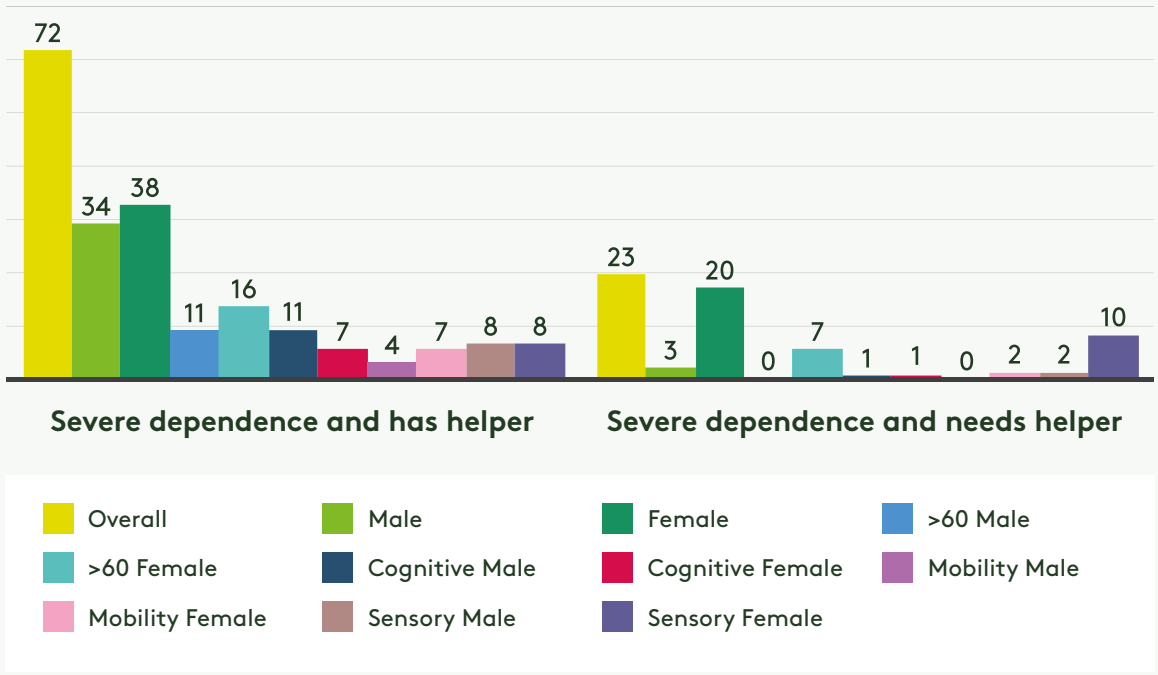
Figures 21 and 22 provide an analysis of the two indicators by disability type and age. These indicate that the group with the highest level of dependence are participants over 60 years of age (67% have moderate and severe dependencies), and participants with cognitive disabilities

(56% have moderate and severe dependencies). This corresponds to a higher level of unmet needs for people aged over 60, but not for people with cognitive disabilities. This indicates that individuals with cognitive disabilities are generally provided with the help they needed from within the family structure. Additionally, people with sensory disabilities had a high comparative number of individuals that require help. These trends were found in both Nertiti and Zalengi, but were starkly pronounced in Zalengi with 81% of people over 60 with moderate and severe dependency.

The gender profiles within these groups shows that female participants over 60 years of age had a significantly higher level of moderate and severe dependency (76%) compared to males over 60 (59%). Similarly, females with sensory disabilities experienced moderate and severe dependency which was twice as high as males within the same group. This trend is more pronounced in Zalengi than Nertiti.

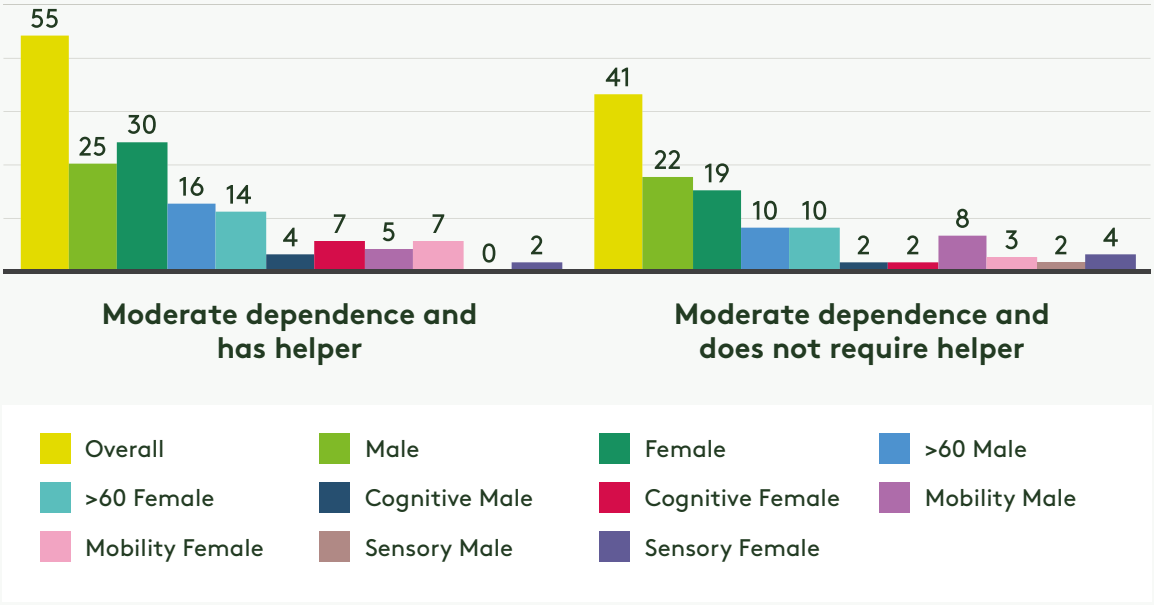
Overall, as shown in Figure 23, 76% of the participants with severe dependency had helpers, while 24% did not. This 24% was primarily composed of females. Of this category of participants, females over 60 and females with sensory disabilities had the most significant levels of unmet needs. These trends are replicated among the Zalengi participants. There were only two participants in Nertiti with unmet needs and severe dependency. This seems to indicate that in the rural context, support systems within the family might be stronger.

Figure 23: Severe Dependence vs Unmet meets



For participants with moderate dependence, in both locations, no participant mentioned unmet needs. All individuals with moderate dependence noted either having someone to help them already or not requiring help. Forty-three percent of individuals with moderate dependencies noted that they did not need a helper (see Figure 24). The team expected a higher number of people with moderate dependencies to state that they needed helpers, and is an interesting area to explore further.

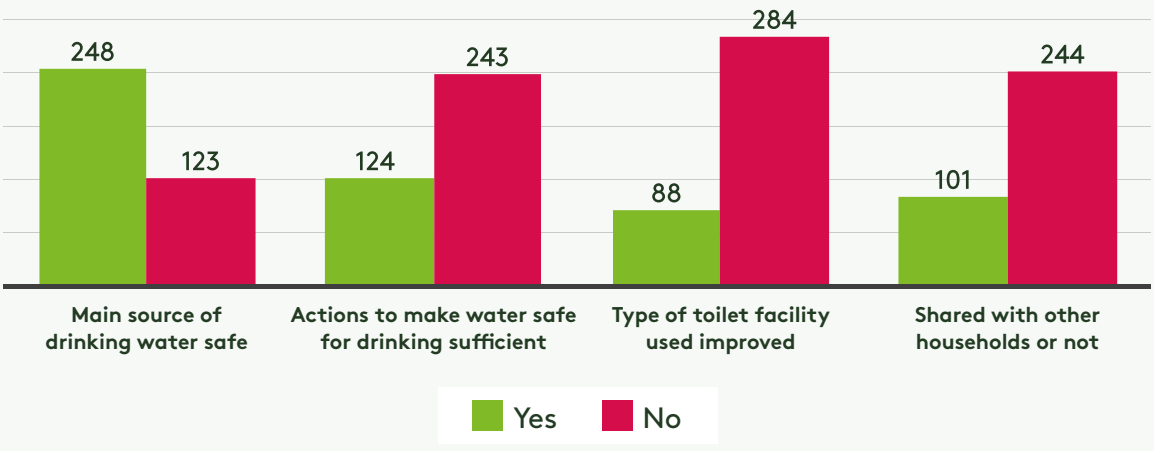
Figure 24: Moderate Dependence vs Unmet meets



Module 3: WASH

For the WASH module of the RAM-OP tool, participants were asked to respond to four questions, two each on access to water and sanitation. The responses provided insights into whether respondents had access to safe drinking water and whether they had access to improved non-shared sanitation. Figure 25 provides a summary of the responses.

Figure 25: Response Frequencies to WASH Questions



Overall, 67% of the respondents confirmed having access to safe drinking water, but only 33% confirmed taking actions (chlorine disinfection, water filter usage etc.) to make water safe for drinking. The numbers between the two locations Zalengi and Nertiti differ significantly in line with the national averages reported in Chapter 2. In the city of Zalengi, 92% of respondents reported having access to a source of safe drinking water and 55% reported taking actions to make water safe for drinking. In the rural context of Nertiti, this trend is reversed, where 39% of the respondents reported having access to safe drinking water sources, and only 10% reported taking actions to make water safe for drinking.

In terms of sanitation, the majority of the respondents (76%) reported using non-improved toilet facilities. Most of these non-improved facilities (69%) though seemed to be toilet facilities only used by one household and were not shared. In Zalengi, a comparatively smaller proportion of respondents (57%) reported using non-improved toilet facilities. This number rises in Nertiti, where almost all the facilities (97%) are non-improved. In both sites, toilet facilities are not shared by households (78% Nertiti, 64% Zalengi). But whilst they are not shared, they are not classed as improved.

Based on the responses provided to the four questions noted above, each participant was given a code to indicate whether they had access to safe drinking water and access to improved non-shared sanitation. Figures 26 and 27 summarise the code allocated by the WASH module. This shows that 70% of participants had access to safe drinking water (Figure 26) whereas only 20% had access to improved non-shared sanitation facilities (Figure 27).

Figure 26: Access to Safe Drinking Water

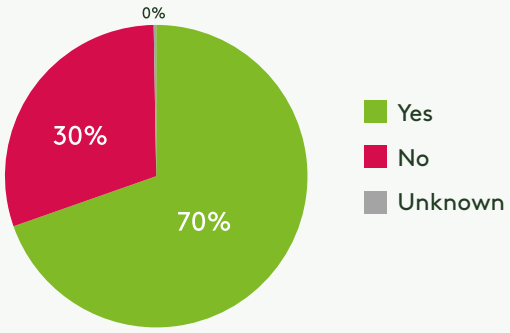
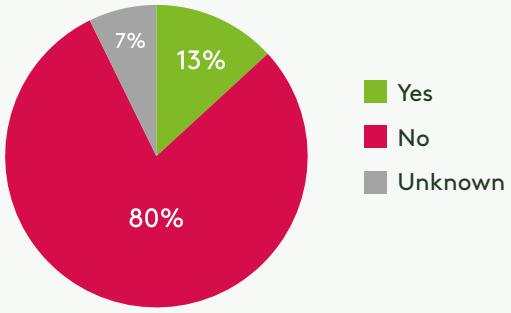


Figure 27: Access to Improved Non-Shared Sanitation



The 70% of respondents with access to safe drinking water (Figure 26) is strongly skewed by the Zalengi based participants where 96% of participants had access to safe drinking water. In Nertiti, this proportion is significantly lower at 41%. Similarly, Figure 27 shows that 80% respondents do not have access to improved non-shared sanitation. In Nertiti, 92% of respondents reported not having access, while in Zalengi around 68% of participants reported not having access to improved non-shared sanitation. Thus geographical location does appear to be a key determinant of access to safe water and improved non-shared sanitation facilities, with rural areas such as Nertiti being more deprived than urban IDP camps such as Zalengi. These results are in-line with national averages for urban and rural populations (see Chapter 2).

Figure 28: Access to Safe Drinking Water by Gender

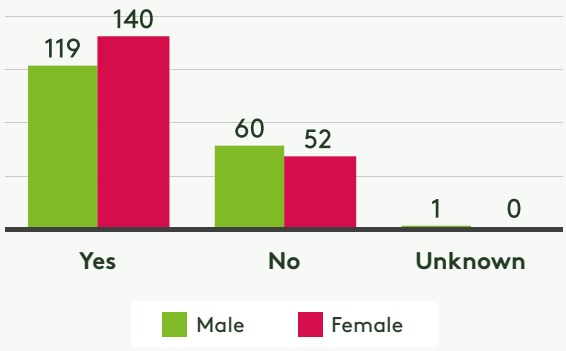
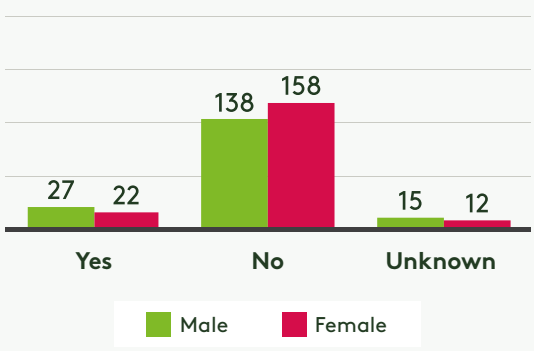


Figure 29: Access to Improved Non-shared Sanitation



Figures 28 and 29 compare gender-based differences in access to safe drinking water and improved non-shared sanitation. Female participants claimed to have access to safe drinking water at a slightly higher level compared to male respondents (73% vs 66%). This trend does not hold in Nertiti, where female participants reported significantly lower levels of access to safe drinking water (48% vs 33% for males).

With respect to sanitation, male participants had slightly better access to improved non-shared facilities (15% vs 11%). In Nertiti, almost no participants had access to improved non-shared sanitation facilities.

Figure 30: Access to Safe Drinking Water by Disability Type

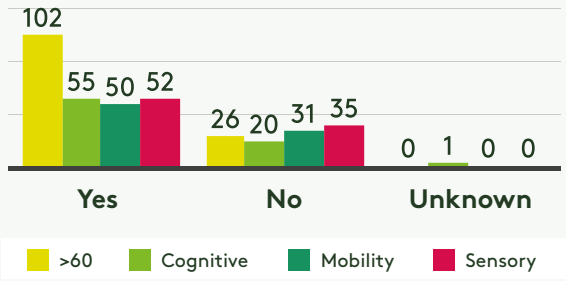
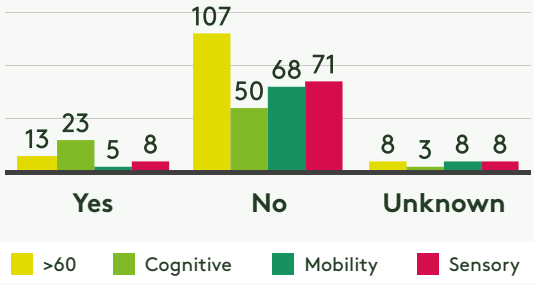


Figure 31: Access to Improved Non-Shared by Disability Type



Figures 30 and 31 compare access to safe water and sanitation based on type of disability. Levels of access to safe drinking water are skewed by the Zalengi results. The lowest level of access to safe drinking water was reported by participants with mobility (38%) and sensory disabilities (40%). Additionally, male respondents with sensory and mobility reported having lower levels of access to safe drinking water. In Nertiti, this lack of access by these sub-groups was more pronounced at 62% for people with a mobility disability and 83% for people with a sensory disability. Males for these groups in Nertiti seemed further disfranchised with lack of access at 74% and 95% respectively.

Lack of access to improved non-shared sanitation facilities seems to impact across all groups with the highest level for participants over 60 and those with mobility disabilities (84% for both). Male participants with mobility disabilities and female participants with sensory disabilities were reported to be impacted the most (87% and 92% respectively).

4.3 Accessibility and Safety Audit Group Activity: Latrines/Toilets and Water Points

The latrines/toilets and water points were audited based on a set of criteria deemed to be relevant for ascertaining the extent to which older people and people with disabilities are able to easily access and safely use the facilities, and to identify areas for improvement.

The criteria audited were: location of the facilities, type of the facilities, organisation and responsibility for maintenance and cleanliness, materials and technology used, path to the facilities, getting in/out/on the facilities, safety, hygiene, and other issues of relevance.

This qualitative data collection tool involved open-ended questions structured around three assessments:

a. **Assessing the availability of the facility**
b. **Assessing the accessibility to the facility**
c. **Assessing the usability of the facility**

In addition participants were asked to make recommendations to improve inclusivity of the facilities.

4.3.1 Results
Availability of the latrine/toilet and water points

The results are presented by research location.

Nertiti

All participants in Nertiti confirmed that they used the latrines that were located at the health centre which is near where they live. The latrines were constructed from bricks and cement with a roof made from zinc sheeting. The latrines were free to use and were managed by Islamic Relief. Thus, it would appear that a shared safe latrine/toilet was available to all participants in Nertiti.

Credit: Sebit Patrick 30 July 2019 - A structure of Pit-Latrine in South Sudan.

All but one group in Nertiti reported that they accessed their water from bole holes with a hand pump. The other group stated that they used a water tap. Thus, for all those participating in the research a source of safe drinking water was available. Access to water was free for all participants, but a number of older men with a disability reported that people often make a financial contribution towards the maintenance of the water points as there was no proper management structure in place to undertake repairs.

Zalengi

All participants in Zalengi confirmed that they used the latrines located at the health centre which is near the residential area. The latrine was a traditional pit latrine with a cement slab with walls made from bricks and cement with a zinc sheeting roof. As a participant explained:

> **'The pit is covered with cement slab. It has no doors, no seats or ventilation. It is unsafe specially during the rainy season. The width of the door is 60cm and the length is 2m. Constructed from bricks and the roof covered with zinc sheets. No water or soap.'** (Older male with disability, Zalengi)

The latrines were free to use and were managed by the health centre which is overseen by an NGO. It would appear that a shared latrine/toilet was available to all the participants.

Participants in Zalengi reported that they used the water points at the youth and women's centre which was in the middle of their residential area. They used both taps and bole holes with hand pumps. The water points were free to use but nobody was responsible for the management of the facilities. Thus a safe drinking water source was available to all those participating in the research.

Accessibility of the latrine/toilet and water points

Nertiti

All participants in Nertiti agreed that it was difficult to access the latrine, especially for older people and those with disabilities. They reported that there was rubbish and stones on the path to the latrines that was uneven and was often wet and slippery due to poor drainage. They complained that there were a series of high steps at the gate to the latrine. There was also a set of uneven steps to navigate to enter the latrine, and that the corridor to the latrine was too restrictive and that the doors to the latrine were too narrow. As this quotation illustrates:

> **'The height from the ground is 7cm. The height of the gate to the latrine is 69cm, width is 28cm. The height of the first step is 7cm and the second 4cm. The main entrance to the latrine is 39cm.'** (Male with disability, Nertiti).

Participants noted that the space inside the latrine was not adequate to allow the movement of a wheelchair and that there were no handrails to provide support. There were complaints that the latrines were dirty and required regular cleaning and maintenance. There was praise for the fact that the latrine doors opened outwards and that there was water available inside some of the latrines for hygiene purposes.

All participants in Nertiti agreed that it was difficult to access a water point. The main barriers to older people and people with disabilities were reported as:

- **The water point was distant from their home.**
- **The roads/path to the water point was uneven with potholes and stones and was not wide enough.**
- **The entrance to the water point was narrow and there were steps at the gate to the water point that were uneven and slippery.**
- **The surface area surrounding the water point was uneven and there was stagnant water.**
- **There were no signs to guide people to the water point.**
- **There was no light at night on the road/path to, or at, the water point itself.**

The following quotation summarises the situation:

> **'There are steps at the entrance. Steps are not even and [are] slippery. The entrance is not wide and the people are crowded at the entrance thus creating difficulties to for old people and persons with disabilities.'** (Male with disability, Nertiti).

Zalengi

Many participants reported having difficulty accessing the latrines. The main reasons included:

- **There was rubbish and obstacles on the path leading to the latrine.**
- **There were high steps at the gate to the latrine.**
- **The corridor to the latrine was too narrow.**
- **Latrine door was too narrow.**
- **The latrine did not have enough space to allow for the movement of a wheel chair.**

All participants stated that they had difficulty accessing the water point. The main barriers were:

- **Distance from their homes (approximately 120m).**
- **Uneven narrow roads and paths with potholes and stones.**
- **There was no ramp.**
- **There was no lighting at night.**
- **There were no signs to guide people to the water point.**
- **There were steps at the entrance.**

These points are illustrated as follows:

> **'There are many difficulties in accessing water point as it is difficult to get in and out of the water site. The length/height of the entrance is 2 m and width is 60cm. There is only one tap at the collection point. There are high steps and no paved corridors/ ramps to facilitate mobility of old people and persons with disabilities. The floor is uneven and the soil is muddy.'** (Older female, Zalengi).

Usability of the latrine and water points

Nertiti

All participants in Nertiti reported that the usability of the latrines was limited by: the lack of a water tap; the fact that the latrines were very narrow; and that there was a lack of seating in the latrine. However, participants did comment that the floor of the latrine itself was even and was not slippery. These concerns particularly affected the usability of people with mobility issues and those reliant on a wheelchair. As one participant summarises:

> **'It is not safe to use the latrine by old people and persons with disabilities.....There is no water tap and the area is not wide enough.....There are no seats and nothing to lean on.'** (Male with disability, Nertiti).

Most groups in Nertiti reported difficulties in using the water point without help and support, particularly as taps were often broken, the apron to the water pump was narrow and slippery and that stagnant water accumulated there. As explained here:

> **'Ensure there is adequate space for the apron around the water pump. There should be a system for drainage and collect of excess water.'** (Female with disability, Nertiti).

The issues of maintenance and signage were also raised as barriers to usability.

Zalengi

Usability of latrines in Zalengi was limited by:

- **Lack of a water tap, seats and handles or other supports.**
- **No doors.**
- **Latrines were dirty.**
- **There was no light.**
- **No water or soap.**
- **Floor was muddy and slippery.**
- **No separate latrines for females.**

The main issues raised by the groups in Zalengi with respect to the usability of water points were:

- **There were no seating areas.**
- **The floor was muddy and slippery.**
- **The water point area was very small and crowded with people and water containers waiting to be filled.**

> **'It is difficult to operate the hand pump. The floor is muddy and slippery. There is no platform to sit/or something to lean on while drawing water.'** (Female with disability, Zalengi).

Some participants resort to other sources of water, especially in the rainy season as explained:

> **'There is no access to safe water (no pump/tap) in some residential areas and people obtain water from wadi a zoom, an open water source, where water accumulates during the rainy season.'** (Female with disability, Zalengi)

Recommendations for improved inclusivity

Nertiti

The participants in Nertiti made the following recommendations to improve inclusivity at latrines/toilets and water points:

- **Install solar energy to provide light at night.**
- **Improve security.**
- **Fill in pot-holes, remove obstacles and level the road/path.**
- **Construct a platform and seating area.**
- **Install water pipes in houses and provide mobility aids to assist older people and people with disabilities to use facilities.**

Zalengi

The participants in Zalengi made the following recommendations to improve inclusivity at latrines/toilets and water points:

- **Install solar energy to provide light at night.**
- **Put doors on the latrines**
- **Increase the number of water points so they are closer to people's homes.**
- **Redesign water pumps so they can be easily operated by older people and people with disabilities.**
- **Regular maintenance and appointment of person responsible.**
- **More support from organisations.**
- **Separate latrines for females.**

4.4 Social Model of WASH Inclusion: Barriers to and Solutions for Inclusion: Group Activity

The social model of WASH Inclusion activities involved a mixture of open - and closed-ended questions structured around two issues:

1. Barriers to Inclusion
2. Solutions for Inclusion

The social model activities were based on four main criteria deemed to be relevant for identifying and removing barriers faced by older people and people with disabilities in accessing and using WASH facilities. These were: nature of barriers and significance; proposed solutions; obstacles to remedying the situation; recommendations on responsibility.

4.4.1 Results

Barriers to inclusion

The ranking of the barriers by participants in each locality is shown in Table 10.

Table 10: The top five barriers to WASH inclusion ranked by importance to participants by research location.

Barrier as ranked in importance by participants	Nerfiti	Zalengi
1	Natural/environmental barriers	Infrastructural barriers
2	Infrastructural barriers	Policy/Institutional barriers
3	Social, Cultural and Attitudinal barriers	Natural/environmental barriers
4	Policy/Institutional barriers	Social, Cultural and Attitudinal barriers
5	Individual barriers	Individual barriers

It is interesting to note the difference in the order of importance of the types of barrier by research location. The difference may be explained by the geography of each location, the age of the camp as well as the management and resourcing of each camp. Further research is required to explore these differences.

Infrastructural barriers were highlighted as most urgently needing attention by older people and people with disabilities (both male and female), caregivers (male and female), and community representatives in both research locations. In Zalengi it was identified as the most important issue that needed addressing and in Nertiti it was ranked second. The infrastructural barriers most frequently identified included the lack of seats in latrines, lack of space in the latrine especially space for a wheelchair, the presence of steps at the entrance to latrines and difficulty in using hand pumps at water points.

The majority of participants, both male and female, as well as older people and people with disabilities, from both research localities also identified natural and environmental barriers to WASH facilities as those that also needed addressing urgently. In Nertiti this was identified as the most pressing issue, whilst in Zalengi it was ranked third. The most commonly cited barriers within this category included pot-holes and stones on the road and path to the facilities as well as uneven surfaces and poor drainage. As one participant explained:

> **'We are unable to move wheel cart because of stones, pits and improper drainage.'** (Male with disability, Nertiti).

Many older people and people with disabilities who find it difficult to walk to WASH facilities rely on the use of a cart to access water points and latrines, so simple maintenance of roads and paths to these facilities would make a huge difference to older people and people with disabilities access to WASH facilities.

Social, cultural and attitudinal barriers together with individual barriers were ranked as third and fifth most pressing barriers at Nertiti and as fourth and fifth in Zalengi. The associated barriers mentioned the most included a perceived lack of acceptance of people with disabilities and negative attitudes towards older people and people with disabilities. This resulted in social stigma of older people and people with disabilities which was translated into a lack of self-esteem by these participants. The result was perceived to be a lack of participation by older people and people with disabilities in WASH programming.

Interestingly whilst **policy and institutional barriers** were ranked second in Zalengi and fourth in Nertiti, there was very little discussion as to what these barriers consisted of. However the lack of financial resources, dearth of trained staff and a lack of a data base and information about older people and people with disabilities was identified as contributing to the barriers experienced by older people and people with disabilities accessing WASH facilities and programming in both research sites.

Solutions for Inclusion

Participants at both research sites agreed that there is an urgent need to level and clear roads and paths that led to WASH facilities. They suggested that if tools were provided then the community would be able to maintain and widen the roads and paths. As this participant explains:

> **'Refilling pits and holes we need tools and equipment for cleaning and increase the width of roads.'** (Older female with a disability, Nertiti)

In effect this is a barrier that communities could solve collectively if they were provided with the appropriate tools and training.

In both Nertiti and Zalengi older people and people with disabilities, both males and females, suggested the following infrastructural solutions: to increase the number of and re-construct accessible and usable WASH facilities; and to provide separate male and female latrines. In both research sites participants requested that older people and people with disabilities should be consulted on the design of facilities to ensure accessibility and usability. Participants in Zalengi also suggested a management structure be put into place to maintain and repair WASH facilities.

To address social/cultural/attitudinal barriers, participants at both research sites suggested there should be awareness raising campaigns about the rights of older people and people with disabilities in particular focussing on WASH facilities and programming as well as improving community attitudes within the community focussing on reducing stigma and discrimination. This should include addressing the use of derogatory terminology, in particular, terms used to describe people with disabilities. It was also suggested that there should be community consultation and awareness raising concerning the participation of older people and people with disabilities in WASH planning and decision making processes.

With respect to policy and institutional barriers, participants from Zalengi suggested that older people and people with disabilities should be included in the social security programme, but details were not given. Also that there should be community awareness raising campaigns concerning the inclusion of older people and people with disabilities in WASH programming. They suggested this could take place through workshops and lectures targeting community members as well as older people and people with disabilities, as well as information slots on the radio and TV.

The main problems and obstacles to addressing these barriers was identified by the majority of participants as a lack of financial and human resources, including experts and trained staff. When asked who or what organisation should be responsible for addressing the barriers identified the majority of participants in both research sites stated that government organisations and non-profit organisation should be responsible for addressing: natural and environmental barriers; infrastructural barriers; policy/institutional barriers; and social, cultural and attitudinal barriers. They also identified that community members should contribute to addressing social, cultural and attitudinal barriers. Interestingly individual barriers were not mentioned.

4.5 Peer-to-Peer Conversations: Social/Cultural/Attitudinal and Individual barriers

Peer-to-Peer conversations involved open- discussion themes and topics structured around two themes:

1. **Individualised barriers**
2. **Social/Cultural/Attitudinal barriers**

The Peer-to-Peer Conversations were based on six main criteria deemed to be relevant for ascertaining the extent to which Social/Cultural/Attitudinal and Individual barriers affected access to and the use of WASH facilities for older people and people with disabilities. These were: perceived individual feelings; perceived social/cultural/impacts; perceived community attitudes; perceived participation levels; perceived knowledge of policies; other comments.

Data was analysed using thematic analysis. Four main themes emerged from the analysis: individual's feelings; perceived community attitudes; community participation; and knowledge of WASH policies. Participants were also asked to give recommendations to improve inclusivity with respect to WASH programming.

4.5.1 Results

Individual feelings

Participants were asked to share their individual feelings about being older and/or disabled and their access to and use of WASH facilities.

Older participants, both male and female living in both Nertiti and Zalengi stated that whilst they faced many problems they did not feel ashamed of being older people. In fact as the quotations below show they felt that their age meant they were respected.

> **'I'm considered an elderly person and I do not have problem with this. I'm respected by others due to my age.'** (Older male, Nertiti).
>
> **'They call me 'haboba zahra' or grandma. I'm happy with this name as it reflects love and respect for old people.'** (Older female, Nerfiti).

However, when it came to accessing WASH facilities the older participants mentioned having difficulties using latrines because they did not have seats, that the long distance to collect water was a barrier for them and also meant they could not always attend meetings. These issues were raised by both male and female older participants as illustrated as follows:

> **'I cannot collect water and undertake household activities. I do not have a seat to use in the latrine. I bath and use latrine without support.'** (Older male, Nertiti).
>
> **'I have difficulties to use our latrine because the area is small and there is no seat. It is particularly difficult to use the latrine at night because I have to carry water and flash [light] and sometimes my flash [light] has no battery.'** (Older female, Nertiti).

All older participants stated that they relied on the support of caregivers, mainly their children and grandchildren, to access WASH facilities, as the following quotations illustrate, this extends to more than just using the latrine and bathing:

'My children provide assistance and support. My children wash my clothes and collect water. I cannot go to the market.' (Older female, Nertiti).

'I think my dignity is affected, and I, and I feel I increased the burden on my family as I need assistance to use the latrine and bathe.' (Older female, Zalengi)

'I walk with a stick and I need support of my children even to get drinking water. I feel happy when my children help me to bath, because this is what I expect from them at this age.' (Older male, Zalengi).

Many participants, both men and women with a disability (mobility and/or sensory), felt excluded by their family and community and misunderstand. Older disabled participants felt particularly discriminated and stigmatised by their families and communities. The following quotes are typical:

'I faced discrimination by my father because of my disability. He paid school fees for my brothers and sisters. He bought new clothes for them and he always excluded me. My mother supported me very much; she encouraged me to go to school, to socialise and become part of the society.' (Male with sensory disability, Zalengi).

'Some people think that my disability was an effect of gin/devil [witchcraft]. People think I'm a beggar. When I go to the shop, the shopkeeper does not listen or ask what I want, he says God gives you.' (Male with sensory disability, Zalengi).

'I'm happy and my children and grandchildren love me. I think my rights to WASH services and programmes have been violated as a result of my disability. The community and government organisations do not care about rights recognised by the international community.' (Older disabled woman, Zalengi).

Issues of accessing WASH facilities and services differed by type of disability with those with mobility disabilities having the most challenges:

'I have difficulties of accessing and collecting water, using latrine and washing my clothes.' (Male with mobility disability, Nertiti)

'I have hearing impairments. I have no problems collecting water and accessing latrines.' (Female with sensory disability Nertiti)

'I think my dignity is affected and I feel I increased the burden on my family as I need their assistance to use latrine and bathe. But I do what I can. This is God's decision.' (Female with sensory disability, Zalengi)

Interestingly younger men and women with sensory disabilities did not feel as excluded or discriminated by their families and neighbours:

'My sisters and my neighbours extend their assistance and support. They always help me with cooking, ironing my clothes, accompany me for shopping etc.' (Younger female with sensory disability, Zalengi).

'People call me by my name. I'm respected and my family is also respected. I have not been excluded by our family or the community because I participate in all activities and I help people who need support.' (Younger male with sensory disability, Zalengi).

(Source: Muslim Aid - Group Activity for research Central Darfur.)

(Source: Muslim Aid - Training of data collectors in Zalengi, Central Darfur)

Perceived Community Attitudes

In Nertiti there appears to be a difference between how older people feel they are perceived by their community and those that have a disability. Older males and females reported that they liked being called 'grandma' or 'old man' by the community as these terms were a sign of respect and made them feel proud.

'People call me grandma and very happy because it reflects love and respect for older people.' (Older female, Nertiti).

'People love me, no discrimination or exclusion. All people talk to me nicely, smile.' (Older male, Nertiti).

But some older people did feel excluded and treated differently by the community as some participants explain:

'I think sometimes I'm excluded because community members do not listen to me or consider my ideas and views. I participate in some social events. But I do not like that old people are seated together (assign one place for old women). I would like to mix with other women.' (Older female, Nertiti).

'I'm respected by most of the community members. But once I have been excluded by our community members. There was a meeting to establish water committees and I wanted to be a member, but they refused because I cannot see. I felt so bad. I cannot describe my feelings at that moment.' (Older female, Zalengi).

'The community have mixed views: some accept me and others do not, some respect and others consider me unequal, inferior and has low status.' (Older male, Zalengi).

However, it was very different with disabled participants, who got very angry when labelled as disabled by the community. This was particularly the case for participants who had mobility disabilities. They felt that unacceptable derogatory terms were used.

'Some people call me with unacceptable name "umkura'a" "a woman with one leg". I do not like this name but I keep quiet.' (Female with mobility disability, Nertiti).

'In the camp they call me by an unacceptable name "abkarank" – "handicapped". I do not like this name.' (Male with mobility disability, Nertiti).

Others felt that the community was ashamed of them and treated them as inferior.

'They consider me unequal and I feel ashamed and embarrassed. I do not see change in perceptions and attitudes of community members. No respect, no acceptance, and no support.' (Male with mobility disability, Nertiti).

Community Participation

Most older people, including those with disabilities, both male and females, living in Nertiti agreed that they participated in social events, but not formal meetings. Financial constraints were given as the major reason for not attending meetings, particularly if they were some distance from their residence and especially if they were held outside the camp.

'I participate in some social events in the camp. I do not go outside the camp because I cannot walk for a long distance.' (Older male, Nertiti).

'I participate in social occasions within the family only. I do not participate in others outside because it requires transportation and money.' (Older male with mobility disability, Nertiti).

In Zalengi there was an interesting difference between participants who had a sensory disability and those that had a mobility disability. Many males with sensory disabilities did attend social and public meetings, whilst those with mobility issues felt excluded. The following quotations are illustrative:

'I participate in public events. I want to participate to fight for my rights.' (Male with sensory disability, Zalengi)

'I participate in social events if invited. I face communication problems and feel lonely because people do not understand sign language, but still I participate and I do not feel unhappy.' (Male with sensory disability, Zalengi)

'I do not participate in social events and marriage parties because I am not invited and people do not like to socialise with me. I do not participate in public events due to transportation problems.' (Male with mobility disability, Zalengi).

Women, particularly younger women with a disability, on the other hand reported limited participation in social events and public meetings. The main reasons given were that they were not invited to the event and for younger disabled female participants that their parents refused to allow them to attend for reasons of personal security.

'I would like to participate in social events and celebrations but my mother would not allow me because of fear that I cannot run away if there is a problem.,' (Younger female with mobility disability, Zalengi).

'I do not participate in meetings because community leaders do not invite us.' (Younger female with sensory disability, Zalengi).

Knowledge of WASH Policies

In Nertiti IDP camp only older males reported that they were aware of WASH policies but felt they had no influence. No older female participant said they were aware of any WASH policies.

'I participate in social events and also I participate in the meeting of the DPO. I'm aware about policy on disability but did not see any change.' (Older male, Nertiti).

In Zalengi IDP camp all older participants (male and female) reported that they were not aware of WASH policies:

'I have no knowledge about policies, and I feel our rights are always violated.' (Older female, Zalengi).

'I do not know about organisations that provide support for older people and people with disabilities and have no knowledge about WASH policies.' (Older male, Zalengi).

Some male and female participants with a disability in Nertiti camp said they would like to participate in meetings where WASH issues were discussed. But cost and access to transport was a real barrier to them.

'I wish to participate in these meetings to discuss issues related to maintaining and improving water points to be clean and easily, it requires transport or using a donkey.' (Female with mobility disability, Nertiti).

Others stated that they had not been invited to WASH meetings and even if they were invited they would not attend.

'I was not invited for meetings about WASH and I do not like to participate in the future in meetings.' (Male with mobility disability, Nertiti).

'I did not participate in meetings and I do not like to participate in the future.' (Female with mobility disability, Nertiti).

Only a small minority of participants, mainly males with a disability reported being aware of some policies relevant to people with disabilities, but these participants were in a minority.

'I'm aware about the CRPD and Sudan Disability Act. I think the government should activate these tools to ensure effective participation and to realise the rights of people with disabilities.' (Male with mobility disability, Nertiti).

Recommendations

Each participant was invited at the end of the conversation to make recommendations to improve the inclusivity of WASH programming. Table 9 provides a summary of the main recommendations made.

It is interesting to note that females were reticent to make recommendations, perhaps due to their status within the community and the fact that they felt disempowered. Also it suggests that there is a greater awareness of rights amongst people with disabilities than older people. This perhaps suggests that awareness raising needs to target older people, in particular women.

Table 11: Main recommendations from Peer-to-Peer Conversations

Research Location	Older People	People with Disabilities
Nertiti	The majority of recommendations came from males. Females very reticent to make any recommendations. • Apply construction standards that facilitate the accessibility to water points and latrines. • Support livelihoods. • Provide transport. • Provide services for older people.	Recommendations made by males and females with sensory disabilities. • Establish schools for deaf people. • Establish vocational training. • Provide hearing aids for people with hearing difficulties. • Provide medical insurance. • Display signs in government institutions/ buildings to guide/direct people with hearing impairments. • Support livelihood activities. Few females with mobility disabilities made any recommendations. All males with disabilities (mobility and/or sensory suggested the following: • Apply construction specifications to ensure water points and latrine facilities are suitable and accessible for people with disabilities. • Provide mobility aids. • Construct water tanks and pipe networks to ensure the availability of water. • Fill potholes and improve road conditions. • Provide financial and material support for people with disabilities and their families. • Increase community awareness about disability concepts and rights.

Zalengi	Recommendations were made by both males and females. • Using road construction standards that meet the requirements of older people and people with disabilities. • Provide latrines that suit the needs of older people and people with disabilities. • Increase the number of water points including hand pumps and taps. • Providing medical support and mobility aids to older people and people with disabilities. • Emphasise the importance of inclusion and realising the rights of older people and people with disabilities.	Recommendations were made by both males and females. • Provide adequate, safe and healthy water points. • Construct accessible latrines and bathrooms that suit older people and people with disabilities. • Provide food and income generating activities for people with disabilities and their families. • Provide mobility support for people with disabilities. • Increase community awareness about disability and people with disabilities. • Provide training and awareness on CRPD and International Standards on WASH. This training should target DPO executive committees, people with disabilities and their families, government and humanitarian organisations.

The three main recommendations concerned the provision of WASH infrastructure and programming were as follows:

- **Facilities** should be provided that are accessible and usable by older people and people with disability in addition ensuring the environment surrounding and giving access to facilities were safe and secure, including signage. The provision of separate facilities for males and females was emphasised as well as the provision of water for hygiene purposes at latrines as well as solar powered lighting so facilities could be more easily and safely used during the evening and night.
- **Services** such as schools and vocational training should be established for disabled people and their families, including livelihood opportunities, as well as affordable and suitable transport. In addition, the provision of disability aids such as wheelchairs, spectacles and hearing aids, as well as suitable medical services.
- **Awareness raising and changing community attitudes** to older people and people with disabilities was emphasised with the recommendation that training should be given at all scales to ensure that the rights of older people and people with disabilities to WASH programming are understood and protected.

4.6 Mapping International Standards of WASH Inclusion: Focus Group Discussions

The focus group discussions involved open- topics structured around two themes:

1. **Barriers to WASH inclusion in International Standards**
2. **Solutions for WASH inclusion in International Standards**

The focus group discussions were based on four main criteria deemed relevant for discussion on the International Standards for access by older people and people with disabilities to WASH programming, identify gaps and make recommendations for improvements. These were: gaps in International standards; suggestions as to how WASH inclusion could be improved; obstacles to remedying the situation; recommendations to progress WASH Inclusion.

4.6.1 Results

All participants recognised that there were gaps in WASH inclusion of international standards in their communities. The majority of participants (6 out of 8 FGDs) identified the following three barriers as being the most important: natural and environmental barriers; policy and institutional barriers; social, cultural and attitudinal barriers. It is interesting that infrastructural barriers were referred to peripherally under natural and environmental barriers and individual barriers were not mentioned.

In terms of proposing solutions to the natural and environmental barriers, participants recommended the following: ensure that roads were clear from obstacles and were accessible to older people and people with disabilities; provide machinery and tools for clearing rubbish to clean up the environment. Participants proposed that donor organisations, government institutions, local committees and local leaders should be responsible for actions to improve the natural and environmental barriers to WASH inclusion.

With respect to policy and institutional barriers, the following were suggested as solutions: design and build water points and latrines that were accessible and usable by older people and people with disabilities (overlaps with infrastructural barriers); providing mobility aids for older people and people with disabilities; offering vocational training for people with disabilities to increase their livelihood opportunities and improve their economic status. In addition, it was recommended that information and data concerning older people and people with disabilities should be collected for planning purposes and that budgets should be allocated accordingly. Participants also stated that the laws and legislation of private and public institutions should include protecting the rights of older people and people with disabilities. No details were provided as to what participants were referring to, but it was suggested that older people and people with disabilities should be included to ensure their effective participation in WASH programming. It was recommended that committees be set up to monitor inclusive WASH activities and to supply hygiene kits. Participants highlighted that government and other organisations (no details given) should take responsibility to address these barriers.

The recommendations to provide solutions for social, cultural and attitudinal barriers to WASH inclusion was to advise that community awareness raising takes place concerning disability, how to communicate with people with disabilities and to involve them in WASH programming, as well as informing the community about the rights of older people and people with disabilities. It was

suggested that training should also be given, or intensified, to staff working in the IDP camps. It was also suggested that older people and people with disabilities should participate in decision making related to WASH programming at all stages, but few details or examples were given as to how this could be achieved. When asked who should be responsible to address these issues participants mentioned 'organisations' but gave no details, as well as the government and the community itself.

(Source: Muslim Aid - Data collectors in Central Darfur)

4.7 Semi-Structured Interviews: The Social/Cultural/ Attitudinal and Individual barriers in WASH programming

The semi-structured interviews involved a mixture of open- and closed questions structured around two themes:

1. **Community attitudes and social norms to WASH inclusion**
2. **Impact of community attitudes and social norms on WASH inclusion**

The semi-structured interviews were based on six main criteria deemed relevant for identifying Social/Cultural/Attitudinal and Individual barriers that excluded older people and people with disabilities from WASH programming. These were: (1) Community's attitudes towards older people and people living with disability; (2) Community's attitudes towards older people and people living with disability with respect to their access to WASH facilities; (3) The impact of community attitudes on older people and people with disabilities and their families; (4) Participation of older peoples and people with disabilities in community decision making regarding WASH programming; (5) Suggestions/recommendations as to how to improve community attitudes; (6) Other relevant comments.

4.7.1 Results

The majority of male participants from both research sites reported a positive community attitude towards older people and people with disabilities. It appeared that impairment and disability was less stigmatised when somebody was older. The following quotations are illustrative of such positive attitudes:

> **'A person who is old and has physical disability is treated with respect.'** (Male care giver, Nertiti).
>
> **'The family pay special attention to older people and people with disabilities because they are people with special needs and it is important to accompany them to access facilities located at a long distance.'** (Older female with disabilities, Nertiti).

Both men and women participants from both research sites stated that older people and people with disabilities were provided with essential services such as food, water, washing and cleaning by their family and wider community. In Nertiti it was reported that these positive attitudes depended on which community the older people and people with disabilities belonged to (ethnicity and class), the type of disability they had and their financial standing.

By contrast, most female participants stated that older men and men with disabilities were treated more favourably by their families and wider community than their female counterparts. This they suggested reflected the low status that women have in society. Negative attitudes were manifested through bullying and children teasing them. This difference is explained by a female community representative as follows:

> **'There is difference based on gender. This is because men have already special status in the community. Men have a decision making role while women's responsibility is in the house.'** (Female community representative, Nertiti).

There was also a difference between male and female responses with respect to the community's attitudes towards older people and people with disabilities using WASH facilities. In Nertiti all male participants confirmed positive community attitudes towards inclusive WASH access, as exemplified by this quotation:

'It is difficult to access WASH services as it requires special mobility aids and support which are not available. Therefore, older people and people with disabilities get support from their families and community members to access WASH facilities.'
(Male community representative, Nertiti).

Female participants in Nerfiti stated that these positive family and community responses depended on the community they belong to and the type of disability and financial standing of the older and/or person with a disability. As a female community representative explains:

'Depending on the type of disability, the family will be responsible to support older people and people with disabilities to access latrines and other services...in Nertiti, only families help older people for food, cleaning but they cannot be helped for special needs such as hearing aids or glasses for those with visual impairments.' (Female community representative, Nertiti).

A female caregiver concludes:

'Older people require special attention...but some community members have a negative/inhuman perception.' (Female caregiver, Nertiti).

The vast majority of participants, both men and women, in Zalengi reported that as older people and people with disabilities receive almost all their support from their families, people with no family receive less support and are thus very vulnerable. Women in both research sites thought that women community members manifested more positive attitudes towards older people and people with disabilities who had little or no family support. Age is an important social issue as a female caregiver in Zalengi explains:

'The age is very important. There is more respect for people at ages above 30. But there is no respect for old people in the society.' (Female caregiver, Zalengi).

The majority of participants in both Nertiti and Zalengi agreed that this lack of respect from community members had psychological effects on older people and people with disabilities. The following quotations illustrate this:

'People with disabilities and their families face negative attitudes from the community. This discourages people with disabilities to leave the house.' (Male with disability, Nertiti)

'Because of bullying and tease, older people and people with disabilities stay at home in isolation from the community.' (Female community representative, Nertiti).

Whilst the majority of participants in both research sites recognised that older people and people with disabilities should play an important role in their communities, they also agreed that their views on WASH programming were not considered.

> **'Old people are considered as a reference on social issues and their views are considered due to their long experience. But older people are not consulted about [WASH] programmes because they do not know about it.'** (Female community representative, Nertiti).

Some of the participants did however recognise the lack of participation by older people and people with disabilities in decision making regarding WASH programming depended on the community's level of awareness of the rights of older people and people with disabilities, as well as the responsibility of communities.

> **'Participation depends on community: for some who are well informed and have good awareness, older people and people with disabilities are allowed to participate. For others they are not.'** (Male community representative, Nertiti).

Participants were asked to give suggestions or recommendations as to how to improve community attitudes towards older people and people with disabilities and their access to WASH programming. Apart from requesting that WASH facilities are built closer to residential areas, and that roads and paths to them should be repaired and maintained to make them accessible, and asking for the provision of mobility aids and assistive devices such as wheel chairs, hearing aids etc, participants suggested an intensive community awareness campaign to dispel negative community attitudes towards older people and people with disabilities. A number of women also asked for gender equality training within the community:

> **'Why they [the community] do not respect women?'** (Female caregiver, Zalengi).
>
> **'Why there are always differences between men and women?'** (Female caregiver, Zalengi).

It would thus appear that female older people and those with disabilities have the least respect within their communities. So awareness training should not just address challenges associated with old age and disability but should also include gender issues. Thus demonstrating the need for an intersectional approach to inclusive WASH programming.

4.8 Conclusion

These six research tools and activities have put older people and people with disabilities at the centre of this research. They have produced interesting results that demonstrate the value of investigating the issues of inclusive WASH programming using the Social Model of Inclusion through an intersectional lens. These results will be discussed in the following chapter.

Chapter 5: An Intersectional Model of WASH Inclusion for Older People and People with Disabilities.

5.1 Introduction

In order to investigate the aim of this research, a rights-based approach (based on UNCRPD) was implemented using the Social Model of WASH Inclusion as the conceptual framework (Jones et al, nd; WaterAid, 2010).

The Social Model of WASH Inclusion is based on the principles of equity, namely the principal of fairness and inclusion, which is the process of ensuring that all people are able to participate fully (WaterAid, 2010), including older people and people with disabilities. The Social Model of WASH Inclusion identifies three major barriers to WASH inclusion: environmental, attitudinal, and institutional/organisational. The Social Model of WASH Inclusion and the research design were described in Chapter Three. Using this framework and employing a Participatory Action Research Methodology and Methods enabled the research to put older people and people with disabilities at the centre of the research and to allow their opinions and experiences to be heard. The results of each of the methods used in the research were presented in Chapter Four.

This chapter will bring together the results of the research and will propose a more detailed Model of Social Inclusion of WASH based on the research results and analysis from the data collected in the IDP Camps in Central Darfur. In particular, it will stress the need for an approach that does not standardise the categories 'older people' and 'people with disabilities', but instead takes an intersectional approach. An intersectional approach recognises that age, gender and the types and severity of disabilities can have a significant impact on how clusters of people within these standardised groups are able to access, use and influence WASH programming.

This will be followed by a discussion of the challenges experienced by the research team and the limitations of the tools used with suggestions as to how they can be effectively used in humanitarian situations. The chapter will end with a set of recommendations as to how inclusive WASH programming in humanitarian settings, based on UNCRPD, can be improved to ensure older people and people with disabilities have access to and are involved in WASH programming and that their human rights are protected.

Credit: Albert Gonzalez Farran/UNAMID/CC BY-NC-ND - A woman living with disabilities carrying water at a camp for internally displaced people.

5.2 An Intersectional Model of WASH Inclusion for Older People and People with Disabilities.

The results presented in Chapter Four were analysed and four interconnected factors were identified as being fundamental to the inclusion of older people and people with disabilities. These are:

1. The characteristics and needs of users.
2. WASH facilities.
3. Institutional barriers.
4. Social factors

These are shown in Figure 32 and each factor will be discussed in turn.

Figure 32: An Intersectional Model of WASH Inclusion for Older People and People with Disabilities.

5.2.1 Characteristics & Needs of Users: Type(s) & Severity of Disability, Age & Gender

The results of the research demonstrated quite clearly that the characteristics and needs of older people and people with disabilities with respect to WASH programming is highly complex.

The types and severity of disability combined with age and gender produces a multifaceted situation that requires attention if WASH Programming is to be truly inclusive and that the human rights of these members of society are to be respected. The recognition that older people and people with disabilities are not homogeneous groups, but have very different needs, social standing and experiences is crucial if WASH Programming is to be UNCRPD compliant.

Type & Severity of Disability

There was no data available on the types and severity of disability in the two IDP Camps that participated in this research. The team therefore had to do a rapid survey of the situation using three modules from the RAM-OP Tool (see Chapters Three and Four).

The RAM-OP Disability Module indicated that mobility disability (difficulty walking or climbing stairs) was the most common disability reported by participants (26%). This was followed by difficulties with sight (20%), difficulties in hearing (19%), difficulties in remembering or concentrating (18%) and difficulties in communicating (17%). These results indicate that sensory disabilities (sight, hearing and communicating) were the most common disabilities at 56% of the total disabilities reported, followed by mobility disabilities (26%) and cognitive disabilities (18%). However, within the sensory disability category, visual problems were reported as a greater barrier to WASH inclusion than difficulties in hearing.

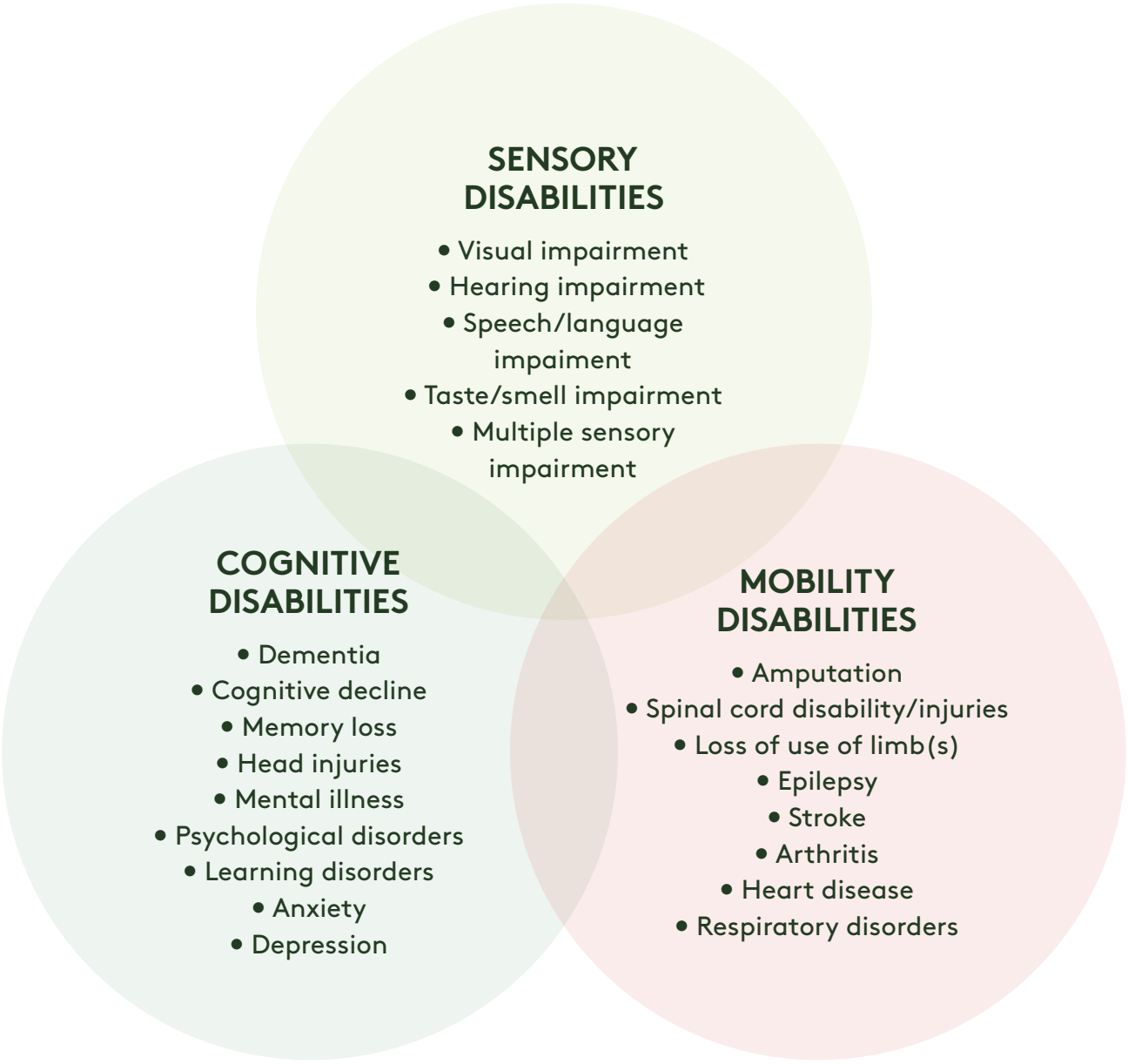
When the data was analysed by severity of the reported disability, participants with cognitive disabilities were noted as having the highest percentage of moderate to severe disability (89%) compared to 80% sensory and 73% mobility. This suggests that WASH programming must take measures to include sensory and cognitive disabilities as well as mobility difficulties when designing WASH facilities. Few reports discuss the WASH needs of people with different types and severity of disability or acknowledge that many people will be living with multiple disabilities. The results showed that 38% of participants had multiple disabilities, meaning their WASH needs were complex.

The data suggests that inclusive WASH programming must take into account that disability comes in different forms and severity and that many people are living with multiple disabilities. Examples of different forms of disability are listed in Figure 33. The results of this research suggests that people with multiple disabilities are likely to experience more barriers to WASH inclusion than people with a single disability. It is assumed that people living with mobility, sensory and cognitive difficulties face the most serious barriers to WASH programming and services. More research is needed on the barriers to WASH facilities that people with multiple disabilities confront in order to understand their needs and to take into account their views of WASH programming.

Unfortunately, people with cognitive disabilities were not included in the qualitative elements of this research due to lack of gatekeepers. This research suggests that cognitive disabilities comprise a significant proportion (18%) of disabilities within the sampled populations, and have some of the highest levels of severity. It is therefore suggested that more research needs to be done on

the barriers faced by people with cognitive difficulties in accessing WASH programming as these 'hidden disabilities' are often neglected in the planning of WASH programming.

Figure 33: Examples of Sensory, Mobility and Cognitive Disabilities



It is thus important for the complexity of the disability situation of a population in a particular situation to be screened. This should include type(s) of disability as well as the severity of the disability. The proportion of multiple disabilities is also pertinent. This can easily be undertaken using the RAM-OP Disability Module. This will enable appropriate planning to be undertaken to ensure inclusive WASH Programming is available to as many people as possible. This is particularly important when the humanitarian circumstances progress from an emergency to a development situation as was the situation in the IDP camps involved in this research.

Age & Gender

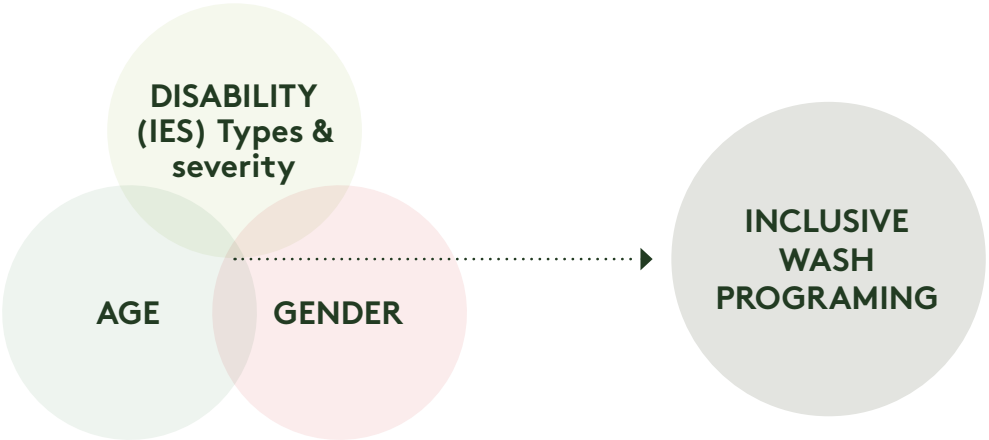
Not only do planners and providers of WASH need to take account of the different types and severity of disabilities, but age and gender issues must also be considered.

. Women in this research had a slightly higher level of moderate to severe disabilities, including multiple disabilities, than men. The Katz Index indicated that female participants over the age of 60 had a significantly higher level of moderate to severe dependency on helpers (76%) compared to males (59%). Similarly, females with sensory disabilities experienced moderate to severe dependency on helpers, which is twice the rate of males in the same age cohort. In addition, women also had specific needs when they were menstruating as well as serious concerns with regard to security. Many women participants reported the need for female-only latrine blocks, with locking doors and suitable hygiene facilities. They also asked for solar lighting at water points and latrines so they could use the facilities in safety during the hours of darkness.

Older disabled people with severe mobility disabilities reported having excessive challenges accessing and using WASH facilities. Those with visual disabilities also reported great difficulties accessing and using WASH facilities. Those with hearing impairments did not report having any significant problem using WASH facilities. Interestingly younger men and women with sensory disabilities did not feel excluded or discriminated by their families and neighbours and could call on them for help when needed. All older participants stated that they relied on the support of caregivers, mainly their children and grandchildren to access and use WASH facilities. Thus for most older people and people with disabilities family support is essential to enable them to access WASH facilities. Those without this support network are regarded by participants as a highly vulnerable group that require special consideration with respect to accessing WASH programming.

Figure 34 demonstrates the complex situation concerning older people and people with disabilities in IDP Camps in Central Darfur. The results of this research clearly demonstrate that age, gender and the type and severity of disability are interlocked and cannot be easily separated. These combined characteristics result in specific WASH needs that very often are not accommodated in standardised responses to humanitarian crisis. If real inclusion of older people and people with disabilities into WASH Programming is to be achieved and UNCRPD to be implemented, then the intersection of age, gender and disability type and severity must be considered together.

Figure 34: Older People and People with Disabilities: The intersectionality of age, gender and disability (type and severity) to produce inclusive WASH Programming



5.2.2 WASH Facilities: Availability, Accessibility & Usability

Not surprisingly the main comments made by participants in this research concerning WASH Programming was the availability, accessibility and usability of WASH facilities, in particular latrines/toilets and water points. The RAM-OP WASH module indicated that 70% of participants had access to safe drinking water whereas only 13% had access to improved non-shared sanitation (the figure was 0% in Nertiti). The figures differed by location, with the urban IDP camp (Zalengi) having better access to safe drinking water and improved non-shared sanitation than the rural IDP camp (Nerfiti). However, there was no significant differences in access to either by age or gender.

The higher proportion of participants reporting access to safe drinking water reflects the Sudanese Government and donor priority to provide safe drinking water in IDP camps, with the provision of improved non-shared sanitation lagging behind.

Availability

All participants stated that they had access to improved shared latrines; these were usually located in public facilities such as health or community centres. The same was the case for safe drinking water, with public hand-pump boreholes and taps being accessed at locations such as youth and women's centres. It was reported that the use of these shared facilities were free. Some participants did however mention that they did occasionally make a financial contribution to the maintenance of the facility when repairs were needed. This was particularly the case with water points. With respect to disability, the lowest levels of access to safe drinking water were reported by participants with sensory (40%) and mobility (38%) disabilities. Lack of access to improved non-shared sanitation facilities was widespread, but men with mobility disabilities (87%) and women with sensory disabilities (92%) were the most severely affected.

All participants complained that shared latrines/toilets and safe water points were often located some distance from residential areas and were not well maintained. Participants reported that water points were often waterlogged and that shared latrines/toilets were habitually filthy. Thus, many participants preferred to use unsafe water sources and to defaecate in open spaces, especially in the rainy season. Everyone called for non-shared WASH facilities to be provided within each compound, however they recognised this might not be feasible and asked that more shared latrines/toilets and water points should be built and that these be closer to residential areas. Some focus groups suggested that community management groups should be set up to manage and maintain the WASH facilities. They requested that training, tools and resources be made available to facilitate this.

Accessibility

The main complaint concerning the accessibility of WASH facilities by older people and people with disabilities was the access path or road and the immediate environmental surroundings. Participants at both research locations reported that uneven potholed, narrow paths limited the use of a walking frame or wheelchair, and were often strewn with rubbish and stones that hindered access to latrines/toilets and water points. They also complained that the paths often had vegetation over hanging them and were often wet and slippery due to poor drainage near the facilities and especially during the rainy season. This was mentioned by many participants but in particular those with a visual disability. This was the case at both latrines/toilets and water points. Participants also commented that it would be helpful to have benches along the path so

that frail people could take a rest. A number of focus groups suggested that with some training, tools and resources the local community could attend to these issues, through the setting up of a management committee with representation from older people and people with disabilities.

A number of women's focus groups mentioned safety issues associated with using WASH facilities after dark. They were frightened of being assaulted and felt that if there was solar powered lighting along the path and at the facilities this would give them the confidence to use the facilities in the evening.

Usability

Most of the usability issues raised by the participants concerned the design of WASH structures. In particular participants criticised the number of steps and their depth at both latrines/toilets and water points. They suggested these should be replaced with gently sloping ramps that were wide enough for a wheelchair or walking frame. It was also suggested that handrails be installed to assist people with mobility as well as visual difficulties.

Participants were particularly vocal about the barriers faced by them in using the latrines/toilets. They complained that the entrances to the facilities were too narrow as were the corridors and doors to latrines/toilets. It was also requested that latrine/toilet doors should open outwards to facilitate use by people with disabilities. Again, this was mentioned with respect to wheelchair or walking aid access. The majority of problems raised, concerned the size of latrine/toilet cubicles, which were often small and thus prohibited the entrance of a wheelchair and/or a helper. Participants of all ages, genders and types of disability requested that there should be seating in the latrine/toilet and handles for support. In addition, participants criticised latrines/toilets for being dirty, slippery and with uneven floors with no light for use after dark. People also criticised the lack of water and soap at the site of latrines/toilets to allow for general toileting hygiene. This was particularly mentioned with respect to Covid-19 advice. Safety issues were again raised by female participants who requested that there should be female and male latrine blocks with locking doors and that solar lighting should be installed.

With respect to water points, participants were critical of the width of access and that there was often a number of steps to enter the water point. In addition, the area around the pump or tap was often criticised for being slippery due to poor drainage resulting in pools of stagnant water. Many participants found the use of water hand pumps to be difficult or too heavy for them to use and would prefer a tap, which would make it easier for older people and those with disabilities to collect water.

Thus, it would seem that some changes in the design of these facilities could enable more older people and people with disabilities to use the facilities. For example, replacing steps with gentle ramps with a handrail, making the latrine/toilet cubicle bigger and adding a seat and handles would make a huge difference. Replacing hand-pumps with taps would enable the elderly and frail to use them. The provision of seating was mentioned so people could rest whilst waiting to use the facilities. This was particularly requested at water points where people often have to queue for some time to fill their water containers. In addition, participants suggested that providing hygiene services and solar lighting would also encourage people to use the facilities, particularly females.

5.2.3 Institutional Barriers: Building Standards & Guidance, Consultation, Management & Resources

Building Standards and Guidance

It did not appear that any building standards or guidance were in place in the two IDP camps with respect to latrines/toilets or water points. This may be because the camps were set up 19 years ago (2003) and since then adhoc changes have been made as the population of the camps grew and aged, and facilities had to be repaired or replaced.

Interestingly the authors could find no evidence of building regulations, standards or guidance relating to the construction of latrines/toilets or water points that were accessible to older people or people with disabilities in IDP settings. Most policy documents that do mention these demographic groups often state that due to the complexity of the needs of these groups of people it is not possible to prescribe or recommend suitable structures. However, whilst the situation concerning access to WASH facilities such as latrines/toilets and water points is complex, this research asked participants to make recommendations as to what improvements could be made to enable them to more easily use these facilities. Whilst the type of disability and the severity of the disability was a fundamental consideration, a number of suggestions were made that would enable a range of older people and people with disabilities to more easily use such facilities.

Consultation

As there did not seem to be any standardised guidance or designs being used to build latrine/toilet and water point structures that were accessible to older people and people with disabilities it would seem reasonable that the providers of these facilities to consult with local communities; and in particular those who may have difficulty using WASH facilities due to old age and/or disabilities. This could ensure that structures were as universally accessible as possible. However, in neither IDP camp did there appear to be any consultation mechanism in place to include older people and people with disabilities in decisions concerning the location and design of WASH facilities.

Many participants stated that they were not invited to such meetings and if they were, they often could not attend due to financial constraints, in particular the cost of transport. This was especially pertinent if the meeting was some distance from their home or even outside the camp. This was particularly the case for people with mobility disabilities. Men with sensory disabilities on the other hand did report attending such public meetings, although deaf people did have difficulty in communicating during the meetings.

Women, particularly younger women with a disability, reported restricted attendance at public meetings, usually because their parents refused to allow them to attend citing personal security as the issue. Thus, age, gender and type and severity of disability were all factors that determined if older people and people with disabilities were invited to public meetings and if they were able to participate. This means that many older people and people with disabilities felt disempowered with respect to inclusive WASH programming.

Management and Resources

The main issues raised by participants in both locations, by age, gender and type and severity of disability concerning the management and resourcing of WASH programming in the IDP camps were:

- Absence of baseline data on older people and people with disabilities living in IDP camps, particularly information relevant to WASH programming.
- Lack of consultation with older people and people with disabilities by the providers of WASH facilities and programming.
- Dearth of financial resources, tools and trained staff to maintain, repair, replace or build new WASH facilities.
- Poor local management with respect to daily management and hygiene of WASH facilities.
- The need for vocational training for people with disabilities to provide them with income generating skills and to provide livelihood opportunities for them and their families thus improving their self-esteem.
- The provision of disability technical support such as hearing aids, spectacles and mobility aids to allow people to become more independent and their disability mitigated.

5.2.4 Social Factors: Attitudes, Stigma & Discrimination, and Family Support & Resources

Attitudes

Most participants commented on an apparent lack of acceptance of people with disabilities within their community and a negative social attitude in particular towards older people with disabilities. These social attitudes were perceived by the participants as a major barrier to WASH inclusive programming. People with disabilities were particularly critical of the derogatory terminology used to describe them within their communities. However, most felt unable to challenge the use of such terms for fear of further stigma and discrimination. It was suggested that awareness raising campaigns, nationally and locally might improve the situation by educating people and communities concerning the human rights of older people and people with disabilities and thus facilitate the inclusion of older people and people with disabilities in WASH programming.

Stigma and Discrimination

Older participants both male and female living in both IDP camps stated that whilst they faced many problems, they did not feel ashamed of being older people. Many felt that they were respected within their families for the wisdom that a long life gives them. The majority of male participants reported that they experienced positive community attitudes. Nevertheless, some older people did report that they were treated differently by the community and that their views and opinions were not invited or were ignored. Older women in particular felt disregarded and excluded by their community. By contrast, many people with disabilities, both male and female, felt misunderstood and ignored by their family and community. Older disabled participants felt particularly discriminated and stigmatised by their families and communities with their disabilities often blamed on witchcraft.

So there appeared to be a difference in the way older people and people with disabilities felt they were perceived and treated by their communities. Most females stated that they felt older men and men with disabilities were treated more favourably by their families and the wider community than their female counterparts. This they suggested reflected the low status women were afforded in their society. Negative attitudes were reported to be manifested through bullying and children teasing them.

Negative social attitudes concerning older people with disabilities resulted in stigma and discrimination, which was then translated into a lack of individual self-esteem. The combination of stigma, discrimination and low self-esteem were suggested by participants as important reasons for the lack of participation in WASH Programming by older people with disabilities. Many stated that they were ashamed of their situation and did not want to be a burden on, or bother, family members for help and support.

Family Support and Resources

The vast majority of participants both men and women reported that older people and people with disabilities receive almost all their support from their families. Older people and people with disabilities that have no family receive less support and are thus very vulnerable and are reliant on community charity and help.

The Katz Index results indicated that 56% of those who participated in the RAM-OP ADL module reported moderate or severe dependence on helpers to use WASH facilities. The main form of assistance came from family members, mainly females. This is interesting as the Katz Index by gender indicates higher levels of moderate and severe dependency amongst women compared to men, with 61% of those reporting severe dependence being female. Seven percent of participants reported that they needed help but did not have regular access to any (unmet need for help); 87% of these were female. The Katz Index also indicated that participants over 60 years of age had the highest levels of dependency (67%) followed by people with cognitive disabilities (56%). However, the Katz Index suggests that whilst 56% of people with cognitive disabilities had moderate or severe dependency, they had low levels of unmet need. This means that these people are generally provided for and cared for by family members.

Most participants explained that the amount of help and support that a family could give to an older person or somebody with a disability depended on the type and severity of the disability and the resources available to the family. All agreed that older people and people with disabilities were provided with essential services such as food, water and personal hygiene care by their families. However, the family's ability to provide disability aids, such as hearing aids, spectacles and walking frames was compromised by poverty. Thus, a number of participants emphasised the need to improve the livelihood opportunities of families caring for a person with a disability so that technical aids could be bought or that organisations provide access to such assistance.

5.3 Limitations of the tools used

This research was conducted using a Participatory Action Research methodology. It used a range of complementary research tools to elicit information associated with inclusive WASH programming with special reference to older people and people with disabilities. It paid particular attention to intersectionality including age, gender and type of disability. Five research tools were used in the research as follows:

- **Adapted RAM-OP (Modules: WASH, Disability, Activities of Daily Living) (individual Survey)**
- **Accessibility and Safety Facility Audit (Group Activity)**
- **Social Model of WASH Inclusion (Group Activity)**
- **Peer-to-Peer Conversations (Individuals)**
- **Mapping International Standards of WASH Inclusion (Focus Group Discussion)**
- **Semi-Structured Interviews with community members and members of DPOs (Individuals)**

Despite the research being lead by a strong international and national research team some of these tools were quite challenging to administer in the IDP context and with the sample we were researching. Although the local researchers were given in-depth training in the ethical processes of the research, the purpose of the research, how to administer the tools and they piloted the tools, a number of researchers found the process demanding. One reason for this was their lack of detailed background knowledge concerning the international standards of WASH inclusion as well as issues associated with the lived experiences of older people and people with disabilities. Researchers were encouraged to do background reading (references and web links provided) prior to under taking the data collection. It is recommended that researchers are given the time to do this reading and to reflect on it and the tools. Many researchers also lacked experience of undertaking qualitative research and many found facilitating the FDGs and Peer-to-Peer Conversations particularly challenging. It is therefore recommended that researchers are given training and the opportunity to undertake role play and pilot the tools. They should be given the opportunity and time to reflect on the tools and to be able to ask for guidance, advice and support.

Table 12 summarises the purpose and usefulness of the tools we used, as well as recommendations for their implementation We recommend that the tools which involve group activities, such as the Accessibility and Safety Facility Audit, Social Model of WASH Inclusion activity and the Mapping International Standards of WASH Inclusion FGDs are simplified and adapted to the context and sample being researched and that they are tested as part of WASH programming. However, all tools produced rich data and have the potential to produce results that are invaluable to stakeholders involved in inclusive WASH programming.

Table 12: The purpose of the research tools used, their usefulness and recommendations for their use.

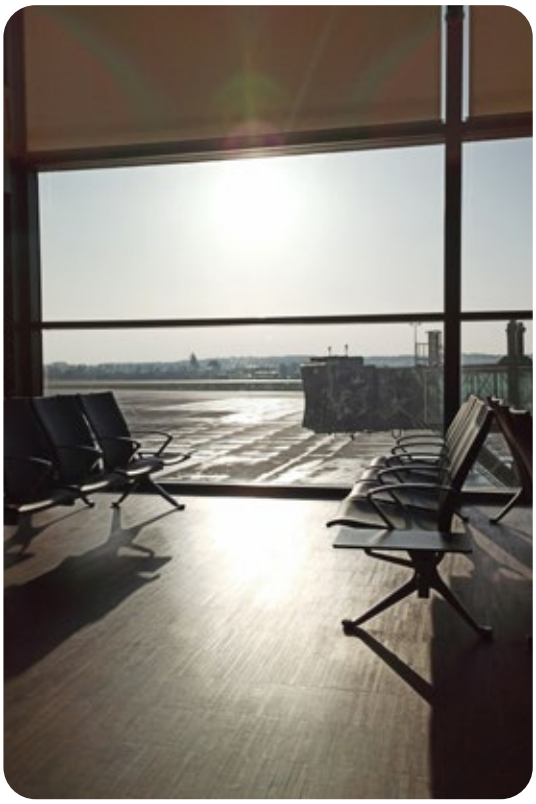
Research Tool	Purpose of the Tool	Individual or Group Activity	Ease of Use	Recommendations
RAM-OP Modules: Disability, WASH, ADL	To acquire baseline information on disability, access to WASH facilities and information on ADL (severity of disability.	Individual	Easy	Researchers found this tool easy to use. All questions must be answered. The calculations cannot be completed if there is missing data.
Accessibility and Safety Facility Audit	To ascertain the availability, accessibility and useability of typical latrine/toilet and water point by older people and people with disabilities. To ask participants for suggestions concerning changes and improvements to the facility and/or its surroundings to improve use of the facilities and address safety concerns.	Group Activity	Easy/ medium difficulty	The tool we used was adapted from Water Aid tool, but was in parts too complex for our sample, in particular the technical aspects such as drawing a plan/ diagram of the facility and including measurements. We suggest the audit is simplified and that a photo is taken of the facility itself and that the facilitator focuses on availability, accessibility, useability and safety observations and discussions of the participants. Notes need to be taken of the group's discussionincluding their recommendations for improvements.
Social Model of WASH Inclusion	Explored the barriers to inclusive WASH programming. The group discussed, ranked the barriers using the Barriers to Inclusion Framework. The participants then suggested and explored solutions to the barriers identified and prioritised them according to urgency. These were then mapped against the components of the Social Model of WASH Inclusion.	Group Activity	Medium difficulty	Facilitator needs to be familiar with the Barriers to Inclusion Framework and the Social Model of WASH Inclusion. Needs to be trained to facilitate discussions and allow everyone the opportunity to contribute. Should note down the dynamics of the group.

Peer-to-Peer Conversations	Generated insights into the social norms, community attitudes and internalised barriers experienced by older people and people with disabilities concerning inclusive WASH programming.	Individual	Difficult	Peer-to-Peer researchers need to be trained in this technique, so that it is a meaningful conversation not an interview. It was difficult for researchers to take notes whilst meaningfully participating in a conversation. Permission should therefore be sought from participants to audio record the conversations so they can be transcribed in full. If that is not possible then a note-taker should be present to enable the researcher to focus on the conversation.
Mapping International Standards FGD	Focussed on the gaps in the International Standards in WASH inclusion in the research locality. Asked participants for suggestions as to how WASH inclusion can be improved in their locality and to discuss any obstacles to remedying the situation. Group put forward recommendations to progress WASH inclusion in their community.	Group Activity	Medium/ Difficult	Facilitator needs to be familiar with the International Standards in WASH inclusion and be able to direct the discussion to cover the main themes of the standards. Facilitator needs to be trained to facilitate discussions and allow everyone the opportunity to contribute. Should note down the dynamics of the group.
Semi-Structured Interviews with community members and members of DPOs	Explored with community members and members of DPOs the community's attitudes, cultural perceptions and social norms concerning older people and people with disabilities with respect to access to and use of WASH programming.	Individual	Easy	Researchers found this tool easy to use. Recommend that researchers do not ask closed questions, but instead explore relevant themes and ask participants for examples.

5.4 Challenges

The research had to deal with a number of challenges. The main ones are as follows:

- **The Covid-19 Pandemic:** The pandemic had a number of impacts on the research.
  - First, it meant that the international researcher was unable to travel to Sudan to lead the training of researchers and to oversee data collection. Instead detailed researcher guides were written and training was given on-line. The international researcher set up a password protected ShareDrive so that the national researcher and local researchers could upload research results onto the ShareDrive so that the international researcher could monitor data collection and offer any guidance in a timely fashion. In addition, the international and national researcher kept in regular contact via WhatsApp as well as email (internet connections in Sudan permitting).
  - Secondly, the pandemic and national Covid-19 travel restrictions restricted travel to the research localities and so delayed data collection.
  - Thirdly the research tools had to be adapted to ensure they were Covid-19 regulation compliant and bio-security measures had to be implemented in the research localities.



Credit: Freepik - Empty Airport due to flight cancellations because of Covid 19 pandemic

- **Access to research locations:** the timing of data collection had to be adjusted due to security issues in Central Darfur and the availability of air and road transportation to the research locality. The choice of locations had to be kept under constant review as a result of the very fluid security situation, as well as the fact that a number of groups of IDPs were able to return to their homes.

- **Recruitment of suitable local Researcher Assistants:** it proved difficult to recruit local research assistants in Central Darfur who had the relevant knowledge and skills to undertake the research. They were given intensive training in person and were managed by the national researcher who monitored and guided the data collection process in the research localities. Despite this, some gaps in the data collected occurred, so a second period of data collection was undertaken. This allowed for the collection of missing data and data verification.

- **Recruiting Participants:** it had been expected that our local partners (DPOs) would be able to assist in recruiting participants to the research. This proved to be problematic as due to the security and Covid-19 situation our partners were either absent or not operating at full capacity in the research localities and did not have the resources to fully support the research. In addition, there was no DPO that was working with people with cognitive disabilities so that meant we could not include these people in the qualitative sampling. As a result, the research team had to spend more time than expected in recruiting participants to the study.

5.5 Recommendations

1. **Older People and People with Disabilities should be at the centre of WASH programming. However, they are often treated as homogeneous groups by policy makers and those providing WASH programming. This is clearly not the case as this research demonstrates. This study suggests that using an intersectional lens can facilitate more effective inclusive WASH planning and implementation.**

This research recommends the following:

- Collect baseline data and information concerning types and severity of disabilities, by age and gender. This can be done quickly and simply by using relevant RAM-OP modules and stratifying the sample by age, gender and disability type. The results thus provide a foundation to enable more effective and more targeted strategies to be developed and operationalised.
- Need to ensure people with cognitive disabilities are represented as they are often ignored or neglected in the data and appear to represent a significant proportion of disability that is often hidden from view and highly marginalised.
- Assess the extent and types of multiple disabilities and the barriers faced by these people in accessing and using WASH facilities. Their needs might be complex and need greater attention than currently given.
- Older people and people with disabilities should be involved in assessing the availability, accessibility, usability and safety of WASH facilities. A group-based Accessibility and Safety Audit is helpful and can reveal unexpected findings, especially with respect to gender and safety issues. Asking participants to make recommendations for improvements can produce good practical solutions that often can be facilitated by the community with training and support.

  It is recommended that this consultation should be formalised into programming plans, so that existing gaps can be identified prior to the design of new facilities. Such consultations will allow the experiences, views and proposed solutions to accessibility, availability and useability of WASH facilities by older people and people with disabilities to be heard. This could compensate in part for the exclusion of these groups in local community WASH committees.
- Preferably construct more non-shared latrines/toilets and water points in compounds, or provide more shared latrines and water points nearer residential areas.
- Set up local management committees with representation from older people and people with disabilities of various ages and genders to maintain and ensure hygiene of shared WASH facilities.
- Training, construction and hygiene tools and other resources to be made available so that local communities can effectively manage the daily functioning of WASH facilities. In particular to ensure paths and roads are well maintained, are of a good width to provide access for wheel chair users, are clear of potholes and obstacles, with hand rails where appropriate and benches for people to rest to ensure inclusive public health is prioritised.

2. **Providers of WASH facilities and programming should be trained in UNCRPD and national legislation (eg Sudan Disability Act) and work together with local communities to develop appropriate local building standards and guidance to ensure WASH facilities are as inclusive as possible and that communities are more aware of the needs and human rights of older people and people with disabilities.**

The team recommend:

- This should be done by inviting older people and people with different types and severity of disabilities representing different ages and genders to consultation, planning and implementation meetings.
- Meetings should be held at times and places that are convenient and accessible to older people and people with disabilities with no financial cost to them, in particular providing free transport if required.
- Arrangements should be made to ensure all have the opportunity to participate in the meeting, such as providing a sign language translator, information in large print or braille etc. Also ensuring that women have the opportunity to make their views heard.
- Should provide training, construction and hygiene tools and other resources to facilitate local community management groups to maintain and ensure hygiene of WASH facilities.
- Following consultation with older people and people with disabilities, design WASH facilities that can be more easily used by these groups. This could include:
  - Replacing steps with gentle ramps with hand rails.
  - Building separate male and female latrine/toilet blocks.
  - Ensure latrine/toilet cubicles have space to accommodate a wheel chair and/or helper.
  - That latrine/toilet doors open outwards and are lockable.
  - Providing seats and support rails in latrine/toilet cubicles.
  - That access gates, doors and corridors are wide enough for walking frame and wheelchair access.
  - Replace hand pumps with taps.
  - Ensure surfaces at latrines/toilets and water points are even, not slippery and with good drainage.
  - Provide hygiene services, such as soap and water at latrine/toilets.
  - At water points make benches available so people can rest whilst waiting to collect water.
  - Install solar lighting at latrines/toilets and water points to provide security and allow people to use the facilities during the evenings.
- Help should be put in place specifically for older people and people with disabilities who do not have a family support network and as such are highly vulnerable. These people need to be specifically targeted by WASH programming.

3. **National and local government bodies should work in partnership with private businesses, INGOs, NGOs, CSOs and local communities to tackle poverty as well as the stigma and discrimination faced by older people and people with disabilities in IDP camps.**

The following are recommended:

- Support is needed for the few organisations that are present in the IDP camps that work with older people and people with disabilities.
- Facilitate the setting up of DPOs to advocate and support people with cognitive disabilities.
- Provide (free or at reasonable cost) technical help such as hearing aids, spectacles, mobility aids, incontinence pads and commode chairs to those who need them, to give them more independence and improve their self-esteem.
- To offer vocational training for people with disabilities and family members to provide them with income generating skills and support livelihood opportunities for them and their families.
- Sponsor and participate in national, local and community-based campaigns to raise awareness of the human rights of older people and people with disabilities with a special focus on inclusive WASH programming.
- Programmes to be put in place to tackle the stigma and discrimination faced by older people and people with disabilities in IDP camps. This should include challenging the use of derogatory terminology.
- Support and training for families who are caring for older people and people with disabilities to ensure these vulnerable people are treated with as much dignity and respect as is possible, to ensure their human rights are honoured.

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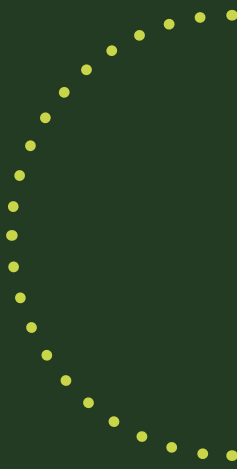

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