DISABILITY AND EDUCATION

Qualitative study from Zambia on barriers to and facilitators of life-long learning

QUALITATIVE STUDY FROM ZAMBIA ON BARRIERS TO AND FACILITATORS OF LIFE-LONG LEARNING (SUMMARY OF RESULTS)

Central Statistical Office
Lusaka, Zambia

Ministry of Community Development and Social Services
Lusaka, Zambia

DECEMBER 2018

Professor Jacob R.S. Malungo

Professor Dabie Nabuzoka

Dr Ravi Paul

Mr Nkenda Sachingongu
(University of Zambia)

Editors:

Gloria Azalde

Stine Hellum Braathen
(SINTEF Digital, Department of Health Research, Norway)

CONTENTS

LIST OF ABBREVIATIONS

CBR	Community-Based Rehabilitation
CHReP	Community Health Restoration Programme
COIHEP	Community Integrated Health Education Programme
CRPD	(United Nations) Convention on the Rights of Persons with Disabilities
CSO	Central Statistical Office
DPO	Disabled People's Organization
EP	Eastern Province
FGD-PWD	Focus Group Discussion with Persons with Disabilities
ILO	International Labour Organisation
MCDMCH	Ministry of Community Development, Mother and Child Health
MCDSS	Ministry of Community Development and Social Services
NGO	Non-Governmental Organisation
NVRC	National Vocational Rehabilitation Centre
PTA	Parent–Teacher Association
RA	Research Assistant
TEVET	Technical Education, Vocational and Entrepreneurship Training
TEVETA	Technical Education, Vocational and Entrepreneurship Training Authority
UNICEF	United Nations Children's Fund
UNZA	University of Zambia
UTH	University Teaching Hospital
ZAFOD	Zambia Federation of Disability Organisations
ZAPD	Zambia Agency for Persons with Disabilities

ACKNOWLEDGEMENTS

The Research Team
University of Zambia
SINTEF Digital, Department of Health Research

EXECUTIVE SUMMARY

The objective of Component 2 of the National Disability Survey was to carry out a qualitative, in-depth study of the barriers to and facilitators of life-long learning and skills development for children and young persons with disabilities in Zambia. The study was carried out by the University of Zambia (UNZA), in collaboration with SINTEF Digital, Norway. The key findings have been summarised into broad categories with some recommendations.

GENERAL KNOWLEDGE ON DISABILITY

People in the various communities studied had a good understanding of what it means to have disabilities and most informants suggested causes that are widely accepted. However, there was also a significant lack of knowledge which may give rise to stigma, fear and social isolation on the part of the community. Such lack of knowledge also affected people's perspective of what persons with disabilities' participation in society should entail.

The findings indicate that the key to changing this perspective as well as misinformation on the causes of disability is to provide society, communities, and teachers with education and information. Since there is a move towards inclusive education in Zambia, it is important for teacher's education to include both updated knowledge and an activity-limitations perspective on disability.

Disabled People's Organizations (DPOs) working together with the media or local projects could also try to be more proactive in reaching communities with information. Schools are also good arenas for changing future community perspectives.

KNOWLEDGE OF POLICIES

There are many laws and policies that include persons with disabilities in Zambia, but their implementation is limited. The Disability Act of 2012 ensures full and equal human rights and freedoms to persons with disabilities. However, there was the perception of a gap between this Act and its implementation at local level.

It is crucial for persons with disabilities to have better knowledge of this Act to be able to demand the rights included therein. This Act ensures access to education and addresses many of the systemic barriers described by many informants in the study.

Disseminating knowledge of the Disability Act in society could also serve to create more jobs for persons with disabilities since the Act guarantees tax incentives for businesses interested in hiring persons with disabilities.

Perhaps the greatest hindrance in securing the rights of persons with disabilities in Zambia is the lack of knowledge of the Disability Act by persons with disabilities and their families. Without knowledge, they are not able to demand the rights outlined in this act.

COOPERATION BETWEEN MINISTRIES

The findings pointed to many systemic barriers that need to be resolved, and involve several ministries. These included lack of assistive devices, tools, interpreters and assistants which were mentioned as hindering participation and as added barriers to inclusion.

The Ministry of Community Development and Social Services (MCDSS) has the overall responsibility for the welfare of children with disabilities, and through the Zambia Agency for Persons with Disabilities (ZAPD) for implementing the Disabilities Act of 2012. As such, it is in an excellent position to encourage tighter cooperation from different ministries to enable the implementation of the Act.

Working together with the Ministry of Health, it could enable provision of a standardized medical assessment of children with disabilities before the start of each school year, which would include any necessary prescription as well as the provision of necessary assistive devices.

Some informants expressed a great need for an organized and preferably a governmental provision of assistive devices. Currently, assistive devices are only sporadically provided by multiple NGOS. Children grow, and the need for yearly assessment of both physical health and assistive devices is necessary.

The MCDSS could also work more tightly with the Ministry of Education to ensure educational assessment of children before they start school. Together, these assessments would improve the ability of the teacher to adapt their classroom and curriculum appropriately to the needs of the child involved.

Assessments could include all aspects of the environment surrounding the child: the physical environment, assistive devices, adapted curricula, transport, medication, and any other aspects, including financial barriers keeping a child from accessing education. Addressing all potential barriers to education for children with disabilities would involve many ministries.

RESOURCES FOR EDUCATION

Most of the barriers identified were rooted in the lack of resources in education. There needs to be political will to invest largely in education –

including the education of children with disabilities – to achieve an inclusive education system.

First, infrastructure need to be built on the principles of universal design, i.e. the built environment should be accessible to all regardless of physical capabilities or age. Therefore, no child should need to crawl on dirty bathroom floors nor need assistance to access classrooms.

Second, curricula should be revised frequently and should be inclusive in its design. Teachers spend too much time updating outdated curricula and adapting them to the individual child.

Third, a general investment in textbooks is necessary, and children with visual and hearing impairments should be provided with accessible textbooks and teaching formats. It should be unnecessary for teachers to spend time reading textbooks out loud to blind students.

Fourth, schools should have more assistant teachers as well as other assistive personnel to free teacher capacity and enable individualized learning. This would also allow for a good student-teacher ratio, which is currently a barrier to the quality of teaching. As suggested by some informants, assistants could be used for remedial learning while other assistive personnel could provide other types of care for students with disabilities. Improving classrooms for children with disabilities will also improve classrooms for other children.

TRAINING OF TEACHERS

Many teachers involved in the study, especially those working in special schools or with children with special needs, expressed the need for continuing education. Most of these teachers were generalists and felt the need to learn sign language or braille to facilitate teaching to children with impairments. This need for training was also identified for teachers in mainstream schools.

With the move towards inclusive education, some informants were critical towards inclusive education plans were being implemented without guidelines, follow-up, support or training for generalist teachers or school administrators. It is necessary for all generalist teachers to learn about disabilities, about how to adapt teaching methods to disabilities, and about how to improve classrooms for children with disabilities.

Generalist teachers could work together with specialist teachers to provide quality and relevant education for students with disabilities.

EMPOWERMENT

Access to learning requires awareness on the part of children with disabilities and their parents. If parents lack knowledge about the right to education, then they will not believe that their child with disability can go to a mainstream school, attend a trade school, or acquire life skills.

DPOs could play a role in empowering children with disabilities and their parents. They could work to raise awareness of the rights of persons with disabilities concerning education, and thus increase enrolment in schools, and to encourage participation in school politics.

As suggested in the results of this study, a network of parents and guardians could be established where information on disabilities and services would be exchanged.

Finally, DPOs should monitor and ensure that the Disability Act is implemented by all stakeholders.

AFFIRMATIVE ACTION

Many barriers faced by young people with disabilities were identified in their transition to employment and income-generating activities. Firstly, few persons with disabilities are able to attain a high level or specialized education due to system-wide obstacles, as well as cultural barriers. Secondly, even if they

are well qualified, they will not be considered for a job, because employers cannot see beyond the disability. Thirdly, when seeking employment, not only are persons with disabilities competing with persons without disabilities, but they are also far outnumbered by candidates without disabilities; it is therefore easy for employers to avoid selecting them. Finally, very few buildings are accessible to persons with disabilities.

Affirmative action was named as an important policy in employing persons with disabilities. There was a general frustration that persons with disabilities were educated or given skills, but not given the opportunity to use them.

However, some persons with disabilities had been helped by affirmative action policies, but not to the degree desired.

Since many persons with disabilities employed themselves, there was an expressed need for the availability of larger loans to help them establish their businesses.

CONCLUSIONS

This qualitative study has uncovered several barriers affecting inclusive and quality life-long learning and skills development for persons with disabilities in Zambia. Though the Living Conditions Survey (Eide and Loeb, 2006) and the survey component of the Zambian National Disability Survey both point to gaps in educational access for children with disabilities, data are lacking on the how and the why – both of which are necessary to make recommendations and ultimately produce tangible change. The barriers identified in the qualitative component of the survey point to some of the answers to such questions.

BACKGROUND TO THE REPORT

This report summarizes the qualitative component (Component 2) of the Zambian National Disability Survey, financed by UNICEF Zambia (RFP/ZAMA/2012/9110185). SINTEF Technology and Society carried out this study, in collaboration with the Central Statistical Office of Zambia (CSO) and the University of Zambia (UNZA). In addition, to support the study in critical phases, an international team was subcontracted, comprising three leading scientists from Stellenbosch University (South Africa), University of Cape Town (South Africa) and University of Melbourne (Australia).

The main purpose of the Zambian National Disability Survey was to determine the prevalence of disability among adults and children in Zambia; to analyse the socio-economic and demographic characteristics of persons with disabilities,[1] including children; and to assess the main issues that affect their quality of life in terms of participation and use of basic social services. The results of the study will be used to establish a sound evidence base for policy formulation and programming to promote the inclusion of persons with disabilities, including children, and to contribute to the effective implementation of the Persons with Disabilities Act 2012. The Government of Zambia, through the Ministry of Community Development and Social Services (MCDSS), took the initiative for this study.

To reach the above-stated aims, the Zambian National Disability Survey was split into two distinct research components. Component 1 was a national, representative household survey that was implemented by the CSO in collaboration with SINTEF. Its aim was to determine the prevalence of disability and the socio-economic and demographic characteristics of persons with disabilities. **This report summarizes Component 2**, a qualitative, in-depth study of the barriers to and facilitators of life-long learning and skills development for children and young persons with disabilities in Zambia. Component 2 was carried out by the University of Zambia (UNZA), with overall project management, support, study design and training provided by SINTEF, Norway.

---

[1]   This report will follow the adoption by the UN Convention on the Rights of Persons with Disabilities of the use of 'persons with disabilities'.

INTRODUCTION

Internationally, the right to education is protected in various articles of milestone documents, including Article 26 of the United Nations General Assembly's Universal Declaration of Human Rights (1948), and Article 28 of the United Nations Convention on the Rights of the Child (1989). Furthermore, the right to education for persons with disabilities is distinctly recognized in Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006) and latterly in Goal 4.5 of the UN's Sustainable Development Goals, which ensures inclusive and equitable quality education and promotes life-long learning opportunities for all, including persons with disabilities (United Nations, 2015).

Though Zambia first ratified the CRPD in 2008, the country has included persons with disabilities in various policies and laws ever since the amended constitution of 1996 (Republic of Zambia, 1996a). Currently, there are several laws and policies in place that cover persons with disabilities, including some specifically within the field of education, such as the National Policy on Education (Ministry of Education, 1996), the Education Act (Republic of Zambia, 2011) and the Technical Education, Vocational and Entrepreneurship Training (TEVET) Policy (Republic of Zambia, 1996b). Nevertheless, the most important act pertaining to persons with disabilities and influencing education is the Persons with Disabilities Act (Republic of Zambia, 2012).

The Persons with Disabilities Act 2012 provides for free primary education, ensures that persons with disabilities are not excluded from accessing secondary and higher education in the communities in which they live, ensures vocational training on the basis of disability and guarantees special schools for persons who cannot be enrolled in schools offering inclusive education. It also ensures physical access to educational institutions, ensures individualized support and access to alternative forms of communication, as well as allowances to cover extra costs attributed to learning. However, these measures fall far short of being implemented.

Currently, the welfare of persons with disabilities is the responsibility of the Ministry of Community Development and Social Services (MCDSS). This ministry has six departments, several of which work (in one way or another) to provide support for persons with disabilities. For instance, while the Mother and Child Health Department in the MCDSS has responsibility for children with disabilities, the Social Welfare Department deals with persons with disabilities who need welfare support, such as cash transfers. The MCDSS is also responsible for the Zambia Agency for Persons with Disabilities (ZAPD). Briefly, ZAPD has responsibility for implementing the Persons with Disabilities Act and any policy or national strategy on disability. This agency was established under the Persons with Disabilities Act 1996 and continued under the act of 2012.

Traditionally, Zambia has had special schools for persons with disabilities, such as the University Teaching Hospital (UTH) Special Needs School and Munali Secondary School in Lusaka, or Magwero Secondary School in Chipata, Eastern Province. These currently fall under the Ministry of General Education. There are now plans to invest in inclusive schools, where all students – including those with disabilities – are taught together. This project is supported by the International Labour Organization (ILO) and other partners. Currently there are five vocational schools in Zambia that have served as pilots for inclusive education: National Vocational Rehabilitation Centre (NVRC) and Luanshya Trades (both in Copperbelt Province), Kaoma Trades (Western Province), Mansa Trades (Luapula Province) and Lusaka Business and Technology

College. In line with the TEVET policy of 1996, these vocational schools are the responsibility of the Department of Vocational Education and Training within the Ministry of Higher Education.

In 2002, free education was introduced for all children in the first six years of primary school. This had the direct effect of increasing the net enrolment rate from 68 percent in 2000 to 96 percent in 2006 (Miles, 2011). However, the same trend was not observed among children with disabilities. A 2006 survey of living conditions among persons with disabilities in Zambia reported that, though eligible, around a quarter of all individuals with disabilities did not attend primary school (Eide and Loeb, 2006). However, given the opportunity to attend school, persons with disabilities matched the achievements of those without. The survey also highlighted other substantial challenges faced by persons with disabilities. It found that unemployment rates were significantly higher among persons with disabilities than without. It also found that there were great gender differences, with women – both with and without disabilities – scoring lower on many indicators. The survey also pointed out problems of social exclusion, including individuals with disabilities not taking part in their own traditional ceremonies, not making decisions about their own lives, not getting married and not having children. Furthermore, in all of the challenges mentioned above, there was a 'physical disability bias', where persons with sensory, intellectual and psychological disabilities were worse off on important inclusion indicators, and experienced greater activity limitations and restrictions in social participation. As far as access to health services was concerned, 20 percent reported not having access to the health services they needed, and major gaps were found in the provision of services needed by persons with disabilities, such as vocational training, welfare services, assistive devices and counselling. When persons with disabilities were asked what type of assistance they needed in daily life, emotional support was mentioned more often than economic support (Eide and Loeb, 2006).

> *Building on relevant policy and research, the thematic scope of this qualitative project has been to carry out an in-depth exploration of factors relevant for the inclusion and exclusion of persons with disabilities in activities of life-long learning and skills development in Zambia.*

OBJECTIVES

The objective of the qualitative part of the Zambian National Disability Survey was to carry out a qualitative in-depth study on the barriers to and facilitators of life-long learning and skills development for persons with disabilities:

- Focusing on children and young people before, during and shortly after primary and secondary education, including both those who are attending or have attended formal education and those who are not attending or have not attended formal education

- Focusing on both life skills and scholastic skills (including formal education, informal learning at home/in the community, vocational training/skills centres, special education, etc.)

- Studying the transition into formal and informal employment

- Studying **both** barriers **and** facilitators from the perspectives of families/individuals with good access and families/individuals with poor access.

RESEARCH QUESTIONS

Factors relevant for the inclusion and exclusion of persons with disabilities in activities of life-long learning and skills development were studied, with the aim of answering the following research questions from the perspective of local authorities, service providers, children and young persons with disabilities and their families:

1. What services and activities are there at the local level and what is the relevance and quality of these services in terms of catering for and including persons with disabilities?

    ○ What mechanisms lie behind possible inclusion or exclusion (stigma, discrimination, systemic, physical barriers, environmental barriers, and so on)?

    ○ How are these dealt with by the individuals/their families?

2. What is the experience of children and young persons with disabilities (including the parents of children with disabilities and other family members/caregivers) in accessing and using the services and activities identified?

    ○ In what areas do they experience participation restriction and exclusion or inclusion, and what mechanisms lie behind this?

3. What kind of assistance/change is needed to improve inclusion?

4. How are infants and children with disabilities raised/educated/socialized in order to prepare them for life as adults (from the perspective of parents/caregivers/guardians)?

    ○ Thoughts about their possible futures; participation in education and employment, their contribution to household (chores/income/caregiving).

METHODS

SAMPLING SITES AND INFORMANTS

Four study sites were selected: two urban sites (one in Lusaka and one in Copperbelt) and two rural sites (one in Western Province and one in Eastern Province). Purposive sampling guided the process. The sites were chosen to represent the following characteristics:

- Well-serviced areas **and** poorly serviced areas: in terms of relevant educational, learning and training institutions, programmes run by disabled people's organizations (DPO), cash transfer programmes and so on

- Urban and rural areas

The informants were identified through pre-visits to the four study sites described above and through 'snowballing'. The pre-visits were carried out to ensure successful entry into the local communities and to obtain all the necessary local permissions to carry out the research. The pre-visits included an initial mapping of the study site with local authorities, in order to identify available learning and skills-development services and activities available in the community. The mapping focused on community, government and non-governmental organization-based institutions and activities providing both life skills and scholastic skills, including (but not restricted to) the following:

- Formal education: pre-school, primary, secondary and tertiary education

- Informal learning at home/in the community

- Vocational training/skills centres

- Special-education institutions

A combination of focus group discussions/group discussions and individual in-depth interviews were carried out among the following types of informant:

- Service providers

- Adults with disabilities (sensory/physical/psychosocial)

- Parents/guardians of children with disabilities

DATA-COLLECTION INSTRUMENTS

The following data-collection tools were utilized in the different qualitative components (see Appendix 1 for detailed tools):

- Community mapping

- Individual interview guides for:
  - Service/activity providers
  - Children and young persons with disabilities
  - Guardians/family members of children and young persons with disabilities

- Focus group discussion guides for:
  - Service/activity providers
  - Children and young persons with disabilities
  - Guardians/family members of children and young persons with disabilities

These tools functioned only as guides – they were not exhaustive lists of topics and questions to be covered. The researchers and research assistants involved in data collection were encouraged to be mindful of new topics and questions likely to emerge, and to consider whether topics were relevant to the interview at hand. A key part of qualitative research is to be prepared for and able to adjust to such changes and developments.

THE FIELD TEAM

The international and Zambian research team has extensive experience of carrying out qualitative data collection, including with the use of unskilled research assistants (RAs). In this project, we used a few local research assistants, but to ensure the quality of the data, the RAs were followed up closely by skilled researchers. A team of four experienced qualitative researchers from UNZA and 12 research assistants carried out the qualitative fieldwork. They were divided into four field teams, one in each study site. The field team in each site consisted of:

- One researcher from the University of Zambia
- Three research assistants speaking the language relevant to the specific site
- One driver (car)

The RAs were trained during a one-week workshop in November 2014. They were taught basic qualitative research skills and given an introduction to the field of disability. They also practised facilitating and participating in in-depth interviews and using the research tools for this particular project. In the training, we also discussed translations of the tools into the three local languages that were used in the project. The RAs were responsible for the transcription and translation of the interviews they carried out. This was also taught in the training. Twenty RAs were trained, of whom 12 were selected to participate in the fieldwork.

DATA ANALYSIS

A thematic content analysis approach was used to analyse the data and to establish major categories in the data and linkages between them (Silverman, 2013). Previous quantitative research in Zambia (Eide and Loeb, 2006)) was used as a starting point to adopt a largely deductive approach to coding. Suggestions for coding were developed in part to allow for cross-site comparisons, although these were not exhaustive and did not prevent new codes and themes emerging from the data. Thus, themes that were produced were both deductive and inductive in nature (Joffe and Yardley, 2004; Willig and Stainton-Rogers, 2008). Though guidelines do exist, there are no standardized methods of qualitative data analysis, and different approaches to the method of discovery are often utilized (Leavy, 2014).

ETHICAL CONSIDERATIONS

APPROVAL FROM ETHICAL COMMITTEES AND PUBLIC AUTHORITIES

The project followed ethical standards and guidelines set out by both Norwegian and Zambian law and upheld by national ethics committees. The project was assessed for ethical approval from both the Humanities and Social Sciences, Research Ethics Committee, University of Zambia, and the Norwegian Centre for Research Data.

The Ministry of Education facilitated access to relevant public authorities, as requested by the project. These included the heads of local health and education departments in the four study sites. Local gatekeepers were also approached, including provincial, district and community-based social welfare officers and community-based leaders dealing with disability.

INFORMED CONSENT

Before each interview, every participant was informed of the purpose of the study, and informed consent was obtained. Direct consent was obtained from informants above the legal age (18 years), while guardians provided consent for people below 18 years of age or with reduced ability to consent. However, participants still had to assent to the interview. Participation in this project was voluntary: participants could withdraw at any time and could decline to answer any question during the interview. Participants did not receive payment for their participation.

CONFIDENTIALITY

The confidentiality of the participants was ensured by using pseudonyms and labelling the interviews according to general area, date, type of interview and type of informant. For example, EP-01072015-FGD-PWD would be a focus group discussion (FGD) with persons with disabilities (PWD) in Eastern Province (EP). Interviews were recorded only if informants consented, and the recordings were deleted after transcription.

PARTICIPANT PROTECTION

Persons with disabilities are among the most vulnerable and marginalized of any population, and so this project was particularly sensitive to how they were interviewed. Great care was taken to avoid disrupting the daily lives of participants (practically, financially and emotionally), to ensure that sensitive issues were brought up properly and contextually, and to avoid creating false expectations.

DESCRIPTION OF THE SAMPLE

Three types of informant were interviewed – in total 94 young persons with disabilities, 104 service providers and 83 family members, neighbours and friends in the 4 study areas. The interviews were divided into 41 group interviews (including some focus group discussions) and 70 individual in-depth interviews.

The following types of disability were represented in the interviews with children and young persons with disabilities and their caregivers/proxies/family members:

- Physical
- Sensory disability/impairment
  - Visual disability/impairment
  - Blind
  - Hearing disability/impairment
  - Deaf
- Developmental disability/impairment
- Psychosocial disability/impairment
- Epilepsy

The interviews with young persons with disabilities included all age ranges – from children in pre-school to young people over 18 years of age. They also included young persons with disabilities with all levels of education and training, including those with tertiary education. Family members, friends and neighbours were also interviewed. Among the direct interviews with young persons with disabilities, approximately 25 percent were under the age of 18, and both genders were represented in almost equal numbers.

The interviews with service providers included informants within the following:

- Non-governmental organizations (NGOs), DPOs and ZAPD
- Educational institutions: primary and secondary
  - Including boarding schools
- Skills training and vocational training: NGOs, DPOs, church organizations, technical colleges (formal and informal)
- Special schools/institutions
- Service provision authorities

Approximately 70 percent of these informants were teachers or school administrators, while 25 percent offered other types of services to persons with disabilities, such as rehabilitation services, provision of assistive devices, economic support (fees), capacity building and community sensitization activities. The rest of the informants were officials in a government provincial office.

DESCRIPTION OF THE SITES

As mentioned above, the study sites included two urban sites (Lusaka Province and Copperbelt Province) and two rural sites (Western Province and Eastern Province). What follows are descriptions of the sites provided by the lead researcher at each site: Dr Ravi Paul in Lusaka Province, Mr Nkenda Sachingongu in Copperbelt Province, Professor Jacob R.S. Malungo in Western Province and Professor Dabie Nabuzoka in Eastern Province.

LUSAKA PROVINCE

Interviews in Lusaka Province were conducted in two districts, Lusaka and Chongwe (Figure 1).
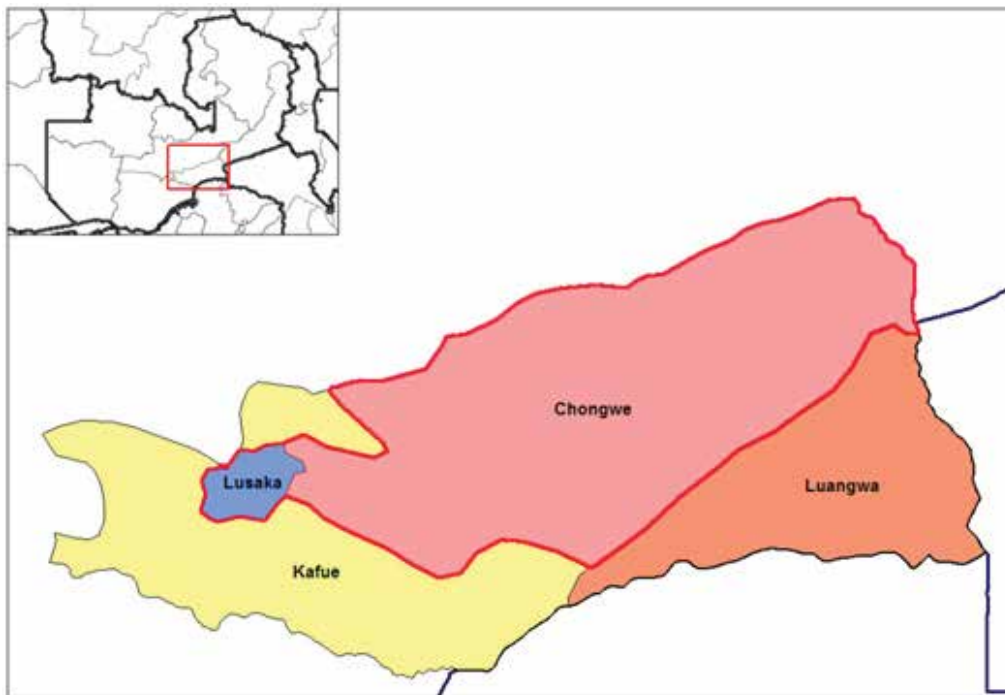
Figure 1: *Lusaka Province*

The mapping of the study site was done in conjunction with the MCDSS. The following institutions were identified as relevant and were directly targeted for interviews or used to identify other informants:

1. The Technical Education, Vocational and Entrepreneurship Training Authority (TEVETA) of the Republic of Zambia is one of two regulatory and standards control statutory institutions under the Ministry of Higher Education. It was created under the TEVET Act 1998

2. Lusaka Vocational Training Centre

3. Cheshire Homes

4. Zambia Agency for Persons with Disabilities (ZAPD)

5. Zambia Institute for the Blind

6. Bauleni School: Bauleni caters for children with physical as well as intellectual disabilities. It runs vocational training in carpentry, baking, sewing and mat making. The staff is trained in handling children with developmental disabilities

7. University Teaching Hospital, Special Needs School: the school has four departments – the Multiple Disability Centre; the Hearing and Speech Centre; Cheshire Homes; and the Vocational Training Centre. The school teaches children from pre-school to Grade 10. Extra skills classes are available for those aged 16 years or above. Those who do not do well academically are given skills like making doormats. The school caters to all types of disability: cerebral palsy, developmental disability, autism and epilepsy, as well as physical and sensory disabilities. The school is located in Ministry of Health grounds, but is supported by the Ministry of Education, which pays the staff. The majority of staff have special-education training. They follow the slogan of the district education boards: 'Every Child Should Learn'

8. Munali Senior Secondary School: this school has children with and without disabilities in the same classroom

9. UTH Clinic 6: this is a psychiatric clinic that runs a weekly clinic for children with disabilities

10. District provincial officer

11. Senior Secondary School Chongwe: this school has children both with and without disabilities

COPPERBELT PROVINCE

The qualitative study in Copperbelt Province was conducted in three districts – Luanshya, Masaiti and Ndola (Figure 2).
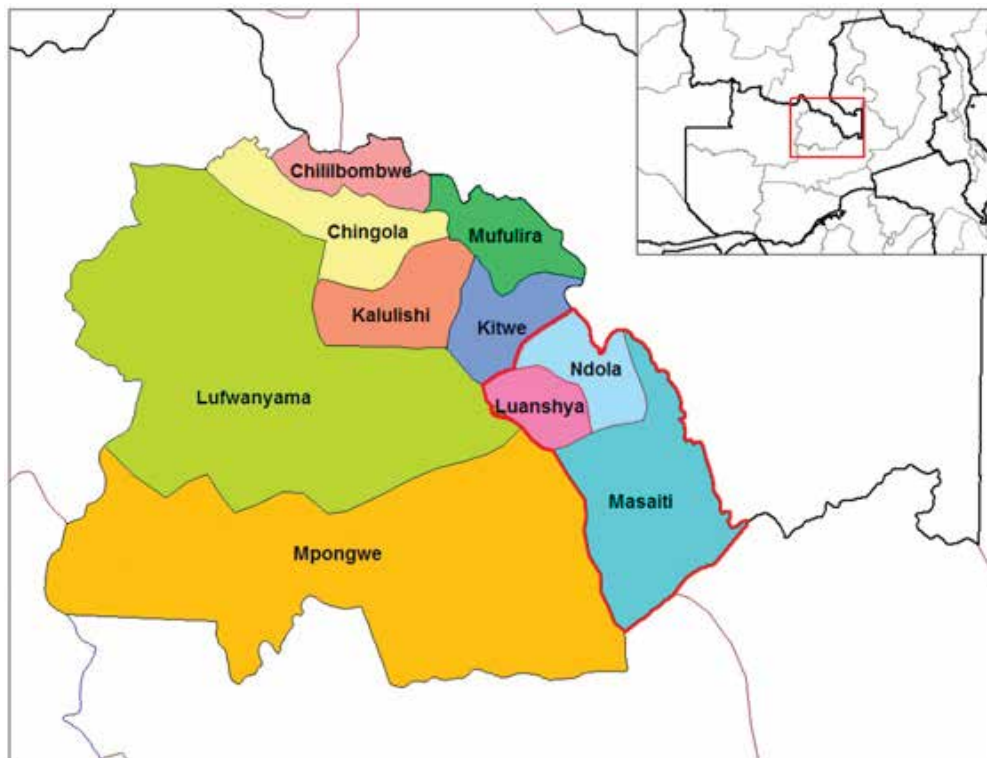
Figure 2: *Copperbelt Province*

The mapping in this province was conducted in conjunction with the Provincial Community Development Office, which also introduced the researcher to the Luanshya District Community Development Office and the National Rehabilitation and Vocational Centre, in order to help identify other key organizations and informants. On their advice, Masaiti District was included as a study site, in order to gain a rural perspective in Copperbelt Province.

Mapping meetings provided some information on the context and educational possibilities for persons with disabilities. Luanshya District was said to be an area with relatively high unemployment and even fewer opportunities for persons with disabilities, as evidenced by the presence of persons with physical disabilities begging outside big shops, and heavy drinking. A number of persons with psychosocial disabilities could also be seen roaming about in town. However, persons with disabilities had access to social welfare programmes through the Department of Social Welfare – such as social cash transfers, which said to mitigate the material and financial challenges they faced. The few persons with disabilities who had relatively regular income were those who ran their own small businesses. In Ndola District, the ZAPD provincial officer reported how various key indicators were having a negative effect on persons with disabilities, including access to education, access to the physical environment (including toilets and hospitals), access to skills training, access to credit, access to health services, access to employment opportunities, and empowerment. Physical distance, poverty, beliefs and attitudes (particularly on the part of parents) were mentioned as some of the key barriers to access and opportunities.

The mapping also provided an overview of some educational facilities and other services available to children and persons with disabilities in Luanshya and Ndola, which are described below.

In Luanshya, two schools were identified: Dagama and Muchinshi Basic School. Dagama provides primary and secondary education (Grades 1–12) for children with physical disabilities, and boarding at the school is possible. However, the school is only available to those children who are able to take care of themselves. Dagama is a fee-paying school and is therefore mainly accessible to families with means. Poor children are able to access it through stipends (bursaries) from the Social Welfare Department. Muchinshi Basic School is a mainstream school that has one class for children with disabilities. The district was said to have only one skills training institution – the Luanshya Skills Training Centre, which does not cater specifically to persons with disabilities.

Luanshya also has several NGOs offering different educational services to children with disabilities – such as Zambian Bridge to Inclusive Living, which offers sign language, as well as Serve Zambia, the Community Integrated Health Education Programme (COIHEP) and the Community Health Restoration Programme (CHReP), which offer some educational (but mostly financial) support to help persons with disabilities access education. There are also several community-based organizations offering other services to the community at large (like psychosocial counselling, home-based care and other community services), and these were also being accessed by persons with disabilities.

In Ndola District, ZAPD is responsible for providing primary and secondary education support, and there are many institutions and NGOs providing services to persons with disabilities, including the National Vocational Rehabilitation Centre (NVRC), Cheshire Homes and many faith-based institutions like Holy Family, St Anthony's School and others.

In Masaiti District, the study team interviewed children with disabilities and their parents, guardians and teachers. It visited Chamunda Primary School (inclusive educational school), Kafulafuta Boarding School (inclusive educational school) and the Blind Centre.

The NVRC was established to provide skills to persons with disabilities, from mild to severe, in four disability areas: hearing, visual, intellectual and physical/neurological. Persons with severe disabilities are also taught daily living skills. About 10 percent of each class (of about 15 students) are non-disabled. Certain vocational courses were designed to target different disabilities. For example, visually impaired students have access to information and communication technology-related courses, such as switchboard operator; while the hearing impaired are taught design, cutting and tailoring, as well as machining. Persons with physical disabilities are allowed to follow all courses, but mostly enrol on electronics and systems repair courses.

However, there were some systemic barriers affecting students' success at this centre. For example, a weak secondary academic background often affects the performance of students with disabilities at the centre. In addition, it does not have the necessary resources to perform assessments of students' disabilities and thus to adapt the courses accordingly. Furthermore, examination questions can be inaccessible and not adapted to the special needs of students with disabilities.

The majority of those who had completed their courses were employed by the government, thanks to current affirmative-action policies. A few were employed by retail stores, motivated by tax incentives for businesses that take on persons with disabilities.

WESTERN PROVINCE

Data collection in Western Province took place in two districts, Kaoma and Mongu (Figure 3).

Figure 3: *Western Province*

This province has district schools with special units for children with special learning needs and an inclusive vocational school, Kaoma Trades. Persons with disabilities at the community level are referred to the District Social Welfare Office or ZAPD for social assistance. There are also DPOs, mostly at the provincial level.

The provincial capital, Mongu, has some NGOs that deal with persons with disabilities. These include the Holy Cross Skills Training Centre and the Western Province Association for Disabled People, an ad hoc organization that attempts to address the business and wellbeing of persons with disability. These, however, are not well established across the province.

EASTERN PROVINCE

Data collection in Eastern Province took place in two districts, Chipata and Mambwe (Figure 4).
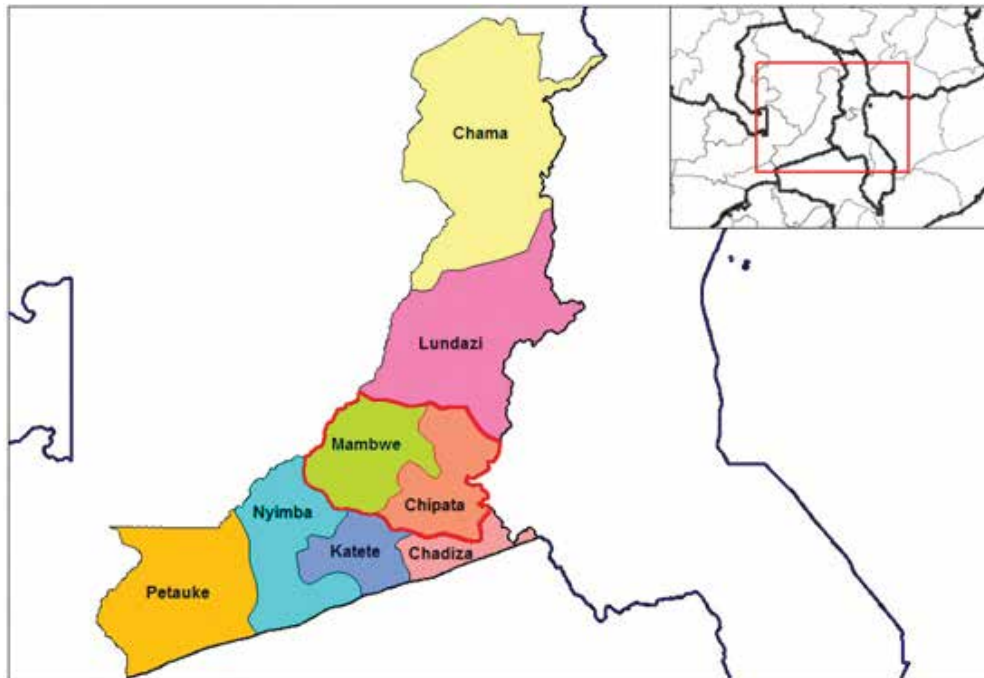
Figure 4: *Eastern Province*

In Eastern Province, during mapping of the study site, the project team approached a number of provincial and Chipata district officers and offices for information regarding services for persons with disabilities, including the following: the provincial permanent secretary, the district commissioner, ZAPD and the MCDSS. The following were also visited: special schools, a trades training institute and a community-based rehabilitation (CBR) association working in the rural outskirts of Chipata and neighbouring Mambwe District.

Three districts, Katete, Chipata and Mambwe, were initially identified as possible sites for the study in Eastern Province because they varied in terms of availability of services and accessibility to persons with disability. Ultimately, Chipata and Mambwe districts were chosen as study sites, as shown in Figure 4, due to the established lines of contact that already existed with the CBR association in charge of both districts. Three of the five operational areas of the association were chosen for the study, including Kamlaza and Chikando in Chipata District, and Kasamanda in Mambwe District. The CBR association provided a direct line of communication with community leaders and key informants in the three operational zones.

KAMLAZA

Kamlaza is about 45 km from Chipata central along the Great East Road, on the western side of the district heading towards Katete. It has a total of 64 villages, divided up into five operational zones for the Chipata CBR association: Chiswa, Katawo, Chingazi, Chivungula and Makungwa. The zones have an average of 12 villages each.

In addition to having a CBR area office, Kamlaza has some health centres, government agricultural officers for the area, a vet and community development officers. There are 10 primary schools, mostly offering basic education up to Grade 9 and a secondary school. In all, there are three health centres in the area, two in close proximity (Kamlaza and Makungwa) and another (Chiswa) about 8 km from the others. World Vision seemed to be the only NGO operational in the area at the time.

CHIKANDO

Chikando is about 46 km from Chipata central in the south-west of the district. It has four zones of operation for the Chipata CBR association. In addition to the area office of the Chipata CBR association, there is one health centre (Chikando Rural Health Centre), three basic schools and a comprehensive school (up to Grade 12). Other services in the area include agricultural extension officers and those operated by the Lutheran World Federation.

KASAMANDA

Kasamanda is in Mambwe District and is 110 km from Chipata central. It is halfway between the district administrative centres of Katete and Mambwe districts. The catchment area of Kasamanda has four primary schools, one rural health centre and a community health centre about 13 km from Kasamanda. Other services in the area include agricultural officers, a veterinary officer and a community development officer.

CBR activities in the area include 'empowering' and training persons with disabilities (referred to as 'clients') in such activities as carpentry and tailoring, as well as physiotherapy exercises run by CBR rehabilitators. Due to limited availability of funds, at the time of the visit activities were mostly focused on exercises for individuals with physical disabilities.

Overall, the following officers and institutions were identified as relevant and were directly targeted for interviews as service providers or used to identify other informants:

1. Government provincial and Chipata district administrative officers (deputy permanent secretary and district commissioner); provincial and Chipata district social welfare officers

2. Provincial coordinator for ZAPD and district officers

3. Chipata CBR association, including the director, project officer and zone coordinators

4. Programme officer for Eastern Centre for Young People with Disabilities, a youth disability group

5. Head and staff of Magwero School for the Blind and some members of staff, and also the head of Magwero School for the Hearing Impaired and some members of staff

6. Principal and staff of Chipata Trades Training Institute

7. Head of Chipata Cheshire Home for children with disabilities and one graduate of the home

8. Deputy head and the special needs coordinator of Hillside School, a mainstream school with a unit for children with disabilities

9. Rural health centre staff from the CBR operational zones

10. Chipata District Hospital, physiotherapy department

SUMMARY OF RESULTS

This section provides a summary of the data analysis from each of the four sites, presented thematically.

GENERAL ATTITUDES TO DISABILITY

KNOWLEDGE OF DISABILITY

All informants had some kind of understanding about what it means to have disabilities. Some mentioned only physical disabilities and loss of bodily function, but most mentioned physical, sensory and developmental disabilities. However, the informants had quite a varied understanding of the causes of disabilities. Though most suggested genetic causes, infectious diseases, accidents, neglect, delay in treatment, labour complications and risk-taking behaviour on the part of the mother, some suggested *kanono* (demonic illness), neglect of cultural practices, witchcraft and the will of God as reasons for disability.

PARTICIPATION

Informants stated that the participation of persons with disabilities in society is dependent on the nature of their disability. They also mentioned that participation could depend on whether parents see the potential of their child with disability to develop, acknowledge and be open about their disability. As one informant put it:

> *'Some people ... like a child is there ... wants to play with others ... "no ... no ... no ... no ...! Come back, here, sit here." If it is work, the wife can get annoyed that you are troubling this child, "don't you see that he/she is disabled, you are a very unfair and exploitative person". If it is the wife who wants to engage the disabled child in activities, the husband may interject and stop her ... "do not do that … eee … don't you have eyes to see that this child is disabled?"'*

However, lack of assistive devices, tools, interpreters and assistants were also mentioned as hindering participation and as added barriers to inclusion.

STIGMA AND DISCRIMINATION

While some informants with disabilities described being loved and included in the family, others experienced stigma from both within their family and from society. Some informants described how in some families with limited resources, parents strive to pay school fees for their children without disabilities, and yet are not willing to spend any resources to send their child with disability to school. Some families are unable to see the potential that lies within the family member with disability:

> *'I have relatives who go round preaching to say: "what will this thing do for us?"'*

It can sometimes be very difficult for a child with disability to accept that those same family members whom they hold responsible for their disabilities are the ones who treat them badly. As one informant with disability said:

'... she was the one [who] caused me this, because she never took [me] to the hospital even when I was [in] pain and eventually I lost my sight. Sometimes our parents treat us so badly they only love those that are not disabled but they brought us on earth, I fail to understand them.'

Sometimes members of the community can see beyond the disability of the child, because they have interacted with the child and have recognized their potential; but often families with children with disabilities find that they need to sensitize the community they live in because of a general lack of knowledge in the community. Some community members are afraid that their children will 'catch' a disability from children with disabilities. Others give well-meaning but bad advice, exploit the work capacity of children with disabilities, or believe that disability is a punishment from God or that children with disabilities, their schools, their teachers and their parents are in some way inferior to children without disabilities, their schools, their teachers and parents. This can be exemplified by a quote from a young person with disability:

'Because we are twins and my twin brother is just okay they mock me and say that [I] am disabled and that I was such a fool to come out like this when my brother was clever to come out able-bodied. But my brother loves me so much.'

The inability of society to see beyond the person's disability leads to much stigmatization from it. Informants described how persons with disabilities are discouraged from participating in activities like sports, and how parents may be reluctant to take children with disabilities to church because of their disability. Others mentioned how society does not seem to perceive persons with disabilities as sexual beings and therefore cannot envisage them being capable of marriage or of having children. Yet others described how the rental market also excludes persons with disabilities, because property owners fail to see beyond their disability. Unfortunately, informants feel that the media reinforce these negative attitudes. This differentiated treatment continues at home and can lead to mocking, laughing and abusive treatment from siblings – and indirectly from the parents who allow this to happen. One informant with disability expressed the following sentiment:

'I am their maid because of my disability; it's really terrible I tell you … they have turned me into a horse.'

ACCESS TO MEDICAL CARE

Though children with disabilities and their parents are more likely to experience stigma when encountering health professionals, it seems that health facilities that are often in contact with children with disabilities tend to provide better services. Parents who have experienced stigma from health personnel distrust the health services and are less willing to take their children to health care facilities. The lack of physical access to medical facilities and the strained communication with health professionals are also barriers to accessing medical care. Informants described how families tend to self-medicate or use traditional medicine when sick, and only resort to health facilities when they are very sick.

SPECIAL ASSISTANCE NEEDS

Participants reflected the feeling that persons with disabilities who are in need of assistance in all aspects of life – like eating, washing themselves and using the toilet – are especially vulnerable. Needing to rely on others is very challenging for both the family and the individual. There is a conflict between the family's needs (like the need to earn a living) and the everyday needs of persons with severe disabilities.

DISABILITY AND POLICY

Participants explained how the Persons with Disabilities Act 2012 guarantees the rights of persons with disabilities in Zambia. However, they remarked that parts of it fall far short of being implemented. They also commented that many parents are unaware that children with disabilities have the right to an inclusive education, to attend mainstream schools, go to trade schools or acquire life skills.

DISABILITY AND EDUCATION SERVICES

GENERAL ACCESS TO SCHOOLS

Local mainstream schools are generally not accessible to children with disabilities. Informants described several barriers that influence accessibility: lack of physical accessibility, lack of specialized teachers, lack of educational resources and an adapted curriculum and lack of assistants. Several informants also pointed out that there are few special schools and vocational schools for children with disabilities. Special schools tend to be located in urban areas, to have a high student–teacher ratio, to provide few enrolment places and boarding opportunities and to lack assistive devices.

POVERTY AND EDUCATION

Poverty is an additional barrier to education for children with disabilities. The inability of parents to afford the transport to and from school, together with the long distances to local schools, the inability of schools to provide transport and the lack of assistive technology all conspire to deter students with disabilities from attending school. One teacher stated:

> *'So when you approach parents about their children starting school, they say "I will not manage" because the bus cannot go round picking minus fuel, so every month they do make a contribution of K50… so K50 is very difficult to find by some parents.'*

Another teacher describes this interaction in the following manner:

> *'Already we have one who is just being carried on the back to come here, so we asked them to maybe find a wheelchair for that child because how will that child be sitting in class, but since the parents left up to now, they have not come back. It is not easy for them to come here due to distances.'*

In addition, parents cannot afford to buy the obligatory school uniform, pay a food allowance for those who board, or buy assistive devices. It is particularly difficult for single-parent homes headed by females to afford the education costs of their child with disability.

Lack of stipends – or discriminatory practices surrounding the availability of bursaries for children with disabilities in schools, boarding schools, trade schools and higher education – makes it even less likely that children with disabilities can attend any kind of schooling. As the parent of a child with disability put it:

'My child has been accepted for bricklaying and plastering. I have the papers here. I went to social welfare to apply for a bursary but it has taken two years but has not been given that bursary yet the normal children apply once and they are given.'

PHYSICAL INACCESSIBILITY

Inaccessible building structures also add to the many barriers that children with disabilities encounter. Stairs, lack of ramps, distances between facilities such as dormitories and classrooms, uncleared bushes, lack of lighting – all contribute to make the physical environment inaccessible to children with disabilities. Lack of accessible toilets is another major deterrent: since wheelchairs usually do not fit in the space allowed for the toilet, children with physical disabilities find themselves crawling on dirty floors in order to use the toilets. One child with disability said the following:

'Whereby you are in a serious condition … and you try to crawl on the ground but on the floor of the toilets there is a lot of liquids and you don't have protective equipment, so you just suffer inwardly.'

Even if a pupil has an assistive device and can get to school independently, the school routes are often not safe, due to lack of pavements, heavy traffic and wide, dangerous roads to cross.

STIGMA AND DISCRIMINATION IN THE EDUCATIONAL SYSTEM

Community mistrust of persons with disabilities is also present in schools and the school system. Informants described how local communities are suspicious of the qualifications of teachers who teach children with disabilities and how communities can dissuade parents from enrolling their children with disabilities in school. They also described how children in schools not only fear children with disabilities, but also fear the social stigma attached to playing or associating with such children. In addition, children with disabilities, who often start school much later than their peers, can feel socially isolated and uncomfortable in classrooms where there is a large age gap between them and their classmates.

Local schools themselves may discriminate: some do not allow children with disabilities who would do well at a mainstream school to enrol, because teachers and school administrators do not think children with disabilities can be taught. In schools where children with disabilities are allowed to enrol, some teachers hinder their learning either by giving them lower priority in the allocation of limited school resources or by denying them access to those resources (like textbooks). Some teachers with no special-education training are impatient with children with disabilities and may blame them for their inability to learn – even though the fault lies with the learning environment. This type of attitude also seems to be present in teaching communities exposed to children with disabilities, as expressed by a mother who was shunned by a school administrator when she tried to enrol her child with learning disabilities in a school for children with physical disabilities:

'she said this child is a fool [chipuba] and this child who is a fool, who is not normal is the one you want to bring to [this school]? Don't you know that [this school] is for the disabled, for you to bring this child who is mad [uwafulungana] at this school?'

SYSTEMIC BARRIERS

Generally speaking, learning environments are not adapted to include children with disabilities. Therefore, their academic performance and retention levels are poor. Informants describe how inclusive education is being introduced without guidelines, follow-up, support or training for mainstream teachers or school administrators. Therefore, learning is not being adapted to ensure success among children with disabilities.

Lack of resources in schools is a general problem, but it disproportionately affects students with disabilities in all types of schools. Informants explain that the government-allocated amount per student is not enough to cover the extra costs needed for special education. As one teacher said:

> *'By then we had 6 children with disabilities so it was difficult for the K282 to be used on all the children, hence we just buy some books for them that is all. It was really little amount of money.'*

There is a general lack of books, laboratories, libraries and computers in most schools. In addition, the student–teacher ratio is high. Even in special-education schools, there is a lack of adaptive learning materials. These schools lack computers for persons with visual impairments, textbooks in braille, books in braille and braille paper. Equipment for the hearing impaired is also scarce. Special schools are often dependent on support from NGOs for these types of resources.

Teachers find that students with disabilities are enrolled without any increase in spending or additional training for teachers. Special-education teachers often work with either old, unrevised curricula or else curricula for mainstream students and mainstream books, which they need to adapt.

Another problem voiced by teachers and learning institutions is that children with disabilities do not undergo educational assessment before they begin school. One informant also stated that, although children with disabilities are required to be clinically assessed before they start school, the quality of the assessments varies greatly, because they are based on a clinician's subjective opinion and experience rather than on a formal test. Attached to the assessment is the parent's own written assessment (and a copy of any prescription that the child might need). This can result in children with varying degrees of disability, knowledge and ability being randomly assigned to a class, instead of being optimally assigned according to intellectual potential, availability of assistive devices, flexibility of the teacher and environmental adaptation.

There is also no coordinated effort or systems in place to ensure life-long learning for children with disabilities. They might be able to attain a certain level of education, but there are no plans or policies in place to ensure further success. For example, not all institutions can cater for children with disabilities sitting written exams, and so – despite attaining a certain level of education – children with disabilities may not be able to take the exams and qualify for further education or employment. This leaves parents feeling as though their children with disabilities are just wasting their time going to school, since they simply return to the same life they led before they started school. Those who can take the tests find themselves sitting exams that are not adapted to their disability. For example, children with hearing impairments are expected to sit Standard English written exams, even though they have only ever used sign language in school. This results in high rates of failure among children with hearing impairments. In addition, many blind students complain that their answer scripts go missing – probably because the examiners do not know braille and just throw these papers away. Some students have failed year after year. Furthermore, children with disabilities are expected to complete the designated curriculum and take standardized exams within the same time allotted to children without disabilities, irrespective of their disability.

In addition, some informants described a system that does not reward special-education teachers. In some schools, special-education teachers were left off the official teacher roster, because special education was not included in the school plans. This means that those teachers are not considered for promotion unless they are also involved with mainstream teaching. The following was experienced by one special-education teacher:

> *'... why do you teach such children? Leave them so that I give you a school [promote you]. I answered that just promote me where I am and he refused and that's how I lost my promotion.'*

Special-education teachers also find themselves defending their qualifications and their decision to teach special-education children:

> *'Sometimes they even ask you saying why did you choose to teach imingulu of all the things; why did you choose to teach these children.'*

They also feel that they are evaluated unfairly – that is, according to the results achieved at Grade 12, rather than according to the individual progress of a child:

> *'They don't really assess them, assessment is not really done ... we are supposed to have pupils at a certain level, but you find that some pupils cannot even read and these are the pupils in Grade 10 and you expect them to learn via reading so how are they going to learn? ... as a teacher I feel it is unfair because when the results are produced at Grade 12 each teacher is evaluated, they look at [the] results that you produced. Then I feel it is not fair to be evaluated over pupils who did not even know how to read.'*

Finally, informants also reported that department heads in special-education units were not being adequately remunerated, unlike those in mainstream education.

QUALITY AND RELEVANCE OF EDUCATION

The barriers mentioned above are having a significant impact on the quality of education that children with disabilities receive. Despite these hindrances, there are children with disabilities who do well in mainstream schools; however, their opportunities to attend secondary and higher education are often cut short due to the additional systemic barriers described above, like lack of physical accessibility, lack of exam adaptation, lack of stipends and lack of individual education plans. This makes them and society around them question the relevance of their education. As one young person with disability said:

> *'This problem of the results missing, he [her father] says it is not the results, he feels that I just did not pass, and he says it was time wasted being in school for all those years.'*

The lack of opportunities for children with disabilities in mainstream education also makes them feel that a more practical education would have been better. This was exemplified by one young person with disability:

'I have not benefited much from my schooling. The practical skills that I use now to make doormats were supposed to be taught to me in Home Economics but this never happened and [I] had to learn this after I had left school.'

One participant who had taken advantage of a policy change that allowed young persons with disability into vocational training, put it very simply:

'We learned gardening, which I have continued doing.'

At the same time, there are children currently in mainstream schools because of lack of assessment, who would do better in trade schools, learning practical skills. The majority of participants mentioned difficulties in enrolling in trade schools and the economic difficulties of attending such schools and paying for school certificates.

TEACHER EDUCATION

Providing quality and relevant education for children with disabilities is also dependent on providing continuing education for teachers, together with additional resources and support.

The teachers of children with disabilities in both mainstream and special-education schools in Zambia maintained that there was a need for continuing education or professional development. Though special-education schools do have some teachers with specialized training from colleges like the Zambia Institute of Special Education, many teachers are generalists without special-education certification. These generalist teachers need to know how to adapt learning to include children with disabilities. For example, teachers of hearing-impaired children need to learn how to teach children to map between sign language and the printed language, particularly since learning resources (such as textbooks) are not adapted to children with disabilities. If these teachers learn sign language, it will enable two-way communication with deaf children and facilitate learning even for those who can lip-read.

SUPPORT

Teachers also need support from the school and from parents, if they are to provide quality education. It is easier to obtain support from families who value education and have the means to send their children with disability to school. However, if parents do not know that their children can attend a mainstream school, a special school or a trade school, and are not aware of their potential, then they will not prioritize their education, and their children's school attendance may be compromised. There is also a lack of awareness on the part of children with disabilities and their parents of the advantages of participating in Parent–Teacher Association (PTA) meetings.

Leaving aside parental support, teachers stated that they often felt overwhelmed, because teaching children with disabilities can be very labour intensive, and the student–teacher ratio is very high. As one teacher put it:

'The situation is we have 21 pupils with different levels of understanding ... and each child will respond differently. To tell you the truth, [I] am failing. What I [do is] simply to group them into 5 groups but when it comes to writing individualized educational activities, [I] am failing to do it, I can't manage. The workload is quite heavy.'

Informants therefore commented on the need for extra personnel in classrooms, to enable teachers to provide individualized learning. Teachers are obliged to get most students through the school's curriculum; but with the current high student–teacher ratio, they do not have time to give extra support to those who need it most. That is something that additional support personnel could provide. For example, teaching children with learning disabilities can be very repetitive, and progress can be very slow. Informants indicated that classroom assistants could be used to provide remedial learning for those children or others who are falling behind; or else they could read out the required material for the benefit of blind children who lack textbooks and other curriculum material in braille. At the same time, classroom assistants could provide caregiver assistance for children with disabilities who need special care or other support.

TRANSITION TO EMPLOYMENT AND INCOME-GENERATING ACTIVITIES

Informants described how persons with disabilities face many barriers in their search for formal employment. First, few persons with disabilities are able to attain a high level or specialized education due to system-wide obstacles, as well as cultural barriers. Second, even if they are well qualified, they will not be considered for a job, because employers cannot see beyond the disability. Third, when seeking employment, not only are persons with disabilities competing with persons without disabilities, but they are also far outnumbered by those non-disabled candidates; it is therefore easy for employers to avoid selecting them. Finally, very few buildings are accessible to persons with disabilities.

Informants called for government involvement in assisting persons with disabilities to find jobs, in providing career opportunities and in being in the forefront of employing persons with disabilities:

> *'You can train them but if you don't help them find the job, they will be doomed, it's the same as not taking them there.'*

There is also a need for loans or capital to enable persons with disabilities to start their own businesses. Persons with disabilities are often unable to get loans, because financial institutions do not think the loans will be repaid. Though young persons with disabilities might be able to get a grant from the ZAPD to start a business, the grants are usually inadequate. One young person with disability had experience of such grants:

> *'The grants from the Zambia Agency for Persons with Disability for the disabled youths are K400, but the Youth Development Fund disburses as much as K49,000. This makes the disabled youths unable to venture into meaningful income-generating activities. So we ask ourselves, does it mean the only business we can do with our disabilities is to sell sweets?'*

In addition, persons with disabilities experience added barriers, like the physical inaccessibility of business registration offices or the need to fill in inaccessible and difficult-to-understand forms, in order to apply for the various government-sponsored programmes targeting persons with disabilities. For example, the forms are generally not available in braille and are thus not accessible to blind people.

DISCUSSION AND RECOMMENDATIONS

This qualitative study has uncovered several barriers affecting inclusive and quality life-long learning and skills development for persons with disabilities in Zambia. Though the Living Conditions Survey (Eide and Loeb, 2006) and the survey component of the Zambian National Disability Survey both point to gaps in educational access for children with disabilities, data are lacking on the how and the why – both of which are necessary to make recommendations and ultimately produce tangible changes. The barriers mentioned in the results above have been summarized into broad categories for discussion.

GENERAL KNOWLEDGE OF DISABILITY

The results showed that people in the communities had a good understanding of what it means to have disabilities, and most informants suggested causes that are widely accepted. However, there were informants who suggested other causes – such as demonic illness. This lack of knowledge may give rise to stigma, fear and social isolation from the community. As certain informants indicated, some parents in communities were afraid of children with disabilities, fearing that somehow they would infect their own children without disabilities. Such attitudes, based on unfounded fears, can lead to self-stigmatization among children with disabilities; they may develop increased mistrust of others and choose to isolate themselves further, rather than be exposed to societal stigma. This is what some informants had chosen to do.

Lack of knowledge also affected people's perspective on the participation of persons with disabilities in society. When describing participation, several informants took a medical perspective of disability, blaming limited participation on a person's disability, rather than on a failure of the environment to adjust to and accommodate this disability. This crucial distinction directly affects the way in which society handles the inclusion of persons with disabilities. Is inclusion something that society can achieve by changing the environment surrounding persons with disabilities, or does the disability of the person make their inclusion unattainable? When the limitation no longer lies within the child, it is easier to see the child's potential and to adapt the environment to harvest it. Some informants mentioned that participation could depend on whether the parents are able to see the potential in their child with disability, to acknowledge the disability and be open about it. The activity-limitation perspective also makes it more difficult to sustain prejudice or to question the worth of persons with disabilities. In the study, many teachers reported experience of how the community at large – and even within the educational system – questioned their motivation and the value of teaching children with disabilities.

The key to changing this perspective and to countering misinformation on the causes of disability is to provide society, communities and teachers with education and correct information. Since there is a move towards inclusive education in Zambia, it is important for a teacher's education to include both updated knowledge and an activity-limitations perspective on disability. DPOs, working together with the media or local projects, could also try to be more proactive in reaching communities with information. Schools are also good arenas for changing future community perspectives.

An activity-limitation perspective should permeate all information being given to society.

KNOWLEDGE OF POLICIES

Zambia has many laws and policies that include persons with disabilities, but their implementation is limited. The Persons with Disabilities Act 2012 ensures full and equal human rights and freedoms to persons with disabilities. However, there is a gap between this act and its implementation at the local level. It is crucial for persons with disabilities to have better knowledge of this act, so that they can demand the rights included in it. The act ensures access to education and addresses many of the systemic barriers that many informants described in the study: inaccessible buildings, non-adapted education, inaccessible transport and lack of monetary support. Disseminating knowledge of this act in society could also serve to create more jobs for persons with disabilities, since the act enshrines tax incentives for businesses interested in hiring persons with disabilities. Lack of knowledge of this act among persons with disabilities and their families is perhaps the greatest hindrance in securing the rights of persons with disabilities in Zambia. Without knowledge, they are not able to demand the rights outlined in the act.

Wide dissemination of the Persons with Disabilities Act 2012 could bring about changes in society and enable implementation of the act in Zambia.

BETTER COOPERATION BETWEEN MINISTRIES

The results pointed to many systemic barriers that need to be removed, but that involve several ministries. As mentioned before, the MCDSS has overall responsibility for the welfare of children with disabilities and, through the ZAPD, for implementing the Persons with Disabilities Act 2012; it is therefore in an excellent position to encourage tighter cooperation from different ministries, in order to enable implementation of the act. Working together with the Ministry of Health, it could enable provision of a standardized medical assessment of children with disabilities before the start of each school year; this would include any necessary prescriptions, as well as the provision of essential assistive devices. As mentioned by some informants, there is a great need for the organized (preferably governmental) provision of assistive devices. Currently assistive devices are provided by a number of NGOs – and then only sporadically. Children grow, and so there is a need for annual assessment of both their physical health and the assistive devices.

In the same manner, the MCDSS could work more closely with the Ministry of Education to ensure the educational assessment of children before they start school. Together, these assessments would help teachers to adapt their classrooms and the curriculum appropriately to the needs of the children involved. The lack of such assessments was one of the many barriers uncovered by the study. Currently, children are assigned to classrooms not on the basis of their potential, but in a rather random fashion. Such an approach does not ensure either inclusion or learning. The official separation of responsibilities among the different ministries should not add to the numerous barriers already in the way of children with disabilities as they try to get an education. Assessments could include all aspects of the environment surrounding the child, the physical environment, assistive devices, adapted curricula, transport, medication and any other aspect, including financial obstacles that prevent a child from accessing education. Addressing all these possible barriers to education for children with disabilities would involve many ministries.

Closer and improved cooperation between ministries could enable inclusive learning based on potential.

MORE RESOURCES FOR EDUCATION

The lack of resources in education is a recurring theme. There needs to be political will to invest heavily in education, including the education of children with disabilities, in order to achieve inclusive education. First, the infrastructure needs to follow the principles of universal design, i.e. the built environment should be accessible to all, regardless of physical capabilities or age. Therefore, no child should have to crawl across a dirty toilet floor or require assistance to access a classroom. Second, the curricula should be revised frequently and should be inclusive in their design. Teachers spend too much time updating outdated curricula and adapting them to the individual child. Third, a general investment in textbooks is necessary, and children with visual and hearing impairments should be provided with accessible textbooks and teaching formats. It should be unnecessary for teachers to have to spend time reading textbooks out loud to blind students. Fourth, schools should have more teaching assistants, as well as other assistive personnel, in order to free up teacher capacity and enable individualized learning. This would also promote a better student–teacher ratio (currently a barrier to the quality of teaching). As suggested by some informants, assistants could be used for remedial learning, while other assistive personnel could provide other types of care to students with disabilities. Improving classrooms for children with disabilities will also improve classrooms for other children.

There needs to be a broad, general investment in education.

INCREASED TRAINING OF TEACHERS

Many teachers in the study, especially those working in special schools or with children with special needs, voiced the need for continuing education. Most teachers in special schools were generalists and felt the need to learn sign language or braille in order to facilitate their teaching. However, teachers in mainstream schools are also in need of more education. With the move towards inclusive education, some informants were critical that these inclusive education plans were being implemented without guidelines, follow-up, support or training for generalist teachers or school administrators. It is necessary for all generalist teachers to learn about disabilities, about how to adapt teaching methods to disabilities, and about how to improve classrooms for children with disabilities. Generalist teachers could work together with specialist teachers to provide quality and relevant education for students with disabilities.

In order to ensure the successful implementation of inclusive education, there is a need for extensive professional development of teachers and school administrators.

There is also a need to address both the heavy demands of dealing with children with multiple disabilities and teacher overload.

EMPOWERMENT OF CHILDREN WITH DISABILITIES AND THEIR PARENTS

Access to learning also requires awareness on the part of students and their parents. If parents lack knowledge about the right to education, then clearly they will not believe that their child with disability can go to a mainstream school, attend a trade school or acquire life skills. This type of awareness is a question of equity. As mentioned by some informants, those parents who had themselves gone to school not only valued education, but also had the means to enrol their children with disabilities in school. In order to increase the enrolment of children with disabilities, it is necessary for children with disabilities and their parents to feel empowered.

One informant noted that the parents of children with disabilities did not attend Parent–Teacher Association meetings. Since PTA meetings are arenas where parents can influence school policies, it is important to encourage parents to attend. Again, this is a case of empowering parents to participate in school politics.

DPOs could have a role in empowering children with disabilities and their parents. They could work to raise awareness of the rights of persons with disabilities in the field of education, increase enrolment in schools and encourage participation in school politics. As suggested by the results, a network of parents and guardians could be established, where information on disabilities and services would be exchanged. Finally, DPOs should monitor and ensure that the Persons with Disabilities Act is implemented by all stakeholders.

DPOs should work to empower children with disabilities and their parents.

AFFIRMATIVE ACTION

Affirmative action is an important policy tool in terms of securing the employment of persons with disabilities. There was general frustration that persons with disabilities are educated and given skills, but then not given the opportunity to use them. Some persons with disabilities have been helped by affirmative-action policies, but not to the extent desired. Since many persons with disabilities employ themselves, there is a need for larger loans to be made available to help them establish their businesses. There is a need to make more widespread and effective use of affirmative action for persons with disabilities.

REFERENCES

- Eide, A.H. and M. Loeb, *Living Conditions among People with Activity Limitations in Zambia: A National Representative Study*, SINTEF Health Research, Oslo, 2006.

- Joffe, H. and L. Yardley, 'Content and thematic analysis', in *Research methods for clinical and health psychology*, 1st ed., edited by D.F. Marks and L. Yardley, SAGE, London, 2004.

- Leavy, P., *The Oxford Handbook of Qualitative Research*, Oxford University Press, Oxford, 2014.

- Miles, S., 'Exploring understandings of inclusion in schools in Zambia and Tanzania using reflective writing and photography', *International Journal of Inclusive Education*, vol. 15, no. 10, 2011, pp. 1087–1102.

- Ministry of Education, *Educating our Future: National policy on education*, Republic of Zambia, Lusaka, 1996.

- Republic of Zambia, *The Constitution of Zambia Act*, Lusaka, 1996a.

- Republic of Zambia, *Technical Education, Vocational and Entrepreneurship Training (TEVET) Policy*, Lusaka, 1996b.

- Republic of Zambia, *The Education Act*, Lusaka, 2011.

- Republic of Zambia, *The Persons with Disabilities Act*, Lusaka, 2012.

- Silverman, D., *Doing Qualitative Research* (4th ed.), SAGE, London, 2013.

- United Nations, 'Sustainable Development Goals', 2015, <https://sustainabledevelopment. un.org/?menu=1300>, accessed 4 April 2018.

- Willig, C. and W. Stainton-Rogers (eds), *The SAGE Handbook of Qualitative Research in Psychology*, SAGE Publications, London, 2008.

APPENDIX 1:

TOOLS FOR DATA COLLECTION

- Community mapping

- Individual interview guides for:
  - Service/ activity providers
  - Children and young people with disabilities
  - Guardians/ family members of children and young people with disabilities

- Focus group discussion guides for:
  - Service/ activity providers
  - Children and young people with disabilities
  - Guardians/ family members of children and young people with disabilities

GUIDE FOR COMMUNITY MAPPING

The initial community mapping should be done together with one or more relevant local authorities in the study site, i.e. village headman, group village headman or traditional authority. The mapping will then continue throughout the fieldwork in the study site to ensure that the mapping draws up a comprehensive and authentic picture of the community.

INTRODUCTION:

- Introduce yourself and give the formal information about the study (as outlined in participant information sheet)

- Informed consent (make sure informant understands his/ her *rights* and *responsibilities*, before he/ she consents)

The mapping is a practical exercise that we do together with the relevant informants, where we start with a blank piece of paper, draw important landmarks, such as rivers, roads, bridges, lakes, trading centres, etc. We then go on to place crucial services and activities of interest on the map, indicating approximate distances (metres/ kilometres/ walking distance in time) between these. The following activities are particularly relevant (not an exhaustive list):

- Formal education: Pre, primary, secondary and tertiary education
- Informal learning at home/ in the community (Families/ Traditional societies/ etc.)
- Child and infant care facilities and structures
- Vocational training/ skills centres
- Special education institutions
- Boarding schools
- Churches (Sunday school)
- Hospitals/ clinics
- Major places of employment

While we do the mapping some *key questions and topics* are relevant to raise and explore together with local authorities. These informants often possess general information on the situation for people with disabilities in the area. Examples of questions that are relevant to ask:

- What is the situation and life like for people with disabilities in the area?
  - How is this compared to the situation for people without disabilities?
- What is the situation related to education and learning in the area (in general and for people with disabilities specifically)?
- What is the situation related to employment and income-generation in the area (in general and for people with disabilities specifically)?
- For those who do not have access to education/ employment; what are the consequences?
- What is done/ can be done to improve access to these services/ activities?

CLOSING THE INTERVIEW:

- Ask if informant has anything else s/he would like to share, or any questions.
- Acknowledge the informant's cooperation, time spent and information shared.

INTERVIEW GUIDE FOR SERVICE/ ACTIVITY PROVIDERS

This interview guide comprises topics that will be relevant in a qualitative study on factors relevant for inclusion and exclusion of children and young people with disabilities in activities of life-long learning and skills development. In an interview situation the guide as presented here is not always used to its full extent. Depending on the circumstances, various sections will be more or less relevant for the interview. The relevance of the topics for each specific interview will vary from one interview to another.

INTRODUCTION:

- Introduce yourself and give the formal information about the study (as outlined in participant information sheet)
- Informed consent (make sure informant understands his/ her *rights* and *responsibilities*, before he/ she consents)

ABOUT THE INFORMANT:

- Type of service provider
- Professional background
- Current position/ Work experience

ABOUT THE SERVICE:

- Describe the service/ activity/ people who work at the service/ clientele (students/ learners/ employees/ etc.)

KNOWLEDGE ABOUT DISABILITY:

- How do you understand disability?
- Knowledge about disability policy/ rights
- Knowledge about disability in education/ employment policies and legislation and how this is implemented at the particular service

ABOUT DISABILITY IN THE AREA:

- What is the situation and life like for people with disabilities (children, young people and adults) in

the area? How is this compared to the situation for people without disabilities?

- What is the situation related to education and learning in the area (in general and for people with disabilities specifically)?
- What is the situation related to employment and income-generation in the area (in general and for people with disabilities specifically)?
- For those who do not have access to education/ employment; what are the consequences?
- What is done/ can be done to improve access to these services/ activities?

ABOUT ACCESS TO THE SERVICES/ ACTIVITY:

- Do you have students/ learners/ employees with disabilities at the service/ activity?
  - Ask about informant's experiences in working with people with disabilities
  - Probe for concrete examples and experiences
  - Probe for different types of disabilities; visual, hearing, physical, psychosocial, developmental, etc.
- Ask about ability/ willingness of staff to work with and assist people with special needs
- Physical access at facility: stairs, elevators, thresholds, etc.
- Availability of material in braille and sign-language interpretation

CLOSING THE INTERVIEW:

- Ask if informant has anything else s/he would like to share, or any questions.
- Acknowledge the informant's cooperation, time spent and information shared.

INTERVIEW GUIDE FOR CHILDREN AND YOUNG PEOPLE WITH DISABILITIES

This interview guide comprises topics that will be relevant in a qualitative study on factors relevant for inclusion and exclusion of children and young people with disabilities in activities of life-long learning and skills development. In an interview situation the guide as presented here is not always used to its full extent. Depending on the circumstances, various sections will be more or less relevant for the interview. The relevance of the topics for each specific interview will vary from one interview to another. It is the informant's history and experiences that will decide which topics it is important to focus on in the various interviews. The questions and topics must be adapted to each informant, taking into consideration their age, gender, position in the household, mental capacity and so on.

INTRODUCTION:

- Introduce yourself and give the formal information about the study (as outlined in participant information sheet)
- Informed consent (make sure informant understands his/ her *rights* and *responsibilities*, before he/ she consents)

ABOUT THE INFORMANT:

- Gender/ Age/ Marital status/ Children (own/ foster care/ step-children/ adopted)
- Educational level (formal/ informal)
- Work status (formal/ informal)
- Area of residence
- Household composition
- Household income and assets (from all household members): Does it sustain the family? (what is the poverty level/ socio-economic status of the family)
- Activities of daily life (ADL) of household members (division of labour in the household)
  - Household activities, learning/ educational activities, employment

ABOUT THE DISABILITY:

- Ask the informant to tell about the reason for the disability, as well as the reason for the onset of the disability – we are also interested in the informant's own perception of disability
  - Please tell or explain to me about your impairment. What happened, when and how? Why do you think this happened to you?
  - How does your disability affect your life; in the past /as a child? Today? In the future?
- Informant's experiences with other people's behaviour, reactions and knowledge to his/ her disability
- What are the informant's thoughts on what it takes to prepare and enable them to live an independent life?
  - From early childhood to adulthood
  - Own role
  - Role of family/ care-giver(s)
  - Role of others

ABOUT ACTIVITIES OF DAILY LIFE:

- Invite the informant to tell about his/ her daily activities. When asking the informant to tell about activities, one has to adjust questions to the informant's age, sex, family position/role etc. Encourage the informant to be specific and to illustrate by examples:
  - Participation in household activities
  - Self-care activities such as hygiene, going to the toilet, dressing etc.
  - Need for and access to health care and health services
  - Participation in social activities
- Relate the activities above to the bodily and/or mental functioning of the informant:

○ Please describe how the disability affects access to and performance of the activities

○ Please describe assistance given and by whom the assistance is given

○ If the person does not participate in some of the activities: Ask the person to reflect on why he/she does or does not participate in the activities

○ Ask the person to describe what others (non-disabled) in the same situation do with regard to the activities mentioned

ABOUT PARTICIPATION IN LEARNING AND EDUCATIONAL ACTIVITIES (FORMAL/ INFORMAL, PRESENT/PAST):

• What is the informant's understanding of and experience with learning and educational activities (formal and informal)?

○ Knowledge of relevant activities (available and unavailable)

○ Own need for these activities

○ Experience with participation in these activities

• Relate the activities above to the bodily and/or mental functioning of the informant:

○ Please describe how the disability affects participation in educational activities

○ Please describe assistance given and by whom the assistance is given

○ If the person does not participate in some of the activities: Ask the person to reflect on why he/she does or does not participate in the activities

• In their opinion, is denied access related to their disability? How? Why? What can be done to ensure better access?

○ Ask the person to describe what others (non-disabled) in the same situation do with regard to the activities mentioned

ABOUT PARTICIPATION IN INCOME-GENERATING ACTIVITIES (FORMAL/ INFORMAL, PRESENT/PAST):

• What is the informant's understanding of and experience with income-generating activities (formal and informal)?

○ Own experience with participation in these activities; past and present

○ How has their learning and educational activities prepared them for/ not prepared them for participation in income-generating activities?

• Relate the activities above to the bodily and/or mental functioning of the informant:

○ Please describe how the disability affects participation in income-generating activities

○ Please describe assistance given and by whom the assistance is given

○ If the person does not participate in income-generating activities: Ask the person to reflect on why he/she does or does not participate in the activities.

• In their opinion, is the lack of participation related to their disability? How? Why? What can be done to ensure better access?

○ Ask the person to describe what others (non-disabled) in the same situation do with regard to the income-generating activities mentioned

CLOSING THE INTERVIEW:

• Ask if informant has anything else s/he would like to share, or any questions.

• Acknowledge the informant's cooperation, time spent and information shared.

INTERVIEW GUIDE FOR GUARDIANS/ FAMILY MEMBERS OF CHILDREN AND YOUNG PEOPLE WITH DISABILITIES

This interview guide comprises topics that will be relevant in a qualitative study on factors relevant for inclusion and exclusion of children and young people with disabilities in activities of life-long learning and skills development. In an interview situation the guide as presented here is not always used to its full extent. Depending on the circumstances, various sections will be more or less relevant for the interview. The relevance of the topics for each specific interview will vary from one interview to another. It is the informant's history and experiences that will decide which topics it is important to focus on in the various interviews. The questions and topics must be adapted to each informant, taking into consideration their age, gender, position in the household, mental capacity and so on.

INTRODUCTION:

- Introduce yourself and give the formal information about the study (as outlined in participant information sheet)
- Informed consent (make sure informant understands his/ her **rights** and **responsibilities**, before he/ she consents)

ABOUT THE INFORMANT:

- Gender/ Age/ Marital status/ Children (own/ foster care/ step-children/adopted)
- Area of residence
- Household composition
- Educational level (formal/ informal)
- Work status (formal/ informal)
- Household income and assets (from all household members): Does it sustain the family? (what is the poverty level/ socio-economic status of the family)
- Activities of daily life (ADL) of household members (division of labour in the household)
  - Household activities, learning/ educational activities, employment
- Relationship to the disabled child/ young person

ABOUT THE DISABILITY:

- Ask the informant to tell about the disability, as well as the reason for the onset of the disability – we are also interested in the informant's own perception of disability
  - Please tell or explain to me about your relative's impairment. What happened, when and how? Why do you think this happened to this person?
  - How does the disability affect his/ her life; in the past /as a child? Today? In the future?
- Ask the informant to describe how he/ she/ the family take care of the disabled family member:
- How does the situation with a disabled family member affect their personal as well as family life? In what way does the disability affect the household members' ability to work, access to employment, go to school or participate in social activities? Ask them to reflect on why the situation is like this.
- Are there enough people in the household to care for the disabled member and to support the family in the daily living? Do family members have to quit their job or not work in the field because of the care needs of the disabled family member?
- What is the informant's opinion on the family's social ranking/class in the community? How does the disabled family member affect this?
- Informant's experiences with other people's behaviour, reactions and knowledge of/ towards the disabled person
- What are the informant's thoughts on what it takes to prepare and enable the disabled child/ young person to live an independent life?
  - From early childhood (infant) to adulthood
  - Own role
  - Role of the disabled child/ young person
  - Role of others

ABOUT ACTIVITIES OF DAILY LIFE FOR THE DISABLED FAMILY MEMBER:

- Invite the informant to tell about the daily activities of the disabled individual. Encourage the informant to be specific and to illustrate by examples:
  - Participation in household activities
  - Self-care activities as hygiene, toilet, dressing etc.
  - Need for and access to health care and health services
  - Participation in social activities
- Relate the activities above to the bodily and/or mental functioning of the disabled individual:
  - Please describe how the disability affects the access to and performance of the activities.
  - Please describe assistance given and by whom the assistance is given.
  - If the disabled person does not participate in some of the activities: Ask the informant to reflect on why.
  - Ask the informant to describe what others (non-disabled) in the same situation do with regard to the activities mentioned.

ABOUT PARTICIPATION IN LEARNING AND EDUCATIONAL ACTIVITIES (FORMAL/ INFORMAL, PRESENT/PAST) FOR THE DISABLED FAMILY MEMBER:

- What is the informant's understanding of and experience with learning and educational activities (formal and informal) for the disabled family member?
  - Knowledge of relevant activities (available and unavailable)
  - The need for these activities
  - Experience with these activities for disabled family member
- Relate the activities above to the bodily and/or mental functioning of the disabled family member:
  - Please describe how the disability affects participation in income-generating activities.
  - Please describe assistance given and by whom the assistance is given.

- If the disabled person does not participate in some of the activities: Ask the informant to reflect on why.
  - In their opinion, is denied access related to the disability? How? Why? What can be done to ensure better access?
  - Ask the informant to describe what others (non-disabled) in the same situation do with regard to the activities mentioned.

ABOUT PARTICIPATION IN INCOME-GENERATING ACTIVITIES (FORMAL/ INFORMAL, PRESENT/PAST):

- What is the informant's understanding of and experience with income-generating activities (formal and informal)?
  - Experience with these activities, past and present
  - How has their learning and educational activities prepared them for/ not prepared them for participation in income-generating activities?
- Relate the activities above to the bodily and/or mental functioning of the informant:
  - Please describe how the disability affects participation in income-generating activities.
  - Please describe assistance given and by whom the assistance is given.
  - If the person does not participate in income-generating activities: Ask the person to reflect on why he/she does or does not participate in the activities.
    - In their opinion, is the lack of participation related to their disability? How? Why? What can be done to ensure better access?
  - Ask the person to describe what others (non-disabled) in the same situation do with regard to the income-generating activities mentioned.

CLOSING THE INTERVIEW:

- Ask if informant has anything else s/he would like to share, or any questions.
- Acknowledge the informant's cooperation, time spent and information shared.

TOPIC GUIDE FOR FGDS WITH SERVICE/ ACTIVITY PROVIDERS

A FGD should consist of 5-10 participants, in addition to one researcher or RA acting as facilitator, and one RA acting as note-taker. The aim is to explore opinions and experiences of the service/ activity providers related to a few topics introduced by the researcher. The researcher must allow for open discussions, while at the same time ensuring that the discussions remain relevant to the topics of interest.

INTRODUCTION:

Introduce yourself and give the formal information about the study (as outlined in participant information sheet)

- Informed consent (make sure all informants understands their **rights** and **responsibilities**, before they consent)

ABOUT THE INFORMANTS:

A brief round of introductions by the informants, covering the following information:

- Type of service provider
- Professional background
- Current position
- Past work experience

KNOWLEDGE ABOUT DISABILITY:

- Understanding of disability
- Knowledge about disability policy/ rights
- Knowledge about disability in education/ employment policies and legislation and how this is implemented at the particular service
- Thoughts about participation of people with disabilities in learning, education and income-generation

ABOUT DISABILITY IN THE AREA:

- What is the situation and life like for people with disabilities (children, young people and adults) in the area?

- How is this compared to the situation for people without disabilities?

- What is the situation related to education and learning in the area (in general and for people with disabilities specifically)?

- What is the situation related to employment and income-generation in the area (in general and for people with disabilities specifically)?

- For those who do not have access to education/ employment; what are the consequences?

- What is done/ can be done to improve access to these services/ activities?

ABOUT ACCESS TO THE SERVICES/ ACTIVITY:

- Do you have students/ learners/ employees with disabilities at the service/ activity?
  - Ask about informants' experiences in working with people with disabilities
  - Probe for different types of disabilities; visual, hearing, physical, psychosocial, developmental, etc.

- Ask about ability/ willingness of staff to work with and assist people with special needs

- Physical access at facility: stairs, elevators, thresholds, etc.

- Availability of material in braille and sign-language interpretation

- Closing the interview:

- Ask if informant has anything else s/he would like to share, or any questions.

- Acknowledge the informant's cooperation, time spent and information shared.

TOPIC GUIDE FOR FGDS WITH CHILDREN AND YOUNG PEOPLE WITH DISABILITIES

A FGD should consist of 5-10 participants, in addition to one researcher or RA acting as facilitator, and one RA acting as note-taker. The aim is to explore opinions and experiences of children and young people related to a few topics introduced by the researcher. The researcher must allow for open discussions, while at the same time ensuring that the discussions remain relevant to the topics of interest. This topic guide comprises topics that will be relevant in a focus group discussion studying factors relevant for inclusion and exclusion of children and young people with disabilities in activities of life-long learning and skills development. The relevance of the topics for each specific FGD will vary from one discussion to another. The questions and topics must be adapted to each discussion, taking into consideration the participants' age, gender and type of disability.

INTRODUCTION:

Introduce yourself and give the formal information about the study (as outlined in participant information sheet)

- Informed consent (make sure all informants understands their *rights* and *responsibilities*, before they consent)

ABOUT THE INFORMANTS:

A brief round of introductions by the informants, covering the following information:

- Age/ gender/ marital status/ children

- Composition of their households

- Level of education/ participation in training/ work status

ABOUT DISABILITY:

- Understanding of disability: Causes for disability

- How does having a disability affect a person's life? (Positive and negative)

- How are people with disabilities viewed by non-disabled people?

ABOUT ACTIVITIES OF DAILY LIFE:

- What are the experiences of people with disabilities in carrying out activities of daily life (self-care, household activities, social activities, staying healthy and seeking health care)?

- What kind of assistance do they get and what do they need?

ABOUT PARTICIPATION IN LEARNING AND EDUCATIONAL ACTIVITIES (FORMAL/ INFORMAL, PRESENT/PAST):

- Knowledge of learning and educational activities

- Thoughts about their own participation in these activities

  ○ Barriers and facilitators

- Thoughts about people with disabilities in general in relation to participating in these activities

ABOUT PARTICIPATION IN INCOME-GENERATING ACTIVITIES (FORMAL/ INFORMAL, PRESENT/PAST):

- Knowledge of income-generating activities

- Thoughts about their own participation in these activities

  ○ Barriers and facilitators

- Thoughts about people with disabilities in general in relation to participating in these activities

CLOSING THE INTERVIEW:

- Ask if informant has anything else s/he would like to share, or any questions.

- Acknowledge the informant's cooperation, time spent and information shared.

TOPIC GUIDE FOR FGDS WITH GUARDIANS/ FAMILY MEMBERS OF CHILDREN AND YOUNG PEOPLE WITH DISABILITIES

A FGD should consist of 5-10 participants, in addition to one researcher or RA acting as facilitator, and one RA acting as note-taker. The aim is to explore opinions and experiences of guardians and family members of children and young people with disabilities, related to a few topics introduced by the researcher. The researcher must allow for open discussions, while at the same time ensuring that the discussions remain relevant to the topics of interest. This topic guide comprises topics that will be relevant in a focus group discussion studying factors relevant for inclusion and exclusion of children and young people with disabilities in activities of life-long learning and skills development. The relevance of the topics for each specific FGD will vary from one discussion to another. The questions and topics must be adapted to each discussion, taking into consideration the participants' relationship to the disabled child/ young person, gender and type of disability of the child/ young person.

INTRODUCTION:

Introduce yourself and give the formal information about the study (as outlined in participant information sheet)

- Informed consent (make sure all informants understands their **rights** and **responsibilities**, before they consent)

ABOUT THE INFORMANTS:

A brief round of introductions by the informants, covering the following information:

- Age/ gender/ marital status/ children
- Composition of their households
- Relationship to disabled child/ young person

ABOUT DISABILITY:

- Understanding of disability: Causes for disability
- How does having a disability affect a person's life? (Positive and negative)

- How does it affect the lives of other people in the family, including themselves?
- How are people with disabilities viewed by non-disabled people?

ABOUT ACTIVITIES OF DAILY LIFE:

- What are the experiences of people with disabilities in carrying out activities of daily life (self-care, household activities, social activities, staying healthy and seeking health care)?
- What kind of assistance do they get and what do they need?

ABOUT PARTICIPATION IN LEARNING AND EDUCATIONAL ACTIVITIES (FORMAL/ INFORMAL, PRESENT/PAST):

- Knowledge of learning and educational activities
- Thoughts about participation of disabled people in these activities
  - Barriers and facilitators
  - Own experiences (in relation to disabled child/ young person)

ABOUT PARTICIPATION IN INCOME-GENERATING ACTIVITIES (FORMAL/ INFORMAL, PRESENT/ PAST):

- Knowledge of income-generating activities
- Thoughts about participation of disabled people in these activities
  - Barriers and facilitators
  - Own experiences (in relation to disabled child/ young person)

CLOSING THE INTERVIEW:

- Ask if informant has anything else s/he would like to share, or any questions.
- Acknowledge the informant's cooperation, time spent and information shared.