**Social Protection for People with Disabilities in Tanzania:**

**Assessing the level of need and inclusion through a mixed methods approach**

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**Abstract**

People with disabilities are more vulnerable to poverty and exclusion from key services, such as health and education. Consequently, they are particularly likely to benefit from social protection, yet may have difficulties accessing these programmes. The aim of this study was to assess the need for and inclusion in social protection programmes among people with disabilities compared to those without, within three districts in Tanzania. Using a mixed methods approach, our study finds that although the need for social protection programmes was higher among people with disabilities compared to the general population, this was not matched by higher enrolment. People with disabilities were aware of social protection programmes in their area but were not targeted specifically and benefit packages offered by the programmes were not adapted to their needs. Modifying mainstream social protection schemes to be inclusive of people with disabilities may therefore be an important step towards addressing poverty alleviation goals including those set out in the recently adopted Sustainable Development Goals (Goal 1, target 3)..

**Key words**: Africa; Tanzania; disability; social protection; inclusion

**Introduction**

Social protection is an umbrella term that covers schemes to address risk, alleviate poverty and enhance living conditions (Barrientos & Hulme, 2009). There is considerable debate as to its precise scope within the academic literature and wider discourses on international development (Gentilini & Omamo, 2011) but it is possible to identify three broad types of social protection instruments (Barrientos, 2011). The first are labour market interventions, which aim to promote employment and protect workers. These schemes include labour standards, minimum wage legislation and other labour market policies and programmes. The second focuses on social insurance to mitigate risk, such as health insurance. The third group covers social assistance, where transfers (in cash or in kind) are made to particular vulnerable groups, such as single parent households. Social protection programmes of all kinds often aim to promote access to basic services, including education, employment and health care (Gentilini & Omamo, 2011).

In developed economies social protection is usually characterised by a system of ‘integrated institutions and programmes’ covering these three areas. In in low-income and middle-income countries there is a stronger focus on poverty reduction and social and economic development alongside risk management, often through a combination of income transfers and interventions to support access to basic services or to promote productive employment and asset building (Barrientos & Hulme, 2009). Multilateral and bilateral agencies also play a greater role in defining the agenda for social protection alongside governments in low-income and middle-income countries. The World Bank, for example, has played a lead role in promoting the concept of social protection internationally and has invested significantly in this area, with finance for social assistance, or ‘safety nets’, in particular growing rapidly since the beginning of the century (De Haan, 2014; World Bank, 2012). The International Labour Organisation’s ‘social protection floors’ concept is also increasingly influential, with a global recommendation adopted by member States in 2012 (ILO, 2012) and a range of technical tools developed, such as ‘assessment-based national dialogue exercises’ to assist governments to design and implement their own ‘national social protection floors’ (Schmitt & Chadwick, 2014). The recently adopted Sustainable Development Goals reflect the growing importance of social protection in global discourses on international development and national strategies for poverty reduction, with the inclusion of a specific target under Goal 1 on poverty eradication to,

“Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable.” (United Nations, 2015) In this context, it is important to consider the inclusion of people with disabilities within social protection programmes. The World Report on Disability estimated that there are over one billion people living with a disability, corresponding to 15% of the world’s population (World Health Organisation, 2011). Disability is closely linked to poverty (Banks & Polack, 2014), and people with disabilities face reduced access to education, employment and health care (World Health Organisation, 2011). This means that people with disabilities are more likely to need and to benefit from social protection. Furthermore, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) calls upon all countries to respect and ensure the equal rights and participation of people with disabilities, including in social protection (United Nations, 2006). The design and implementation of inclusive social protection systems is therefore important both in the context of global development efforts and from a human rights perspective. However, there is a lack of research or evidence addressing the specific challenges that people with disabilities face in accessing social protection and how these might be addressed (Banks et al., 2015; Palmer, 2013). The study described below was designed to contribute towards addressing this gap in the global evidence base by exploring the degree to which people with disabilities were included in specific social protection programmes in the selected research site of Tanzania.

Social protection – especially non-contributory social assistance in the form of cash transfers - is becoming an increasingly common strategy across Africa to alleviate poverty, strengthen livelihoods and promote longer-term human capital development (Chitonge, 2012; Devereux & White, 2010; Niño-Zarazúa, Barrientos, Hickey, & Hulme, 2012). For example, countries such as Ethiopia, Ghana, Kenya and Malawi have all introduced cash transfer programmes targeted at the poor, usually in partnership with bilateral or multilateral donors (Devereux & White, 2010). In Tanzania, there has been a transition in policy priorities among many development agencies from supporting contributory systems of social security for the formal workforce towards assisting in the establishment of a universal ‘social protection floor’ for all citizens (United Nations, 2010); while the Government’s own National Strategy for Growth and Reduction of Poverty for 2010-2015 includes strengthening social protection for “vulnerable and needy groups” as a specific goal, with the purpose of preventing “unacceptable levels of socioeconomic insecurity and deprivation (United Republic of Tanzania, 2010a)”.

Although progress in establishing a national policy framework for social protection has stalled since a first draft was published in 2008, developments have continued at programme level, especially in terms of social assistance for the poor and contributory social insurance for the informal sector. In the former case, the Tanzania Social Action Fund (TASAF) is in its third phase and – with World Bank and other donor support - is scaling up a conditional cash transfer alongside its public works and livelihoods components; taken together, TASAF is expected to reach 1 million direct beneficiaries in 275,000 households between 2012 and 2017 (United Republic of Tanzania, 2013). In relation to social insurance, the Community Health Fund (CHF) - health insurance schemes operated by local authorities at the district level that are designed to be affordable for the rural, informal sector - has been brought under the management of the National Health Insurance Fund (NHIF) and the number of districts operating CHF and overall population coverage have been gradually increasing, covering more than 5% of the population by 2011 (Borghi et al., 2013). To join a CHF, households pay an annual premium, which covers their access to health services available in district level health facilities, and the national government provides a ‘matching grant’ for every household that joins.

Despite specific provisions mandating equal access to social protection within the Tanzanian Persons with Disability Act (2010) (United Republic of Tanzania, 2010b), it is unclear to what extent people with disabilities are included within and benefiting from these key social protection programmes. There is also no evidence available on the contribution of these programmes to promoting access to wider services for people with disabilities within Tanzania, such as health, rehabilitation and education. Given anticipated limitations in programme data on the inclusion of people with disabilities within these programmes, as well as recognition of the importance of understanding the perspectives of people with disabilities and other key stakeholders on the degree to which they included or excluded, a combination of quantitative and qualitative data collection was deemed appropriate for investigating these issues. The overall aim of this study was therefore to use a mixed methods approach to assess the need for and inclusion within the two selected social protection programmes among people with disabilities compared to those without, within three districts in Tanzania.

METHODS

**Study design**

There were four components to the study:

* Population based survey of disability across three districts in Tanzania
* Case-control study nested within the survey to compare people with disabilities identified in the survey (cases) and age-sex-cluster matched controls without disabilities
* Survey of households known to be members of CHF across three districts in Tanzania
* Face-to-face in-depth interviews and focus group discussions with people with disabilities, and semi-structured interviews with government representatives and other key informants in all three districts

**Population based survey**

A population-based prevalence survey of disability was undertaken to estimate the prevalence of disability, inclusion in social protection, and relationship with socio-economic status. The survey was conducted in three geographically dispersed districts in Tanzania where CHF was functionalMbeya Tanga and Lindi between August and September 2014. Tanzania as a whole is characterised by low levels of human development, and the three districts were in regions that were relatively typical compared to other areas of the country (United Republic of Tanzania, 2015).

We conservatively estimated that the prevalence of disability among people ≥5 years was 5% based on global estimates (World Health Organisation, 2011) and the national survey which estimated the prevalence of disability at 7.8% (National Bureau of Statistics, 2008). A sample size of 4,500 people (45 clusters overall - 15 clusters of 100 people per district) was sufficient to estimate the prevalence with a precision of 20%, 95% confidence, a design effect of 1.4 and 20% non-response.

Forty-five clusters were selected through probability-proportionate to size sampling using the 2012 Population and Housing Census as the sampling frame. Households within clusters were selected through compact segment sampling,(Turner, Magnani, & Shuaib, 1996) whereby one segment of a cluster was selected at random and all the households are visited door-to-door, with all eligible people (i.e. residents at least 3 months) included until the sample size of 100 people aged 5+ years was reached.

On arriving at the household, an adult informant from the selected household was interviewed about household characteristics (e.g. household composition), asset ownership (radio/stereo, TV/VCR/DVD, fridge/freezer, telephone/cell phone, cupboard, sofa set/armchair, table, washing machine, sewing machine, air conditioner, bicycle, cooker with gas, cooker with electric, and land for farming or grazing) and inclusion in social protection programmes.

All household participants aged 5 years and above were screened for disability using the Washington Group (WG) short set of questions.(Madans, Loeb, & Altman, 2011) Using this tool we asked the household head or person primarily responsible for the household if people living within the household experienced difficulties with any of 6 activities (seeing, hearing, walking or climbing stairs, remembering or concentrating, self-care, communicating) as a result of a health problem that lasted at least 6 months or was permanent. These were rated by the responder (“no difficulty”, “some difficulty”, “a lot of difficulty”, “unable”). Disability was defined as reporting “some” difficulty with at least two activities or “a lot of difficulty” or “unable” to do at least one activity above. In addition, we asked about the presence of albinism and included this in the definition of disability.

**Nested case-control study**

A case control study was undertaken nested within the survey to compare people with disabilities (cases) to those without disabilities (controls) in order to assess the association of disability with need for and inclusion in social protection programmes.

All people with disabilities (cases) identified in the survey were included within the case-control study. If a household member who was identified by the household head as a having a disability was absent then an attempt was made to revisit the house later in the day. For each case we selected one control who had been screened during the survey and found not to have a disability. The control selected was from the same cluster as the case, of the same gender, and matched by age (within the same 5 year age band). The potential cases and controls were screened again using the Washington Group questions to verify that they had a disability (case) or did not (controls) and were also asked whether they perceived themselves to have a disability.

We estimated that we would identify approximately 180 cases and 180 controls through the survey. This would be sufficient to detect an Odds Ratio of 1.9 for the association between poverty and disability, with 80% power and 5% alpha risk, assuming that 25% of the controls were in the lowest quartile for poverty.

All consenting cases and controls underwent detailed interviews. The interviews included questions on: marital status, educational level achieved, current school enrolment (children<16 years), health, rehabilitation, and enrolment in social protection programmes (CHF, TASAF, Public Service Pension Fund (PSPF), National Social Security Fund (NSSF), Parastatal Pensions Fund (PPF), Local Authorities Provident Fund (LAPF), Government Employees Provident Fund (GEPF) and the National Health Insurance Fund (NHIF)). In addition, participants were asked the WHODAS 12 questionnaire to assess difficulties in functioning. (Sosa et al., 2012) Respondents were asked to state the level of difficulty experienced performing an activity during the previous 30 days using a five-point scale (none = 1, mild = 2, moderate = 3, severe = 4, extreme/cannot do = 5) across five domains (communication, physical mobility, self-care, interpersonal interaction, life activities and social participation). These were summed to produce an overall score.

**CHF questionnaire**

The rationale for including the CHF survey was to compare the poverty and disability profile of the population enrolled in CHF to the general population. There were not expected to be sufficient numbers of CHF participants within the household survey and so this had to be conducted additionally. A list of all households who were members of CHF was obtained for each cluster selected in the survey and we randomly selected two households per cluster. The head of household was interviewed and asked about the same household characteristics as the household survey (household characteristics, asset ownership and disability status of household members) in addition to specific questions about CHF participation (duration, use, satisfaction).

**Face-to-face interviews**

A total of 33 semi-structured interviews were carried out with people with disabilities, representatives of government, NGOs, disabled persons’ organisations (DPOs), TASAF coordinators and CHF coordinators. Interviews were conducted on a first come/first serve basis until data saturation was reached. Participants with disabilities were purposefully selected to include individuals with and without CHF membership. Enumerators conducting the survey also identified some participants with more complex challenges, such as individuals with multiple disabilities, for inclusion in the interview sample. Interview guides were specifically developed for each of the interviewed groups covering: definitions and beliefs about disability; health needs of people with disabilities, costs of health services and barriers to access; attitudes of social protection officials and health service staff; enrolment processes for social protection schemes; and satisfaction among members of schemes with disabilities. Researchers were required to consistently use the guiding questions, tape record the discussions and transcribe these for analysis in order to guard against possible bias introduced by the researchers. A second sample of 34 people with disabilities (19 men and 15 women) were selected from the survey sample to take part in six focus group discussions guided by the same set of research questions. Finally, interviews were carried out with programme officials at national level both before and after the district level fieldwork.

**Training and translation**

The questionnaires used in the survey, case-control study and CHF survey were assessed for local relevance and appropriateness through discussion with local Disabled People’s Organizations and other experts. The questionnaires and survey tools were translated into Swahili and back-translated by independent translators, who were asked to comment on the appropriateness of language used for the target population. A review was held to discuss differences in the translations and to modify them accordingly and finalise the questionnaires. These tools were then pilot tested and were believed to work well so were modified little at this stage. Training for the fieldwork in Tanzania lasted one week. There were 3 survey teams each consisting of one field supervisor and 2 interviewers. There was one overall fieldwork supervisor.

**Analysis of data**

Data were entered into a specifically designed mobile data entry form on a Google Nexus tablet. Data entry was pre-coded with in-built consistency checks. The data were uploaded to a central server each day, and were further checked manually for errors. Quantitative data were analysed using STATA and SAS.

Household survey data: We calculated the prevalence of disability and types of disability. We undertook multivariable logistic regression analyses to estimate the relationship between prevalence of disability and SES characteristics, including age, gender, household characteristics, poverty markers and inclusion in social protection programmes. These analyses were adjusted for mean household age, % female and household size. We constructed a poverty score through principal component analysis (PCA) of household assets. (Filmer & Pritchett, 2001) This poverty score was then divided into quartiles, based on the distribution across the population.

Case-control data: We undertook multivariable logistic and linear regression analyses to identify differences between cases and controls in health, inclusion and functioning. Conditional logistic regression was not attempted since matching was not complete, and so analyses were adjusted by the matching variables of age and gender.

CHF survey data: We calculated the prevalence of disability among the CHF household participants. We undertook multivariable logistic regression analyses to assess the differences between households in the general population (Household survey) and who were members of CHF (CHF survey) with respect to disability, household characteristics and poverty markers. These analyses were adjusted for mean household age, % female and household size.

Qualitative data: Hand-written and electronic notes were taken during interviews. Content analysis was conducted structured by defined themes drawn from the objectives of the study and incorporated into the interview guides described above.

**Ethics**

Ethical approval for the study was obtained from the London School of Hygiene & Tropical Medicine (LSHTM) and the National Institute for Medical Research in Tanzania. Informed oral consent was obtained from the head of household for the population survey and the CHF survey, after explanation of the interview content. Informed written consent was obtained from all participants in the case-control study and qualitative interviews. For children (<16) or those with intellectual impairment consent was sought from a family member, who was present during all interviews. People with disabilities requiring treatment or health services were referred as appropriate (e.g. to local hospital or clinic).

**Results**

**Prevalence of disability**

Through the population based survey, we enumerated 1170 households across the 45 clusters from 3 different districts in Tanzania. Among the 4475 eligible individuals aged 5+ living in these households, 140 were identified as having a disability, to give an overall prevalence of 3.2% (2.7-3.8%). A higher proportion of participants reported “some difficulty” or more in any domain – 13.0% (12.0-14.0%). Overall 126 of 1170 households included at least one person with a disability to give a household prevalence of 10.8% (9.1-12.7%). The most commonly reported difficulties were with vision (seeing - 6%) and mobility (walking - 4%), while difficulties with cognition (remembering/concentrating -2%), hearing (2%) self-care (1%) and communication (1%) or albinism (0.1%) were less common. The prevalence of disability was low in children<16 years (0.7%, 0.4-1.3%), and increased in adults 16-59 (2.7%, 2.1-3.3%) and was highest in adults aged 60+ (16.3%, 12.9-20.5%). The prevalence was similar among females (3.0%, 2.4-3.8%) and males (3.3%, 2.6-4.1%).

119 adults (age >=16) with disabilities (cases) and 120 adults without disabilities (controls) were included in the nested case-control study (Table 1). The prevalence of disability was low in children, and consequently only 8 children with disabilities and 7 controls were identified. Cases and controls were relatively well-matched with respect to gender and age. Almost all the cases (105, 83%) considered themselves to have a disability, but none of the controls self-identified as being disabled.

[Table 1 here]

**Socio-economic characteristics, functioning and health needs**

The population based survey found that households including a person with a disability were significantly larger and included more older people than households without a disabled member (Table 2). They were also poorer on average, when assessed through mean poverty score or the proportion of households in the lowest quartile of poverty.

[Table 2 here]

The case control study found that adults with disabilities were significantly less likely to be the household head and were significantly more likely to have never married and to not have children (Table 1). They were also substantially less likely to have ever attended school, and were six times more likely to be illiterate, compared to controls without disabilities. Among the children, 6 out of the 7 controls were enrolled in school, while none of the 8 children with disabilities included were currently enrolled (p=0.0007). People with disabilities were almost three times more likely to report having experienced a serious illness in the last year (OR=2.8, 1.6-4.9). Only 3 cases and 1 control did not seek treatment when ill, and so it was not possible to assess the link between health seeking behaviour and disability. However, cases with disabilities were somewhat more likely to seek treatment from a hospital than another health facility. There was no difference between cases and controls as to whether they paid for treatment themselves (59% versus 63%), but the amount paid was almost twice as high among cases (£9.50, SD=£11.52) compared to controls (£4.81, SD=£3.69), although this did not reach statistical significance (p=0.17). More difficulties in functioning were reported among the cases (WHODAS score = 17.7, SD=13.0) compared to controls (1.8, SD=4.6, p-value<0.0001). These differences were significant among both males and females, and among younger and older adults (all p-values<0.0001).

Fewer than half of people with disabilities had heard of different types of rehabilitation services, with the exception of traditional/faith healers (Figure 1). Very few people expressed a need for any of these services, or reported that they had ever or were currently using these services, despite screening positive for a disability. Similarly, expressed need for assistive devices was very low among people with disabilities (Figure 2) and very few people reported currently using an assistive device, even when they expressed a need for one.

[Figure 1 and 2 here]

**Enrolment in social protection programmes**

The population-based survey found that enrolment in social protection programmes was low overall, covering only one in five households. Households including a member with a disability were not more likely to be included in a social protection programme, except potentially TASAF (though numbers were very small: six individuals with and seven without disabilities enrolled across the population survey).

There were 804 people enumerated across 181 households enrolled in CHF. Of these, 19 people had a disability, to give a prevalence of 2.4% (1.5-3.7%). Among the 181 households enrolled in CHF, 17 (9.4% of households) included at least one person with a disability. The prevalence of disability was therefore lower among the CHF sample than the general population at both the individual and household levels, but these differences were not statistically significant (p=0.24, p=0.58 respectively). Households enrolled in CHF were slightly larger and included substantially more children than households in the general population. They were also significantly less poor, whether measured through income, meals eaten per day or overall poverty score.

The case-control study also found that enrolment in social protection programmes was not higher among cases despite their overall higher levels of poverty and greater health needs (Table 3). Indeed, cases were half as likely to be enrolled in CHF or any other health insurance scheme compared to controls. Among people enrolled in a health insurance scheme, there was no difference between cases and controls in whether they had paid for the insurance, the amount paid, or use of the scheme. Lack of awareness was the most commonly reported reason for not enrolling in social protection programmes among both cases and controls.

[Table 3 here]

Despite the low overall levels of enrolment among the general population, the survey of CHF members found that they were generally well satisfied with the scheme (Table 4). The vast majority reported that the cost was reasonable and that the health insurance was frequently used. At least one third reported that they perceived that there had been an improvement in waiting time, quality of healthcare and friendliness of staff since joining the health insurance scheme. Nine out of ten reported that CHF is a good way to help solve health expenditure (93%) and that they would encourage others to join CHF (88%). A quarter reported that payments were still requested for services when using the CHF card, which was mostly for drugs.

[Table 4 here]

**Perceptions of people with disabilities and officials**

The understanding of disability among government officials and social protection programme staff was generally focused on the perceived inability of individuals to manage their activities of daily living due to physical or mental functional limitations. As a consequence, their definition of disability reflected a charitable model of support, based on the perceived need for ‘help’ of individuals with disabilities, rather than a rights-based discourse or an awareness of disabling barriers in society.

“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…”

In contrast, people with disabilities were generally able to articulate a sense of their rights as people entitled to the same opportunities as other to marry, work and study.

“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.”

Most people with disabilities said that they felt included within their communities, although a small number spoke of personal experiences of stigma. Interestingly, officials were more likely to highlight the issue of damaging beliefs about disability, with several pointing out that people with disabilities face stigma from their communities.

“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.”

In relation to access to health services specifically, the qualitative interviews carried out with people with disabilities confirmed that the cost of services was a significant burden for many. There was almost unanimous agreement amongst interviewees that health services were too expensive and that limited drug availability further increased these costs by forcing people to purchase drugs through private pharmacies. Interviewees also reported problems with transportation costs, especially to district hospitals which were usually further from people’s homes. Coping methods reported included use of local herbs, not seeking healthcare when ill, requesting family support and paying fees in instalments. Two interviewees reported pleading with health service staff and receiving free services as a result.

Most people with disabilities were positive about the attitude of health staff, although more problems were reported at the larger hospitals. The majority of people with disabilities interviewed in the qualitative study had heard of, but not accessed, the CHF and other social protection programmes. 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. This perception was compounded by a lack of understanding of insurance principles, with a number of interviewees concerned that the annual costs would outweigh the benefits if they did not fall sick within the year. CHF coordinators and public officials confirmed that the programme did not have a specific focus on disability and were aware of its limitations in terms of services for people with disabilities.

“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”

They also noted the lack of training for CHF and health facility staff.

“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.”

Among the small number of people with disabilities enrolled in the scheme, there were some positive experiences of enrolment.

“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”

However, many of those who used to be enrolled in CHF expressed dissatisfaction with the scheme, especially in relation to drug availability.

“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”

Enrolment in TASAF amongst people with disabilities interviewed in the sample was extremely low. This is probably related to the relatively short period of time in which the conditional cash transfer programme had been operational in the study areas (payments only began from mid-2014 onwards) and to the fact that until recently 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 level and consequently were of benefit to all. TASAF coordinators also stated that people with disabilities could send “able” representatives to complete their contribution to a project or be given activities that were suitable to their capabilities. 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 to contribute manpower and bricks and we could not choose otherwise.”

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 people with disabilities may have benefited, they were not specifically targeted through these activities.

Several female FGD participants were now receiving cash transfers through TASAF after responding to a call to attend a village meeting. However, they expressed some dissatisfaction with the amount of the cash transfer, stating that “the money helps for two days”.

Interviews with national officials conducted before and after the district-level fieldwork reflected an absence of systematic attention to the inclusion of people with disabilities in social protection programmes and a lack of involvement of people with disabilities and their representative organisations in programme design. For example, TASAF includes questions on disability within its national household verification questionnaire (used alongside community targeting) but has never analysed this data to establish the number of people with disabilities currently enrolled within the programme nor consulted people with disabilities about their expectations or experiences within the programme. Programme staff stated that for the conditional cash transfer children with severe disabilities were exempted from the requirement to attend school, but were unable to say how often this provision was used (as decisions were made at a local level) and acknowledged that no follow-up system was in place to address the underlying causes of their exclusion. Similarly, officials from the NHIF were not able to identify any specific actions taken to address the issue of disability-inclusion within the CHF at either a national or local level. Officially, District councils are required to provide exemptions for those who cannot afford the contributions, but implementation of exemptions is often very limited (Maluka, 2013) and no specific guidance is provided to Districts on the need to ensure people with disabilities who cannot afford to pay are included.

**Discussion**

The quantitative data show that households including people with disabilities in the three study districts were on average poorer and older than households without a disabled member. People with disabilities were also less likely to be educated, less likely to be married and have children, and more likely to report a serious illness. Although most people needing health care sought care, cases paid almost twice as much for health services than controls, despite the fact that they came from poorer households. There was also very low coverage of rehabilitation services or assistive devices among cases with disabilities.

Despite the evidence of greater need for social protection among people with disabilities, households with disabled members were not more likely to be included in social protection programmes (with the exception of the very small number of individuals enrolled in TASAF). Indeed, households enrolled in CHF were much less likely to be poor, and slightly less likely to include a disabled member, than households in the general population. This potentially implies that the programme was less accessible to poorer households or those with a disabled member, although other explanations are possible such as that CHF enrolment helped participants to reduce their level of poverty.

Our findings are consistent with the general literature which demonstrates that people with disabilities are more vulnerable to poverty. A systematic review of 97 studies from low- and middle-income countries found that the majority reported a positive, statistically significant association between disability and economic poverty (Banks & Polack, 2014). This was true across age groups, location, disability types and study designs. Where studies also explored the relationship between disability and unemployment, 12 out of 17 reported a statistically significant relationship.

The findings also support the general evidence that people with disabilities often have higher health care needs. The World Health Surveys included data from 51 countries and showed that people with disabilities were significantly more likely to seek inpatient and outpatient care (World Health Organisation, 2011). This is confirmed in other studies (Danquah et al., 2014; Kuper et al., 2014). The vulnerability to ill health among people with disabilities may be due to the underlying impairment, or because of a higher risk of chronic conditions and other diseases (Gudlavalleti et al., 2014). Another explanation is that older people are both more likely to have disabilities and to experience ill health. Lack of ability to afford necessary health services may further lead to or exacerbate disability, continuing the cyclical relationship between poverty and disability (Braithwaite & Mont, 2009).

The World Health Surveys showed that disabled men and women were significantly more likely to not receive health care when needed, which contrasts with our findings (World Health Organisation, 2011). Other studies support our findings presented here that uptake of health services does not differ between people with and without disabilities (Trani et al., 2011; Danquah et al., 2014; Kuper et al., 2014). What is clear, however, is that people with disabilities face many barriers when seeking health services (Krahn, Reyes, & Fox, 2014; Mannan & MacLachlan, 2013), and so these data may not reflect the difficulties experienced in accessing services. Others have reported that the cost of seeking health care may be higher among people with disabilities, potentially leading to catastrophic health expenditure (Maulik & Darmstadt, 2007), and there is some support for this trend in our findings.

The evidence on the relationship between social protection and disability is less extensive. A recent systematic review of the global literature found that high quality, robust evidence on this issue is extremely limited, with only fifteen academic articles identified (Banks et al., in press). Those studies that do exist suggest that access to social protection is generally far below the level of need for people with disabilities and benefits are largely limited to maintenance of a minimum living standard, rather than more ambitious goals related to long-term social and economic development. Most of the studies focused on disability-specific rather than mainstream social protection programmes and none assessed equity in access between people with disabilities and the general population. Our study is therefore important in that it demonstrates that greater need for social protection among people with disabilities compared to the general population is not likely to be reflected in improved access to mainstream social protection programmes without specific attention to disability-inclusive programme design.

Tanzania’s law on disability - the Persons with Disability Act (2010) - is compliant with the UN Convention on the Rights of Persons with Disabilities and includes specific references to the need for equal access to social protection programmes for men and women with disabilities. However, our study shows that very little is being done in practice to make existing social protection programmes inclusive of people with disabilities. This was reflected both in national level interviews with programme officials as well as in the findings from the district level qualitative interviews, where no concrete examples of actions taken or policies introduced to include people with disabilities could be identified. Redesigning mainstream social protection programmes to be inclusive of people with disabilities requires attention to a range of factors including: awareness raising among people with disabilities and their active participation in programme design; inclusive eligibility and targeting criteria for beneficiaries; attention to the accessibility of services and facilities; and the provision of additional services to address the specific needs of people with disabilities. Adaptation of the direct services and benefits offered by programmes can also be accompanied by the development of appropriate linkages or referral systems to support access to specialised services where these are beyond the immediate scope of the programme. For example, people with disabilities often need rehabilitation services or assistive technology, yet - in-line with global evidence on this issue (World Health Organisation, 2011) - coverage of these services was very low among the study population. The CHF benefit package could therefore be adapted to include transportation costs for people with disabilities to local facilities but also for onward referral to specialised services (e.g. rehabilitation services) where these are not available within the district. Similar linkages could be developed that increase the impact of the health-related aspects of TASAF’s programme (in this case, with a primary focus on pregnant women and children).

In contrast to the Millennium Development Goals, the newly adopted Sustainable Development Goals include specific targets on social protection and a number of individual targets which refer to the inclusion of people with disabilities (United Nations, 2015). Furthermore, the importance of generating high-quality, disaggregated data on disability for all goals and targets is acknowledged a number of times. Beyond Goal 1 on poverty eradication, social protection programmes will also make a significant contribution to targets such as equal access to all levels of education and vocational training (target 4.5) and the achievement of full and productive employment and decent work for all (target 8.5). In both these cases, the need to ensure people with disabilities is highlighted within the target itself and, as our research demonstrates, it is clear that greater attention to this issue will be required to achieve significant progress on these targets.

Evidence also suggests that Universal Health Coverage – increasingly the dominant health systems framework within international development and a specific target in the Sustainable Development Goals - is unlikely to be achieved without the specific inclusion of people with disabilities as they make up a large population group and are more vulnerable to ill health. Furthermore, provision of rehabilitation services and assistive devices needs to be considered a key component of Universal Health Coverage, due to the high need for these services among people with disabilities, and their importance in facilitating full participation of people with disabilities within social and economic development. Consequently, improving access to both health and rehabilitation services among people with disabilities is a dominant aim of the World Health Organisation’s Global Disability Action Plan 2014-2021.(WHO, 2014) Enrolment in health insurance schemes, such as CHF, alongside adaptation of other mainstream social protection programmes to better address the needs of people with disabilities (and provide appropriate onward referral where necessary) may therefore represent a significant means of supporting the move towards Universal Health Coverage at the same time as addressing the core poverty alleviation goals of social protection programmes and the Sustainable Development Goals.

**Strengths and limitations**

There were a number of limitations to the study. We were under-powered to investigate some of the outcomes given the low participation in social protection programmes and our lower than expected prevalence of disability (3.2%). However, the national survey in Tanzania estimated that the prevalence of “some form of activity limitation” based on the Washington Group short set of questions was 7.8% (with regional variations from 2-7-13.2%) and our estimate of 13.0% using the same threshold therefore fits within this variation. We used the Washington Group questions for all people above the age of 5, although the tool was not specifically designed for use in children. Several psychological functions are also not represented in the short set tool, including anxiety and depression. The screening for disability was based upon the response by a proxy for the most part, though verified for individual cases, and their reported disabilities are not confirmed with a clinical evaluation. Other items in the questionnaire (e.g. access to services) were subject to recall. Although we used validated or commonly used tools where possible, we did not undertake a formal validation or cognitive testing of the questionnaire.

There were also a number of strengths. We used standardised data collection instruments, allowing comparison with other studies. The data were entered using mobile tools, which required all fields to be filled before saving, ensuring a high level of completeness. The study was population based to improve the generalisability of results, and we assessed multiple domains of inclusion. A mixed methods approach using in-depth qualitative interviews alongside quantitative data collection allowed for a greater understanding of the experiences and perceptions of people with disabilities in terms of both their needs and their level of access to social protection programmes within the three study districts.

**Conclusion**

There is a higher need for inclusion in social protection programmes, including health insurance and social assistance schemes, for people with disabilities in Tanzania, given their higher health care needs and higher levels of poverty. However, this is not currently reflected in higher levels of enrolment or participation in these schemes. The adaption of mainstream social protection programmes to better meet the needs of people with disabilities may be required for reasons of equity and to facilitate achievement of poverty alleviation goals and Universal Health Coverage.

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Table 1: Socio-demographic characteristics of cases with disabilities and controls without disabilities (Nested Case-Control Study)

|  |  |  |  |
| --- | --- | --- | --- |
|  | Cases  (n=127) | Controls  (n=127) | Age- sex adjusted OR |
| Sex  Male  Female | 57 (52%)  70 (55%) | 53 (42%)  74 (58%) | 1.1 (0.7-1.9)  Baseline |
| Age  0-15  16-59  60+ | 8 (6%)  61 (48%)  58 (46%) | 7 (6%)  64 (50%)  56 (44%) | 1.1 (0.4-3.3)  0.9 (0.6-1.5)  Baseline |
| Head of household  Yes  No | 53 (42%)  74 (58%) | 77 (61%)  50 (39%) | 0.3 (0.2-0.6)  Baseline |
|  |  |  |  |
| **Adults only** | Cases (n=119) | Controls (n=120) |  |
| Marital status  Married/cohabiting  Divorced/separated  Widowed  Never married | 49 (42%)  15 (13%)  24 (21%)  29 (25%) | 74 (63%)  11 (9%)  26 (22%)  6 (5%) | Baseline  2.2 (0.9-5.2)  1.0 (0.5-2.3)  9.4 (3.5-25.1) |
| Have children  Yes  No | 88 (75%)  29 (25%) | 103 (89%)  13 (11%) | Baseline  2.8 (1.3-6.0) |
| Can you read:  Well  A little  No | 36 (31%)  22 (19%)  59 (50%) | 73 (62%)  17 (15%)  27 (23%) | Baseline  3.2 (1.5-7.0)  6.1 (3.1-12.2) |
| Ever attended school  No  Yes | 41 (44%)  66 (56%) | 28 (24%)  89 (76%) | 3.0 (1.6-5.5)  Baseline |
| Serious illness  No  Yes | 75 (59%)  52 (41%) | 101 (80%)  26 (20%) | Baseline  2.8 (1.6-4.9) |
| Where sought treatment  Hospital  Other | 20 (83%)  4 (17%) | 35 (71%)  14 (29%) | 2.4 (0.7-8.7)  Baseline |

Table 2: Comparison of Household Characteristics and Disability for the Household Survey and CHF survey

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Household survey | | | CHF survey | |
|  | Households with disabled member  N=126 | Households without disabled member  N=1044 | Adjusted p-value\*1 | CHF survey  N=181 | Adjusted p-value\* 2 |
| Household structure |  |  |  |  |  |
| Average household size | 4.4 (2.2) | 3.8 (1.9) | <0.001 | 4.4 (1.8) | <0.0001 |
| % female | 56.7% | 53.9% | 0.61 | 53.8% | 0.92 |
| Average age | 38.2 (13.8) | 29.9 (12.8) | <0.001 | 30.9 (10.9) | 0.12 |
| Average children (<16) | 1.3 (1.2) | 1.3 (1.3) | 0.04 | 1.7 (1.4) | 0.05 |
| Average adults (16-59) | 2.3 (1.6) | 2.2 (1.2) | 0.27 | 2.4 (1.2) | 0.05 |
| Average older adults (60+) | 0.8 (0.9) | 0.3 (0.5) | <0.0001 | 0.4 (0.7) | 0.61 |
|  |  |  |  |  |  |
| Poverty markers |  |  |  |  |  |
| Income  1  2+ | 95 (75%)  31 (25%) | 741 (71%)  303 (29%) | 0.18 | 109 (60%)  72 (40%) | 0.01 |
| Meals per day  1/2  3 | 56 (44%)  77 (56%) | 378 (36%)  666 (64%) | 0.15 | 55 (30%)  126 (70%) | 0.12 |
| Average poverty score | -0.4 (2.3) | -0.07 (1.9) | 0.03 | 0.70 (1.9) | <0.0001 |
| Poverty quartile  1 (lowest)  2  3  4 (highest) | 46 (37%)  33 (26%)  22 (17%)  25 (20%) | 278 (27%)  267 (26%)  253 (24%)  246 (24%) | 0.01 | 20 (11%)  43 (24%)  53 (29%)  65 (36%) | <0.0001 |
| Social protection inclusion  NHIF  CHF  TASAF  Any social protection | 8 (6%)  11 (9%)  6 (5%)  26 (21%) | 33 (3%)  128 (12%)  7 (0.7%)  175 (17%) | 0.34  0.33  0.02  0.51 |  |  |

\* Adjusted for household size, mean age, % female

1 Households with versus without disabled household member

2 Households from survey versus Households from CHF

Table 3: Social Protection enrolment among cases with disabilities and controls without disabilities (Nested Case-Control Study)

|  |  |  |  |
| --- | --- | --- | --- |
|  | Cases  (n=127) | Controls  (n=127) | Age- sex adjusted OR (95% CI) |
| Enrolled in any scheme  Yes  No | 13 (10%)  114 (90%) | 15 (12%)  112 (88%) | 0.8 (0.4-1.9)  Baseline |
| Enrolled in CHF  Yes  No | 6 (5%)  121( 95%) | 14 (11%)  113 (89%) | 0.4 (0.1-1.1)  Baseline |
| Have health insurance  Yes  No | 13 (10%)  114 (90%) | 24 (19%)  103 (81%) | 0.5 (0.2-1.0)  Baseline |
| If yes, paid for insurance  Yes  No | 7 (54%)  6 (46%) | 15 (63%)  9 (38%) | 0.9 (0.2-3.9)  Baseline |
| Amount paid per month | £2.81 (SD=£3.08) | £10.30 (SD=£24.57) | P=0.26 |
| If yes, used in last year  0  1  >1 | 3 (23%)  4 (31%)  6 (46%) | 11 (46%)  5 (21%)  8 (33%) | P=0.13 |
| Health insurance convenient  Yes  Partially/No | 9 (69%)  4 (31%) | 12 (50%)  12 (50%) | 2.7 (0.6-11.7)  Baseline |
| Why not enrolled in social protection  Do not qualify  Do not need  Do not know about it  Other | 9 (8%)  12 (11%)  75 (66%)  17 (15%) | 8 (8%)  16 (16%)  69 (68%)  9 (9%) | P=0.43 |

Table 4: Enrolment and use characteristics among CHF members

|  |  |
| --- | --- |
| Characteristic | N (%) |
| Paid for CHF membership  No  Yes | 8 (4%)  172 (95%) |
| If yes, amount paid per month | £4.08 (SD=£3.44) |
| Costs considered:  Low  OK  High | 45 (26%)  104 (60%)  22 (13%) |
| Anyone insured sought health service in last month  No  Yes | 69 (39%)  112 (62%) |
| Waiting time changed after joining insurance  Improved  Stayed the same  Worsened | 57 (32%)  113 (63%)  8 (4%) |
| Quality of healthcare changed after joining insurance  Improved  Stayed the same  Worsened | 74 (41%)  101 (56%)  6 (3%) |
| Friendliness of staff change after joining insurance  Improved  Stayed the same  Worsened | 58 (33%)  110 (62%)  10 (6%) |
| CHF considered good way to manage health expenditure  No  Yes | 11 (6%)  170 (93%) |
| Would encourage others to join CHF  No  Yes | 21 (12%)  160 (88%) |
| Payments requested when using CHF card  No  Yes | 142 (78%)  39 (22%) |

Figure 1: Coverage of rehabilitation services among people with disabilities

Figure 2: Coverage of assistive devices among people with disabilities