



Inclusion of persons with disabilities in social protection

Qualitative Report, Tanzania



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Originaltext: Keine Bildbeschreibung nur 'Tansania, Kilimanjaro Region, Manushijw Primary School. School of Elisabeth Mallya'. **Vorschlag:** School children at Manushijw Primary School carrying a fellow school mate in a wheelchair down the stairs.

1

Introduction

Originaltext: CCBRT matron Emelda is the head of the nursing services department. She helps take care of the women recovering from fistula surgery, providing comfort and support as well as helping women like Saada (left) and Rahel learn how to knit. CCBRT is a CBM partner hospital in Tanzania. **Vorschlag:** The head of the nursing services department taking care of women recovering from fistula surgery, providing comfort and support as well as helping them learn how to knit.



This report is an output from a two-country research project, 'Applied Research Concerning the Inclusion of Persons with Disabilities in Systems of Social Protection' in Peru and Tanzania. The aim of the project, which was commissioned on behalf of the German Federal Ministry for Economic Cooperation and Development (BMZ) by the Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH, was to scientifically analyse in applied research how social protection systems are and should be designed to adequately and systematically include persons with disabilities. The research activities were led by the London School of Hygiene and Tropical Medicine in collaboration with REPOA, the local research partner in Tanzania.

In Tanzania, the study had a specific focus on Community Health Funds (CHF), health insurance schemes run by local authorities at district level. It also involved a consideration of gender aspects in inclusive social protection systems. This report presents and analyses data obtained during qualitative interviews, which sought to understand the perceptions and experiences of persons with disabilities and the extent to which existing social protection programmes in Tanzania are inclusive of persons with disabilities.

2

Objectives

Originaltext: Theresia (spoken: Theresía), 76 years, cataract. Successful cataract surgery on right eye Project partner: KCMC (P0393). Picture: Theresia before surgery. Dr Heiko Philippin examines Theresia's eyes with the slit lamp. **Vorschlag:** 76 year old woman with a cataract being examined with the slit lamp before surgery on her right eye. .



The overall objective of the study was to investigate the experience of persons with disabilities in social protection programmes, in particular the Community Health Fund (CHF) and the Tanzania Social Action Fund (TASAF).

The specific objectives were to explore:

- Perceptions of disability and awareness of rights within the community, among local officials and among persons with disabilities themselves;
- The availability of data on disabilities at local level;
- The social protection and health needs of persons with disabilities;
- The barriers to inclusion in social protection programmes for persons with disabilities;
- The appropriateness of the targeting and enrolment system for persons with disabilities within the social protection programmes;
- The accessibility (physical accessibility and accessibility of information) of the social protection programmes overall and for persons with disabilities;
- The overall experience of persons with disabilities in the social protection program and their level of satisfaction with the programmes;
- The impact of the social protection programmes on their lives, or those of their family (e.g. poverty alleviation, empowerment).

3

Methodology

Originaltext: Some general information about KCMC: The Department of Ophthalmology at KCMC was one of the original departments when the centre was opened in 1971. A separate wing of the hospital houses the ophthalmic ward and theatre suite, as well as eye outpatients, optical facilities, and administrative offices. This was built with donations from Christoffel Blindenmission (CBM) in collaboration with the Good Samaritan Foundation of Tanzania (GSF). From Hedaru eye outreach, Mwanga district: Remenziana Raphael, 95 years old, cataract. She lives in Marangu and has 5 daughters (only one of them still lives with her, Catherine Raphael Tarimo, 65 years old). Her husband already died and so, it's her daughter who helps Remenziana to handle the daily life. She is a very small woman but though tough, clever and cheeky (she wants to be called 'Bibi' - her nickname). The CCBRT fieldworker Francis Manyanga discovered the cataract one year ago and enabled (with the help of CBM) the cataract operation for free (Remenziana lives a simple life and is very poor). Her vision is very bad and she can only see dimly. She is very hopeful to see again soon and already knows what she is going to do first after having vision again: go to church, thank god and visit the neighbours and children in her village. Here: Remenziana (right hand) back home again, after her operation. Her family is already waiting for her and Remenziana is very happy. Next to her: CCBRT fieldworker Francis Manyanga. .for further information see: TZA-11-0001.pdf **Vorschlag:** 95 year old widow back home after a successful cataract operation being visited by the field worker who enabled the operation after discovering the cataract a year earlier.



The qualitative study was carried out in three districts: Nachingwea (Lindi Region), Muheza (Tanga Region) and Mbeya District Council (Mbeya Region). The districts were purposefully selected in coordination with GIZ and district staff as areas where GIZ is active through the Community Health Fund¹. Semi-structured interviews were conducted in the sample districts with persons with disabilities, government representatives, NGOs, disabled people's organisations (DPOs), GIZ programme coordinators, TASAF coordinators and CHF coordinators. In each district, 15 clusters (villages) were covered. Fieldwork was conducted in August and September, 2014.

3.1 Data Collection Methods

An interview guide was developed containing specific questions to suit each of the interviewed groups. A total of 33 semi-structured interviews were conducted; 21 involving purposefully selected persons with disabilities (both CHF and non-CHF members) and 12 with purposefully selected stakeholders from each of the interviewed groups in the sample districts (see Appendix 1 for details). Two national team members of REPOA, one member from the London School of Hygiene and Tropical Medicine, and three research assistants from REPOA conducted the interviews.

For the focus group discussions, men and women were grouped separately due to cultural barriers in some Tanzania communities – and particularly in Muheza – where women may not feel free to engage in such critical discussion in the presence of men due to religious and cultural values. For consistency, the grouping based on sex applied to all three districts. A total of 34 individuals, including 19 men and 15 women, were involved in six focus group discussions.

To protect the confidentiality of interviewees, names and job titles have been omitted in the report so participants are only identified as individual interviewees, participants in focus group discussions or officials.

3.2 Study Analysis

Hand-written and electronic notes were taken during interviews. Content analysis was conducted by staff from REPOA and the London School of Hygiene and Tropical Medicine, structured by defined themes drawn from the objectives of the study. A country-level dissemination workshop took place in December 2014, whereby the conclusions and recommendations from the preliminary content analysis were reported to the stakeholders for validation of the data and feedback for the final report.

3.3 Research Ethics

An ethics proposal for the project was developed and approved by the National Institute for Medical Research (NIMR). All the required research permits (letters) were also obtained at both regional and district level and copies of the letters were used to introduce the researchers to the ward, village and households. All research guides contained a consent statement, which was read to the participants before beginning the interview or focus group discussion, informing them about the study objectives and their right to choose whether or not to participate. All study participants had to sign a form to consent to participate. To protect their privacy, interviewees' names are not revealed in the study report, only gender, age, sex and job title. Finally, to ensure that there was no coercion, no gifts were given to the interviewees at any point during the interview.

¹ It should be noted that German commitment regarding CHF was not the focus of the study, but it was agreed to focus on areas of German development cooperation, in order to benefit from existing knowledge and relationships at a local level and generate insights that could help guide future activities in supported districts.

4

Findings

Originaltext: Grace together with CCBRT community worker Janeth (32, right). Janeth visits Grace twice a month to see her development and gives advice to her mother. Grace is sitting in her new wheelchair, given to her by CCBRT. Grace (10 years old) has Cerebral Palsy (Athetoid). She lives in a village near Moshi on the slopes of Mount Kilimanjaro/Tanzania. Since 2007 she has been a client of CCBRT Moshi. A community worker of CCBRT visits her regularly. Grace has been through a long rehabilitation process. It took years before she could sit and stand. Walking alone is not possible. CBRT provided a wheelchair to her for better mobility. Today she can attend a Pre-school (Kindergarten), is learning figures and writing. A little success story. **Vorschlag:** 10 year old girl with Cerebral Palsy (Athetoid) in her new wheelchair. A community worker of CCBRT visits her regularly.



4.1 Community perceptions of disability

4.1.1 Defining disability

For both government and social protection programme officials, the definition of disability was linked with the inability of individuals to manage activities of daily living due to physical or mental functional limitations, and was related to poverty. Consequently, many official's definitions reflected a charitable model of 'helping' those who were in need.

'Disability is a situation whereby one cannot help him/herself. People with disabilities need help depending on the type/kind of disability one has, be it blindness, crippled hands or legs or skin condition/albinism [...] Because [they] are from poor families.' (Official 4)

'The person with disability is someone who has/is physically and mentally disabled to the point that such person cannot attend to their daily responsibilities effectively or gets hardship in working or undertaking their development activities like other community members.' (Official 10)

Definitions provided by officials also reflected a medical model of disability, related to body structures and specific impairments, and with little awareness of the social model, rights or the disabling barriers in society.

'Disability is having limitations/shortages/deformity in their body parts.' (Official 9)

'Disability is having a deformity. There are different/several types of disabilities such as albinism, physical disability of hands, legs, being deaf and dumb. All are examples of people with disabilities.' (Official 6)

4.1.2. Beliefs about disability amongst persons with disabilities

Despite the disempowering language used by officials to define disability, and limited knowledge of rights-based terminology, persons with disabilities themselves were generally able to vocalize their rights to the same opportunities as others to marry, work and study.

'I am not aware of the rights for people with disabilities. And I do not think anyone in my family knows. What I know is that a person with disabilities is just like any other person, only she has a mental problem; but otherwise she is just a normal person like me and you.' (Person with disabilities, Muheza)

'People in my household are also aware. I know that a person with disabilities deserves to be given equal rights as other people. For instance, participating in work and other activities that are needed in the community.' (Person with disabilities, Mbeya)

'For me I know that a person with disabilities has all the rights like any other person. The right to marry someone of their choice and have a family. Education should be given to them.' (Female focus group discussion, Mbeya)

The majority expressed a sense of inclusion in their communities, although this was not uniform.

'I have never experienced stigma, I have been receiving equal respect. For example we have theatre groups in our village involving men and women who perform during festivals like Christmas and Farmers Day. I am one of the stage performers.' (Person with disabilities Mbeya)

'There is no stigma here. People with disabilities are respected and considered like any other people.' (Female participant in focus group discussion, Muheza)

One interviewee with disabilities, a respected mother in her community, narrated how she had separated from both her first and second husbands after she discovered that they were calling her a 'kiziwi' (deaf).

Experiences of stigma and isolation amongst adults with disabilities were quite limited, although several officials spoke of stigma and damaging beliefs not mentioned by persons with disabilities themselves. One leader of a disabled people's organisation also stated that there was a traditional belief that sexual intercourse with a person with disabilities could cure HIV and that the risk of sexual violence against girls with disabilities was high, but this was not corroborated in subsequent interviews.

However, in the case of caregiver perspectives on caring for children with disabilities, traditional beliefs such as leaving fate to God and the stigma of having children with impairments were apparent – with consequences on both health seeking behaviour and the child's long-term participation in society.

'My daughter was born with an ear problem but we could not notice until when she was 4 years old [...] We decided to give up and leave it to God.' (Mother of child with hearing impairment, Muheza)

'Indeed most parents do not want to disclose that they have disabled children because of the trepidation that the community will look down on them. Such a situation limits the children with disabilities from receiving appropriate services.' (Official 6)

4.2 Availability of data on disability

Officials were asked whether they collected data on disability for project planning and advocacy. The overwhelming majority of officials suggested that the responsibility for collection of disability data lay with someone else. Most stated that whilst they

requested data from others and perceived the potential benefits better data would give them in terms of improving services, they did not have the capacity to collect data themselves.

'We do collect the data by writing a letter to the Ward Executive Officers directing them to collect the information on people with disabilities in their wards. The Ward Executive Officers direct the Village Executive Officers to collect the same from their villages. Not all the village/ward leaders do bring the data we ask for and we do not have enough Community Development Officers to cover the wards we have.' (Official 1)

However in one district, the CHF coordinator had worked with Village Executive Officers to screen villages for persons with disabilities. The coordinator had then directly requested an MP to pay the CHF contributions for all those identified (570 persons with disabilities). At the point of interview, 70 of these had received a CHF card paid for by the MP in the 'first phase' of the programme. However, none of the individual interviewees or participants in focus group discussions had either received a free card through this scheme or was on a waiting list for it.

4.3 Health needs of persons with disabilities

The majority of persons with disabilities interviewed in the qualitative study had heard of, but not accessed CHF or other social protection programmes. This section therefore explores the overall health needs – both met and unmet – of persons with disabilities in the absence of social protection or health insurance. Sections 4.4 and 4.5 then explore whether and how these needs are addressed through social protection programmes in the study area (CHF and TASAF).

4.3.1 Cost of health services

'One keeps praying to God that the family members should not fall sick because he/she cannot afford the cost.' (Person with disabilities, Mbeya)

Health services were almost unanimously seen as being far too expensive to be used at the point of use. A recurrent issue raised by many interviewees with disabilities was the lack of drugs available from dispensaries and hospitals, leading to high costs when purchased through private pharmacies. This issue arose whether the individual participated in a social protection programme or not and emerged as a critical unmet health-related expenditure for many.

'Demand for health services in this facility is very high so shortage of essential drugs is common. During such shortage moments, doctors tell us to go and buy drugs in the private providers.' (Proxy respondent for child with disability – not involved in social protection programmes)

Other health-related costs which caused problems for interviewees were hospital charges and transport costs to services – district hospitals in particular. Aside from limited drugs availability, a number of interviewees also expressed disappointment at the limited services available at the dispensary level. Lack of capacity to conduct laboratory tests and other procedures in dispensaries heightens the need to travel to district hospitals or even beyond the district itself, incurring further costs.

'Generally, I can say the health care is not accessible. We do not have a dispensary in our village; I can't afford transport costs to the district hospital.' (Person with disabilities, Mheza)

'From here to [the dispensary] it is very far, [especially] for people like me who cannot walk there. I need a motorcycle to take me there. The cost from here is between 1000 – 1500 Tks. Then 100 Tks for the hospital guard and 1000 Tks for the hospital charge. [...] Remember, I have no job, no source of income, so you can be in the house sick and can die in your home.' (Men's focus group discussion, Muheza)

Given the inability to pay for healthcare services, interviewees reported a number of different coping methods. Some interviewees with disabilities turned to local herbs to treat their illnesses, some did not use services at all when they were unwell and others sought partial treatment supported by family members or paid the fees in instalments directly to the doctor who treated them. Two interviewees discussed pleading with health service staff and receiving free services this way, whilst officials mentioned one-off NGO sponsorship of specific treatments (e.g. cataract surgery), highlighting the relatively ad-hoc availability of free services to interviewees and an absence of systematic provision/subsidisation of services. NGOs also work in several districts providing assistive devices or sunscreen lotion for albinism, but access to this support is not uniform either.

Whilst one District Community Development Department reported having a small budget for the facilitation of persons with disabilities' participation in public celebrations and with arts and crafts, no districts had budgets to support persons with disabilities in accessing health care. A member of a disabled people's organisation (although not himself a person with disabilities) stated 'I have never seen people with disabilities being given free health care.' (DPO 2)

4.3.2 Attitudes of health service staff

There were some negative experiences at the point of service provision amongst interviewees with disabilities, especially in the large hospitals. However, predominantly persons with disabilities expressed positive attitudes about health care staff once they reached health facilities.

'For sure, the health service providers are doing their best though sometimes they do not care much about the patients. But there are times they try their best. Sometimes, you can go there and spend hours without having anyone attending you.' (Person with disabilities, Mbeya)

There was no evidence during interviews with persons with disabilities or officials that health care staff had received any disability-specific training.

Participants with disabilities reported different experiences of the accessibility of health information in their communities. Several expressed satisfaction with health information services, pointing out that posters were available and that there were nurses doing outreach work (for example, on malaria). However, the majority expressed dissatisfaction with health information services at the local level.

'Getting the information is not easy even when you are at the hospital. Unless you get a nurse who is kind to show you where exactly you should go. Otherwise, many nurses will tell you to try to ask at that window or go and look for the section the other side. And you may be new to the hospital or at times you are weak and cannot move around that much.' (Male focus group discussion, Muheza)

4.3.3 Physical barriers and infrastructure

Health services were considered generally physically accessible by persons with disabilities in the sample. In particular, many interviewees noted that most health facilities were physically accessible, with the exception of the toilet facilities.

'We have a dispensary in our village and use Muheza hospital as a referral hospital. Both are accessible; I can walk to the dispensary but to get to Muheza hospital I hire a motorcycle. The buildings in both the dispensary and Muheza hospital are appropriate to people with disabilities because there are no long stairs. Exceptions are for toilets; they do not provide a good environment for people with disabilities.' (Person with disabilities, Muheza)

However, the distance to the dispensary (up to three hours for some interviewees), and the lack of specialist services or available medicines that necessitated onwards travel to large district hospitals – at considerable distance and therefore cost – represented a significant additional barrier to accessing services. Public transportation to hospital facilities was also not perceived to be accessible, and some interviewees stated that alongside the costs of transport itself,

they also had to pay the costs for assistance from others to attend.

'To go to hospital, a motorcycle is needed and I also need a strong man to support me from behind. Even if I were to get a card, hiring a motorcycle is also very expensive for me and my family. That's why I tend not to go to hospital whenever I am sick.' (Female focus group discussion, Mbeya)

4.4 Disability Inclusion in Social Protection Programmes

4.4.1 Community Health Funds (CHF)

4.4.1.1 Overview of CHF in the three districts

CHF is an annual contributory health insurance scheme that operates in partnership between communities and the Government, the latter providing a 'matching grant' to CHF schemes at a district level. Households pay annual contributions to complement the Government's efforts in financing of basic health services. Each CHF member household is required to make a predefined flat rate contribution that is intended to compare favourably with existing average per capita out-of-pocket expenditures for health². Under the CHF Act (2001), those who cannot afford the contributions are supposed to be exempted from paying and are entitled to a cost-free CHF card, however in practice most districts have not implemented this policy.

The general premium is Tshs. 12,000 – 15,000 per year per six member household. Individual annual costs for a single person are usually around Tshs. 6,000, whilst secondary school students pay Tshs. 2,000 per person and are advised to create a CHF 'household' of 6 students and pay a combined Tshs. 12,000. However, this premium varies between

² Msuya, J., Jütting, P. and Asfaw, A. (2004) Impacts of Community Health Insurance Schemes on Health Care Provision in Rural Tanzania ZEF – Discussion Papers on Development Policy

districts as CHF is managed by individual District Councils.

Overall coverage in the three districts is higher than the national average, but still relatively low as presented in Table 1:

Table 1: CHF Membership

District	District population	Members	% of pop	Last updated
Muheza	204,461	60,646	29.7	April 2014
Mbeya	305,319	71,659	23.5	April 2014
Nachingwea	178,464	16,700	9.4	March 2014

Population based on 2012 Census.

Participants of the scheme choose each year whether to renew or not. To broaden coverage and raise membership numbers, CHF in the three study districts increasingly enrolls groups such as farmers' unions rather than focusing only on individual households.

4.4.1.2 Targeting and enrolment of persons with disabilities in CHF

The majority of interviewees with disabilities were not members of CHF, although almost all had heard of the programme. The general feeling amongst interviewees was that being a member of CHF still led to considerable out of pocket health expenditure, on top of the significant cost of enrolling in the programme.

Despite the existence of the CHF Act, a very small minority of interviewees were aware that those who were unable to pay were entitled to a free membership. The vast majority therefore saw the enrolment cost (payable upfront and in full) as both the only option available to them, and far beyond their financial capacity. Several participants suggested that if the card was payable in even quarterly instalments,

it would increase the programme's affordability for them.

A significant barrier to persons with disabilities enrolling in CHF was a lack of belief in the value of health insurance, especially considering the upfront costs, and a lack of understanding of insurance principles. A number of interviewees were concerned that the annual cost would outweigh the benefits should they not fall sick within the year.

'I have not joined CHF because I have many family responsibilities that require money [...]. Considering my disability and the level of income, I cannot afford to pay for CHF. It cannot be my priority. And having to pay 5,000 shillings for CHF and at times you may never fall sick to use it; that is the problem.' (Male focus group discussion, Muheza)

Many also felt that even if they were enrolled, they would still need to meet substantial health-related costs themselves. These were most commonly related to unavailability of drugs at the dispensary. Dispensary drugs are covered by CHF, but there is a common perception that frequent drug shortages in the dispensaries mean that beneficiaries are told to purchase drugs privately from a pharmacy. Further, as a result of its district-level structure, the CHF card only entitles the card-holder to free services within the district's boundaries. However, few specialist or rehabilitative services are available at the district level, meaning that the cost of these services and the cost of transportation to these services are not included in CHF support and must be met by the card-holder.

'Access to health care and availability of drugs/medicine is still a challenge. When people join CHF, they expect to get all the services including drugs, treatment at the dispensary, health centre or district hospital so when the services are missing that becomes a problem. The services that are available at the dispensary are not enough to cater for everything that we need. Although it is easy for us to access the dispensary in the village, that does not mean we have access to health care.' (Person with disabilities, Mbeya)

Some CHF coordinators were reluctant to state categorically that there was no targeting of persons with disabilities, but with one exception the interviews highlighted an absence of specific efforts to target, enrol or collect data on persons with disabilities.

‘Some leaders do identification of people with disabilities while others do not; also some leaders tend to provide wrong information. That makes it difficult for the district to have exact number of people with disabilities.’ (Official 6)

‘There is no exact number of people with disabilities since CHF enrolment system does not require to enquire whether the person has any disability of any kind.’ (Official 4)

Despite this, CHF coordinators were aware of disability-related health needs that were not met by the programme.

‘CHF does not have a package for people with disabilities’ needs. For example if a person with disabilities needs a white cane, caps, or lotions for people with skin impairment, they are not available in public health facilities.’ (Official 3)

Moreover, the interviews with CHF coordinators emphasised the absence of training for CHF workers on disability policies and practices, and the lack of budget for facilitating this.

‘For 9 years that I have been in [District], I have never seen any training of the staff and service providers on how to handle people with disabilities.’ (Official 4)

As noted above, the main exception was in Muheza, where 570 persons with disabilities had been identified by Village Executive Officers and a request made to the local MP to pay their contributions. However, although 70 people had apparently received a CHF card, it is notable that no interviewees with disabilities were aware of this initiative.

One CHF coordinator also stated that CHF ‘encouraged’ other service providers, NGOs and village wards to provide free services for persons with dis-

abilities, but that this was not CHF’s responsibility and they did not have the budget or the coverage.

‘There must be many who need the service but they have either not been reached or they are not aware of the service and its availability’ (Official 4).

‘The budget is too small to adequately cover people with disabilities and their needs’ (Official 1).

The CHF coordinator of another district stated that CHF provided transport costs and support for travel to access services beyond the district boundary, but no further evidence of this was identified in other transcripts.

Overall, a distinct lack of coordination and absence of clear responsibilities for facilitating access to CHF amongst persons with disabilities was apparent from interviews with multiple stakeholders. For example, one District-level Community Development Officer reported that his activities included encouraging persons with disabilities to save for CHF cards, whilst the CHF coordinator reported that his activities included encouraging village wards to provide free services for persons with disabilities in dispensaries.

4.4.1.3 Satisfaction with CHF amongst registered persons with disabilities

‘I did not renew my CHF membership because I found the situation to be the same irrespective of whether you have the CHF card or not. If you went for treatment end of the day you will be required to go and buy the medicine.’ (Person with disabilities, Mbeya)

Amongst the comparatively few persons with disabilities in the sample currently enrolled in CHF, the level of satisfaction was mixed. One father who had enrolled himself and his child with disabilities in CHF stated that the CHF card offset some of the transport costs that he would otherwise be unable to afford on top of the medical costs for his child. Two further in-depth interviews with persons with disabilities who were enrolled with CHF also revealed positive perceptions of the benefits of the programme.

'CHF has empowered me and raised my confidence as a man. With CHF my family is fully covered in issues of medical care. But if I did not have CHF, I would be worried of where to get the money if anyone fell sick and in the community people would undermine me because I would not be able to provide for my family.' (Person with disabilities currently enrolled in CHF, Mbeya)

However, some interviewees stated that delays between paying for and receiving cards were common and led to members cancelling their memberships after the first year:

'Sometimes it takes so many months in a year before we can get and use the cards. At that time it is hard to get treatment without showing the health centres that I have paid for my membership. [...] This happens to many people and so they choose not to renew their CHF membership to avoid chaos.' (Person with disabilities not currently enrolled in CHF, Nachingwea)

Similarly, the issue of out-of-pocket costs was again highlighted, specifically in relation to the limited availability of drugs and the need for even those with a CHF card to cover their costs:

'All the times I went to seek health care services and used the CHF card, I never was satisfied. My needs could not be met because all the times I was asked to go and buy the medicine. Sometimes they would give me some of the medicine and ask me to buy others. And because of this and other financial reasons, I never renewed my membership.' (Person with disabilities previously enrolled in CHF, Mbeya)

Others who were not enrolled described the negative experiences of people they knew, including poor treatment of CHF members by healthcare workers:

'My brother [who was a CHF member] was sick and I had to accompany him to the district hospital. [...] After sometime a nurse came and announced that all CHF patients [should] queue separately. We kept waiting for a long time without service while the others were receiving service [...]. The scheme therefore, is not supportive.' (Male, focus group discussion, Mbeya)

4.4.1.4 Exemptions from user fees

In addition to exemption from paying for membership of CHF, it is possible to receive an exemption from the need to pay user fees. Generally, this involves the provision of a letter of exemption, either on a permanent basis or for a specific period. Officials reported providing this letter to those who requested it, usually on the recommendation of a Village Executive Officer or through a direct request from the individual involved. However, as with CHF exemptions, the user fee exemption is intended for those who are too poor to pay, and no specific consideration is given to persons with disabilities in the national guidelines for districts on this issue.

Amongst those few persons with disabilities who had received such a letter, long delays and bad services were reported in addition to the frequent need to pay for drugs.

'Exemption does not work as it is supposed to. I am telling the fact. If you go to hospital and you do not have money, and maybe you want to depend on permits [exemption letter], the troubles that you will go through, you won't ever go back.' (Male focus group discussion, Muheza)

'While waiting for the service the nurse/doctor may bypass you several times; that is when one feels very bad, as it creates so many questions to the patient like, 'What is exemption for if one cannot get services on time?'. But frankly speaking there is no doubt that free is very expensive.' (Person with disabilities, Muheza)

4.4.2 TASAF

4.4.2.1 Overview of TASAF

The Tanzania Social Action Fund (TASAF) is a semi-autonomous government agency which has been implementing poverty reduction programmes since 2000, including public works schemes and livelihood promotion. TASAF piloted a conditional cash transfer in its second phase and is scaling this programme up nationwide during its third phase (2013 to 2017) under the title of the Productive Social Safety Net (PSSN).

4.4.2.2 Targeting and enrolment of persons with disabilities in TASAF

Enrolment in TASAF amongst persons with disabilities interviewed in the sample was extremely low. This was probably related to the relatively short period of time in which TASAF had been operational in the study areas and the fact that, prior to the roll-out of the PSSN, TASAF's activities were focused primarily on 'group' activities such as the construction of health or education facilities rather than on individuals or households. Officials reported that there were no disability-targeting criteria for enrolment or participation, but that the services were provided at a community rather than individual or household level, and consequently were of benefit to all. A TASAF coordinator also stated that persons with disabilities could send 'able' representatives to complete their contribution to a project or would be tasked with activities that were suitable to their capabilities (TASAF Coordinator, Muheza). However, a number of interviewees disputed this, stating that the activities were non-flexible for those with different functional capabilities.

'There is no flexibility in social protection programs. In TASAF for example we had contribute manpower and bricks and we could not choose otherwise.' (Male focus group discussion, Mbeya)

Officials also noted that specific projects were formed to benefit 'vulnerable groups' including widows/widowers, vulnerable children and people living with HIV. However, they acknowledged that although some persons with disabilities may have benefited, they were not specifically targeted through these activities.

4.4.2.3 Satisfaction with TASAF amongst registered PWDs

Amongst the few persons with disabilities who were directly involved in TASAF projects, the level of satisfaction was generally high.

'[The TASAF] scheme met our needs because through TASAF our children can sit in classrooms where they can listen to their teachers properly. The school supported by TASAF accommodates all children including those who come from families with a disabled person. Everyone receives and benefits from the support.' (Male focus group discussion, Mbeya)

Several female FGD participants were also receiving cash transfers after responding to a call to attend a village meeting. However, they were less satisfied with the purchasing power of the cash transfer, stating that 'the money helps for two days.' (Female focus group discussion, Nachingwea)

4.5 Needs and priorities for persons with disabilities as expressed by interviewees

The majority of persons with disabilities interviewed either in depth or in the focus group discussions argued for greater support and assistance in accessing not just health care but livelihood opportunities and in particular the activities of TASAF.

'Programs targeting people with disabilities will give us voice. Common man says aliyeshiba hamjui mwenye njaa [A person with no hunger does not know about the one who is hungry]. So it is appropriate to have programs targeting people with disabilities.' (Male focus group discussion, Mbeya)

'Targeting people with disabilities [would be] appropriate because of our health conditions, our environment and our low income. So, when it comes to talking about including or targeting us in issues of health care it is the right thing to do. It is like a person has come to save us.' (Male focus group discussion Muheza)

5

Discussion

Originaltext: Joel (4) and Stella (9), cataract, successful cataract surgery. Project partner: KCMC (P0393). Picture: Stella after surgery. Eye examination for getting glasses. **Vorschlag:** Girl at an eye examination after surgery. She will next be fitted with glasses.



The qualitative component of the study aimed to understand how respondents defined and perceived disability, the accessibility of services and the inclusion of persons with disabilities in existing social protection programmes.

Whilst officials perceived disability to be a hybrid of the medical and charitable models, persons with disabilities themselves were very clear on wanting assistance and support to maximise their well-being – including their health status – and livelihood opportunities. Relatively low levels of stigma were reported by persons with disabilities, although perceived stigma was a concern for officials, and there were issues related to community behaviour towards children with disabilities in particular. Whilst officials were aware of relevant national policies, they lacked a rights-based knowledge of disability which perhaps contributes towards the limited emphasis on disability in public health and social protection programmes in the districts.

The overwhelming majority of persons with disabilities interviewed in the sample were not currently enrolled in either TASAF or CHF. In the absence of social protection, most of the interviewees stated that health service costs were too high for them to afford and that they consequently did not use services at all. User fees themselves along with the costs of drugs and of transportation to health service providers were the most commonly reported barriers to accessing healthcare, leading to problematic and unsustainable coping methods.

Most had heard of CHF although TASAF was less well known – perhaps due to its relatively recent implementation and low current coverage. However, despite the inability to afford health care in the absence of social protection, many chose not to enrol in CHF because they did not perceive its benefits to

outweigh its costs. The annual upfront cost of the card was in itself unaffordable to many, and the costs not met by the card (including drugs when the facility has run out, transport and any service beyond the district boundaries) further undermined its perceived value.

There was extremely limited awareness of the CHF Act amongst the interviewees and the entitlement to free membership for those who cannot afford to pay; while the few who had tried to claim exemptions from user fees reported very negative experiences of treatment by staff. While not all persons with disabilities are unable to afford CHF members, many have greater and more frequent health needs than the general population and, as the quantitative component of the study demonstrated, they are also more likely to be members of poor households. As such, greater consideration of how to include them within the CHF is need, and this could include an improved, more systematic approach to exemption from payment of membership fees for CHF and/or for exemption from user fees.

Such an initiative should also include training for district level staff involved in social protection programmes and health facilities on disability rights to ensure that staff members treat persons with disabilities with respect, are able to provide appropriate services and are aware of specialised services for persons with disabilities where onward referral is necessary. It could also incorporate training on a standardised way of assessing disability that is suitable for district level staff, so that data can be collected and transparency regarding eligibility for cost-exemption can be ensured. Finally, consideration should be given to improving the accessibility of information on all social protection programmes within the district, including TASAF as well as CHF.

APPENDIX: LIST OF INTERVIEWEES

Official Interviewees

Nachingwea District Council

- CHF coordinator
- Social welfare officer
- Exemptions officer
- GIZ coordinator
- SHIVYAWATA

Mbeya (Rural) District

- CHF coordinator
- District Social welfare officer
- District community development officer
- TASAF coordinator
- CHAWATA secretary

Muheza District Council

- District social welfare officer/CHF coordinator/
Exemptions officer
- TASAF coordinator

Focus Group Discussion*

District	Kind of group	Cluster name	Number of Participants
Nachingwea	Men	Mwenge	9
	Women	Ikungu	5
Mbeya	Men	Shizingo	5
	Women	Shizingo	5
Muheza	Men	Mamboleo	5
	Women	Mamboleo	5

**For cultural reasons, FGDs was conducted separately for men and women to allow freedom of expression.*

In-depth interviews

District	Kind of group	Number of Participants
Nachingwea	Men	1
	Women	3
Mbeya	Men	3
	Women	4
Muheza	Men	3
	Women	7

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