Situational Analysis

ON-SITE SUPPORT FOR FAMILIES OF CHILDREN WITH NEURODEVELOPMENTAL DISORDERS IN ZAMBIA

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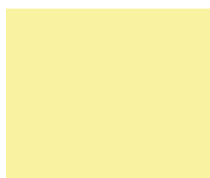

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EXECUTIVE SUMMARY

Neurodevelopmental disorders are the most common cause of disability in children. This project aims to improve the quality of life of children (0-14 years) with neurodevelopmental disorders and their families in the districts of Chongwe, Lusaka and Kafue in Zambia. In order to better understand the context of this target population, as well as enhance decision-making regarding support for this target population, a situational analysis of the project environment was conducted. The situational analysis was conducted using the PESTEL framework which investigates the Political, Economic, Social, Technological, Environmental and Legal factors of the three districts in Zambia. Data was drawn from existing policies, literature, statistics, systematic reviews and qualitative interviews with the target population.
The results of this situational analysis include:

POLITICAL

Inclusion and opportunities for children with neurodevelopmental disabilities in Zambia remains poor. The Zambian government's policies, plans and laws support the inclusion and rights of this target population, however the implementation of these has been limited. All community stakeholders play a role in the life, inclusion and opportunities of children with neurodevelopmental disabilities and their families. Each stakeholder can be either a protective or a risk factor for this target population. Education, upskilling and raising awareness of all stakeholders in the community (including policy makers, community members, family members, teachers) is vital to see improvements in the quality of life of children with neurodevelopmental disabilities and their families.

ECONOMIC

Zambia has high levels of poverty with over 60% of citizens living below the poverty line. The effects of poverty are usually more significant for persons with disabilities and their families. Persons with disabilities have a higher likelihood of experiencing poverty, stigmatisation, physical abuse and food insecurity; while experiencing decreased quality of life; decreased access to services such as water, electricity and education; and fewer employment opportunities. Many caregivers of persons with disabilities report having to stop working to complete their caregiving duties, which results in financial strain. In coping with these challenges, informal peer-support groups have been formed between parents of children with neurodevelopmental disabilities across Zambia. This project aims to support and extend the network of these self-help peer-groups by providing training on neurodevelopmental disabilities, financial management (Village Savings Group approach) and entrepreneurship.

SOCIAL

Zambia's population is rapidly growing. It is a youthful population with 44% of the population below the age of 14 years and a low life expectancy of 64 years. The national prevalence of disability in children is reportedly 4.4%. The World Health

Organisation (WHO) estimates the international prevalence of disability to be 16%. When considering this statistic, Zambia may present with a population of children and adults with disabilities that are undiagnosed and unsupported. Stigma is a significant social factor for children with disabilities and their families within this project's target districts in Zambia. Although interventions to combat stigma and prejudice have been proven to be effective, limited interventions are currently in place in schools, health centres and/or the local communities. This project aims to improve the quality of life of the target population through setting up networks to aid early identification of neurodevelopmental disorders in order to provide families with support, as well as raising awareness of neurodevelopmental disorders in the local communities to combat stigma and prejudice.

TECHNOLOGICAL

In Zambia, the minority (28.5%) of the population are using the internet. Although all provincial centres are linked to fibre internet, last mile connectivity remains a challenge that prevents digital systems being used in more rural and/or sparsely populated areas. Assistive devices are used within the country, yet there is a significant shortfall between the need for and provision of assistive technology. Despite international commitments by Zambia's government to transform the country's digital landscape for persons with disabilities, Zambia does not seem to be ready or getting prepared to embrace the fast-changing technological advancement to increase the knowledge, education, skill-development and inclusion of persons with disabilities. This project will consider the technological profile of Zambia when choosing platforms for its awareness-raising campaigns in order to maximise the accessibility of the content and audience size. This project also aims to increase awareness of assistive devices within the target population and local healthcare centres to better enable families and other stakeholders working with persons with disabilities to advocate for assistive technology for those who need it.

ENVIRONMENTAL

Access to health and education are basic rights to all persons in Zambia. However, there continue to be many access barriers, particularly for children and persons with disabilities. These include inaccessible buildings; the cost of transport and/or medication; a lack of special schools; inadequate government funding; a lack of assistive technology; inappropriate equipment; a lack of inclusive education resources; community stigma; and a lack of staff training on inclusion and disabilities. In the target districts, 8 of the fourteen health centres had no specialist staff to attend to children with neurodevelopmental disabilities. Neurodevelopmental disabilities are not currently covered in the curriculum for health care professionals at tertiary institutions in Zambia. As a result, having specialist staff such as a physiotherapist at the health centre does not ensure that they are equipped to support children with neurodevelopmental disabilities. This project aims to train practicing healthcare providers as well as student healthcare providers in identifying, managing and supporting children with neurodevelopmental disabilities.

— LEGAL —

Zambia's laws support effective protection of children's rights and persons with disabilities. However, there has been a lack of inclusion of persons with disabilities in Zambia's key policies and the implementation of these laws has been poor. Reasons for poor enforcement include lack of enforcing penalties, lack of funding and resources, negative attitudes and low sensitisation of people's rights. This lack of policy and enforcement is evident across all sectors of the economy, including education, healthcare and the justice system. This project aims to raise awareness of the rights of children and persons with disabilities in Zambia with key policy makers, ministers, NGOs, government officials and municipalities. This project will also provide workshops for representatives from organisations that support persons with disabilities to develop their advocacy and fundraising skills.

Through analysing the political, economic, social, technological, environmental, and legal factors influencing children with neurodevelopmental disabilities and their families in Zambia, many risk factors, protective factors, challenges and supports were identified. It is evident that high levels of awareness-raising, health education, skill development and advocacy is needed at all levels of society to improve the quality of life of the target population in Zambia.

INTRODUCTION

Neurodevelopmental disorders are the most common cause of disability in children. Neurodevelopmental disorders are disabilities associated primarily with the functioning of the neurological system and brain. The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5; American Psychiatric Association (APA), 2013) introduced a new diagnostic category called Neurodevelopmental Disorders (NDDs), a group of disorders that commonly begin in childhood, can be chronic and persist for life. NDDs are defined in the International Classification of Diseases – 11th Revision (ICD-11) and DSM-V (APA, 2013) to include, but are not limited to, autism spectrum disorders (ASD), cerebral palsy, attention deficit hyperactivity disorder (ADHD), developmental motor disorders, disorders of intellectual development, epilepsy, developmental speech and/or language disorders and developmental learning disorders.

This project aims to support children with neurodevelopmental disabilities under the age of 14 and their families in three selected districts of Chongwe, Lusaka and Kafue in Zambia. The districts of Chongwe, Lusaka and Kafue were selected because they are the most populous districts in the province of Lusaka with a total of three million people (90% of the province of Lusaka). A higher population density in these districts enables the project to reach more people of the target group. An addition, this project will partner with tertiary training schools from Lusaka, Ndola, Monze, Chisamba and Kitwe. Through incorporating these tertiary training institutions in the aims of this project, the sustainability and multiplier effects may be increased.

The project involves three key areas: training, raising awareness and strengthening support networks. The project aims to train student health professionals and practicing health professions in the early detection and management of neurodevelopmental disabilities; train parents of children with neurodevelopmental disabilities in understanding and managing neurodevelopmental disabilities as well as managing finances and entrepreneurship; and train local self-help organisations of persons with disabilities in advocacy and fundraising skills. The project aims to raise awareness of neurodevelopmental disabilities and the rights of children and persons with disabilities within the local communities, health centres, local development committees and government. Finally, the project aims to strengthen and extend existing support networks, particularly the support groups of parents of children with neurodevelopmental disabilities.

In order to best understand the context and factors that influence the target population of this project, a situational analysis was conducted. The result of the situational analysis may then be utilised to guide decision-making in the planning and execution of this project to maximise the project's effectiveness, minimise project costs and make best use of existing frameworks, resources and relationships within the communities.

SITUATIONAL ANALYSIS

"If you don't know where you are going,
any road will get you there."

~

Lewis Carroll

A situational analysis is a scoping review and analysis of the broader context or external environment in which a project is situated. It is a process of gathering information on the internal and external factors within an environment in order to guide decision-making. For this situational analysis, information is gathered and collated using the PESTEL framework which is an acronym for Political, Economic, Social, Technological, Environmental and Legal factors. This situational analysis will not collect new data, but rather analyse existing policies, literature, statistics, interviews and reports to better understand the context and experience of children with neurodevelopmental disabilities and their families in the three target districts in Zambia. Once the data for each PESTEL factor has been collated, consideration will be made for the project within the established context. Any gaps in knowledge identified in this situational analysis regarding the target population and target districts will be followed up in the project's monitoring and evaluation stage by means of the addition of relevant research questions.

POLITICAL

The political context of Zambia has seen significant change in the last 50 years. In October 1964 the Republic of Zambia gained its independence from British rule. Two months later, Zambia became a member of the United Nations and the Organisation of African Unity (OAU) which has now been transformed into the African Union (AU). In 1973-1990, Zambia became a one-party state with a socialist economic and social structure, under the rule of the United National Independence Party (UNIP). During this time, the country experienced nationalisation of privately-owned industries, subsidisation of the industrial and agricultural sectors and mass social spending in sectors such as education, health and social welfare services. This period of time ultimately led to a national socioeconomic decline (Kaunda, 2016).

In 1991, Zambia pivoted to a democratic, multi-party state under the rule of the Movement for Multi-Party Democracy (MMD) which ruled Zambia until the 2011 general elections in which Michael Chilufya Sata from the Patriotic Front (PF) party became president. The United Party for National Development (UPND) won the general elections on the 11th of August 2021 with Hakainde Hichilema as the country's president. The UPND more closely aligns with a capitalist economy. During this time, Structural Adjustment Programmes (SAP) were used to breakdown the socialist system of governments, decentralise industries, decrease national spending and enable free markets (Kaunda, 2016).

Zambia's Constitution was written in 1991 following the change in political power. It was amended in 2016 and additional key government policies were written such as the National Child Policy (2015) to better reflect Zambia's international commitments, obligations and agreements regarding the protection of the rights of children, women and persons with disabilities. Zambia has ratified the African Charter on the Rights and Welfare of the Child (1990) and the UN Convention on the Rights of the Child (1990). The Human Rights Commission (HRC) of Zambia is mandated to ensure that these rights are protected.

A key government organisation in supporting persons with disabilities in Zambia is the Zambian Agency for Persons with Disabilities (ZAPD) which was established following the Disabilities Act No.33 (1996). Their aim is to support persons with disabilities and their families; establish equal rights for persons with disabilities; and help bring about economic empowerment, social integration and complete access to information and services for persons with disabilities.

Despite the Constitution, laws, policies and organisations being in place, Zambia's progress on child rights and gender equality has not been sufficient to meet the UN Sustainable Development Goals by 2030. The practice of child brides continues in Zambia. In 2018, 29% of all young women aged 20–24 were married before 18 years old, and 5% before turning 15 (UNFPA-UNICEF, 2021). In 2021, 20 000 cases of Gender Based Violence were reported countrywide (Zambia Police, 2022). 5,301 of these reported cases (25.8%) were against children (Zambia Police, 2022).

The government of Zambia has made efforts to provide quality and equitable education to all children, as guided by the country's 7th National Development Plan (2017), Education Act (2011) and the commitment in 2022 to provide free education for all from early education to secondary school (UNICEF, 2022b). In 2022, the education budget was increased by nearly one-third, largely to recruit additional teachers and construct new schools to facilitate the policy for free education (UNICEF, 2022b). Despite this increase, the education budget allocation is still below the recommended global commitments (UNICEF, 2022b) and the quality of education remains below international standards. The PISA international assessment of 15

year olds, revealed alarming statistics that only 5% of students are achieving the minimum level of proficiency in reading and only 2% in mathematics (UNICEF Zambia, 2019). Other areas of concern include the poor learner retention rates, poor access to early childhood education and poor inclusion of children with neurodevelopmental disabilities (UNICEF Zambia, 2019). Regarding retention rates, in 2019 only 67.5% of learners in Grade 7 transitioned to Grade 8 and a mere 48% of Grade 9 learners transitioned to Grade 10. This was largely due to the introduction of school fees in Grade 8 and too few secondary schools available to absorb learners (UNICEF Zambia, 2019). With the new policy for free education, retention rates should see improvement; however there continue to be too few secondary schools. There are currently about 9,000 primary schools while only 1,000 secondary schools (UNICEF, 2022b). Regarding early childhood education, access to early childhood education is low, but has seen improvement over the past 5 years. The percentage of Grade 1 entrants with pre-school experience increased from 26.8% in 2017 to 41% in 2021 (UNICEF, 2022b). Further improvement in access to early education is expected with the introduction of the free education policy. Finally, the inclusion and opportunities for children with neurodevelopmental disabilities remains poor in Zambia (UNICEF Zambia, 2018). The World Health Organization (2023) estimate 16% of the global population to have disabilities. In Zambia, only 3% of all children in mainstream education have a disability and only 2% of all qualified teachers have a special education qualification (UNICEF Zambia, 2018).

In efforts to reach universal healthcare by 2030, Zambia implemented a National Health Insurance (NHI) which was operationalized in 2019 and made accessible by registered NHI members in 2020. The NHI is operated and managed by the National Health Insurance Management Authority (NHIMA) and is financed by NHI contributions from the formal and informal sector, with exemption for citizens who are over 65 and under 18 years old (MoH, 2018). Three key challenges regarding the implementation of the NHI include registration, healthcare infrastructure and an overtaxed formal sector. Firstly, beneficiaries need to be registered via an online platform, which limits registration of people in rural and/or low-income areas where there are low levels of access to technology and digital skills. Secondly, further development of healthcare infrastructure is needed to make the NHI accessible for all, especially in rural areas where health facilities may be too far away to be accessible for some communities. And finally, although NHI contributions apply to both the formal and informal sectors, tracking NHI contribution compliance in the informal setting is challenging due to lack of documentation and formalisation of income. This results in the formal sector (15% of the population) taking on the bulk of the NHI financing. Greater registration and participation of the informal sector is necessary to mobilise resources and ensure equitable access to healthcare (Finch Solutions, 2021).

When considering the political factors surrounding the experience of children with neurodevelopmental disability and their families in Zambia, one can identify the influence of a wide network of stakeholders. According to Bronfenbrenner's ecological theory (1979), a child develops within a complex system of relationships in their environment. This includes their direct contacts (family, friends, school, health centres, clubs, social media) and factors that indirectly affect them such as the government and policies, mass media, the cultural and legal context and their stage of life. At each level of this ecological theory, key stakeholders can be identified as protective and/or risk factors. These include the community members (parents, caregivers, religious leaders), government agencies (policy makers, agencies such as the ZAPD, ministers), the media, social services and infrastructure, traditional leaders and healers, police, health workers, educators, businesses, NGOs and international donors. All stakeholders in the community can play a role in the quality of life, inclusion and opportunities for children with neurodevelopmental disabilities and their families.

This project has considered the political context of Zambia in its design and goals. Firstly, the project aims to raise awareness around gender equality, children's rights and the rights of persons with disabilities in the local communities. This project will raise awareness in the 3 target districts in Zambia through running workshops every month for fathers of children with neurodevelopmental disabilities in communities; running quarterly workshops for healthcare professionals at local health facilities covering neurodevelopmental disabilities and child protection trainings; participating in national action days such as International Day of Persons with Disabilities; running workshops for persons with disabilities to be educated on their rights and the health/social services that are available to them; and the developing of media campaigns and informational pamphlets to be distributed within communities which will be available in English and the local languages.

Secondly, the project identifies the importance of educating community stakeholders in direct, close contact with children with neurodevelopmental disabilities. This includes their caregivers/ parents and healthcare workers at local health centres. This project is utilising the Ubuntu training programme. The Ubuntu program has been successfully used by over 200 organizations in more than 60 countries to support children with Cerebral Palsy. It has been developed in recent years to include children with other neurodevelopmental disorders. Caregivers will be invited to a 12-week training course covering the Ubuntu resource. There will also be monthly home visits for 12 months following the workshop to ensure correct practical application and carryover of skills. By the project's completion in 2024, it aims to have improved parents' and caregivers' knowledge, attitudes and interactions with their children with neurodevelopmental disorders by an average of 70% as a result of the Ubuntu training.

Finally, this project recognises the need to educate government/policy-level stakeholders in Zambia to establish sustained change. This will be attended to through lobbying, networking, advocacy and health education of policy makers and officials. The project team will meet annually with the decision-makers from the ministries and the vocational schools in order to raise awareness and inform them about the progress of the project. The project also plans to provide quarterly presentations at district-level development committee meetings and the national committees for community-based rehabilitation in order to bring persons with disabilities on the agenda of these committees, discuss inclusion and advocate for public budget allocations. This project has also prioritised the strengthening of associations mandated to support persons with disabilities in Zambia. Staff members from targeted organisations will be invited to attend a five-day workshop aimed at developing their advocacy skills and fundraising capabilities. By 2024, the project aims for at least 200 members of development committees at the district and county level to have gained a better understanding of the rights of persons with neurodevelopmental disabilities and for this population group to be prioritised in local development committees and budget allocations.

ECONOMIC

Zambia is a large, land-locked, resource-rich country in the centre of Southern Africa. Forty-five percent of Zambia's population resides within cities, with the majority living in rural areas (World Bank, 2021). Zambia is classified as a low income country with a GDP per capita of $1120.6 (World Bank, 2021). Its economy is primarily driven by mining, agriculture and construction (Ministry of Community Development and Social Services, 2018) and shows an annual growth rate of 3.6.% (World Bank, 2021).

Zambia has high levels of poverty. The majority of Zambians (61.4%) live below the poverty line of $2.15 a day and there is an unemployment rate of 13% (World Bank, 2021). Poverty in rural areas (76.6%) is estimated to be three times more prevalent than in urban areas (23.4%) (Ministry of Community Development and Social Services, 2018). In rural areas, subsistence farming is the primary source of income for most families. In urban areas, the primary source of income for people is wages/salary, followed by non-registered informal business (Ministry of Community Development and Social Services, 2018). Studies show that persons with disabilities are less likely to acquire permanent/formal employment than their non-disabled peers, and are more likely to be in informal jobs/self-employed (Scherer et al., 2022).

The impact of disability affects both the individual and their family. Persons with disabilities have a higher likelihood of experiencing stigmatisation, poverty, physical abuse and food insecurity; while experiencing decreased quality of life, access to services such as water and electricity, education and employment (Scherer et al., 2022). Families with family members who have a disability report higher levels of social exclusion, strained family relationships, absent fathers and negative feelings (blame, depression, hopelessness, frustration, emotional distress). Many caregivers also report having to stop working to complete their caregiving duties, which results in financial strain (Scherer et al., 2022). Participants in the study by the (Scherer et al., 2022) report that due to stigma and prejudice, some members of the community do not buy products from a caregiver or person with a disability.

In Lusaka, in response to these challenges, informal peer-support groups have been formed between parents of children with neurodevelopmental disabilities. Peer-support groups have been shown to reduce internal stigma and self-stigma, decrease stress and bolster advocacy within communities (Scherer et al., 2022). In Lusaka, these peer-support groups usually meet at health facilities while accessing rehabilitative services for their children such as physiotherapy. In addition to peer-support, these groups also offer financial support through the use of group savings, also known as Chilimba or Village Banking (Katongo & Chomba, 2022), which adds to the economic network of families with children with neurodevelopmental disabilities.

In 2003, in an attempt to reduce extreme poverty in Zambia, Zambia's Ministry of Community Development and Social Services established the Social Cash Transfer (SCT) programme. This programme aims to financially support households experiencing extreme poverty and reduce inter-generational transfer of poverty. Beneficiary households that meet this criteria receive 200 Kwacha and those that also have a family member with a severe disability receive an additional 200 Kwacha (Ministry of Community Development and Social Services, 2022). This SCT programme is supporting over 970 000 families in Zambia (Ministry of Community Development and Social Services, 2022). Eligibility for this financial support is strict and requires registration with correct documentation. Documentation includes ZAPD registration and a Disability Card or Medical Assessment Slip (Ministry of Community Development and Social Services, 2022). Despite the SCT programme being established for two decades, many citizens reported that they are not aware of this programme, do not understand the application process

and/or do not know the eligibility criteria (Scherer et al., 2022). Some report being accepted but not receiving money due to a cash flow issue within the government system (Scherer et al., 2022).

In an effort to support citizens develop their income, a range of NGOs and government initiatives have established skills training initiatives. One example of this is the Zambia National Service (ZNS) which provides skills training to youth and women. Government funds such as the Constituency Development Fund is also releasing funding to develop communities which can include training on income generating activities, entrepreneurship and skill development. In the study by Scherer et al. (2022), participants recommended that NGOs partner with the ZNS to develop the skills training program for persons with disabilities and their carers. In the external interim evaluation of the Ubuntu project, one of the recommendations made was for further training to be given to families with children with neurodevelopmental disabilities (Scherer et al., 2022).

This project has considered the economic context of Zambia in the following ways. Firstly, the significant negative effects that stigma can have on the experience of a child with neurodevelopmental disabilities and their family, including their ability to generate income within their communities. This project will run awareness-raising activities involving persons with disabilities, families of persons with disabilities, healthcare professionals, and the greater community through education, media campaigns, involvement in action days, provision of pamphlets and sign boards. Through raising awareness, refuting myths and falsehoods regarding disabilities and enabling people to better understand neurodevelopmental disabilities, this project aims to significantly increase the quality of life of the target population.

Secondly, this project aims to develop the financial and entrepreneurial skills of parents of children with neurodevelopmental disabilities. This will be done through the network of existing peer-support self-help groups and the newly-formed self-help groups established by this project to reach previously unreached parents in the target population. After the completion of the Ubuntu 12-week programme, parents in these groups can choose to attend an optional 5-day workshop to better understand the Village Savings Group approach and/or an optional 5-day workshop to learn how best to increase their income generation. By the end of the project, the aim is for at least 360 families to be trained in the Village Savings Group approach; and for the income within these households to have increased by 50%. In addition, this project aims for all existing and newly formed self-help groups to be formally registered with the relevant Ministry of Community Development, as this will enable the groups to access funding for the groups and support their sustainability.

SOCIAL

Zambia's population of 19.8 million is growing rapidly at a rate of 2.9% per year, when compared to the international average of 0.9% (World bank, 2021). It presents with a youthful population with 44% of the population below the age of 14 years, and 54% between the ages of 15-64 (World bank, 2021). The life expectancy of 64 years is lower than the international average (72.98 years) (World bank, 2021). English is the official language of communication and instruction in Zambia, although there are many other indigenous languages such as Bemba and Nyanja (Ministry of Community Development and Social Services, 2018). 95.5% of Zambians identify as Christians and 2.7% identifying as Muslim (Zambia Statistics Agency, 2021). It is reported that many Zambians combine Christianity with indigenous beliefs (Zambia Statistics Agency, 2021).

In the Zambian National Disability Survey (Ministry of Community Development and Social Services, 2018), the reported prevalence of disability in children (2-17 years) is 4.4% nationally and 4.8% within the province of Lusaka. The prevalence of disability was reportedly higher in urban areas (Ministry of Community Development and Social Services, 2018). This figure may be underrepresenting the population as the World Health Organization's (2023) estimate is that 16% of the global population have disabilities. The most common disability reported by persons with disabilities in Zambia is visual impairment, followed by difficulties with walking, memory, hearing, self-care and communication (Ministry of Community Development and Social Services, 2018). HIV prevalence is also high at 13% of the population (Ministry of Community Development and Social Services, 2018). The main causes of disabilities were reported as disease/illness (32.7%), congenital illness (12.3%), accidents (6.3%) and witchcraft (3.1%). The age of the onset of disability was reportedly most common between 1-20 years (21.6%) and above 60 years (21.1%), followed by onset at birth (9.8%) (Ministry of Community Development and Social Services, 2018).

One of the social barriers of children and adults with neurodevelopmental disabilities in Zambia is stigma and prejudice. This can present in all contexts including education, health, social and religious contexts. In many cases, stigma is perpetuated through myths and misconceptions, particularly in rural areas, such as epilepsy being a result of spirits (Scherer et al., 2022). Scherer et al. (2022) report that there is a community perception in Zambia that children with disabilities cannot achieve and so do not need school. Teachers themselves represent mixed opinions regarding inclusive education. They state the benefits of inclusive education include social acceptance and equity, while also voicing concerns that learners with disabilities may disturb the learning of others and are slower to learn concepts. Teachers feel that there are insufficient materials and/or infrastructure to support inclusion of children with neurodevelopmental disabilities in education (Scherer et al., 2022). Interventions have been proven to reduce stigma in Zambia (Hepperlen et al., 2021; Hearst et al., 2022), however these interventions are not currently being implemented consistently in schools and communities.

Parent groups, churches, sensitisation and community-based rehabilitation services are useful to overcome the lack of disability awareness that restricts participation (Scherer et al., 2022). Scherer et al. (2022) highlight the importance of health education for persons with disabilities. The study recommends providing information in accessible formats, involving persons with disabilities in decision-making and health education provision, peer education workshops, theatre, public address, home-based care travel, support to facilities, collaboration between ministries, utilising grassroots community groups to spread information, and providing accessible health posters with large font.

Self-stigma is a form of stigma that can be reduced for persons with disability through membership to groups that support persons with disabilities. However, the minority (34.9%) of adults with disabilities in Zambia report being aware of local disabled persons' organisations (DPOs) and only 5.3% of persons with disabilities in Zambia report belonging to one (Ministry of Community Development and Social Services, 2018). In urban areas, membership was higher in adults with moderate/severe disabilities than in adults with mild disabilities. In rural areas, there was higher membership to DPOs for adults with moderate disabilities, but no membership of adults with severe disabilities (Ministry of Community Development and Social Services, 2018).

In lieu of membership to formal DPOs, as stated earlier in this report, informal peer-support groups have been formed between parents of children with neurodevelopmental disabilities across the province of Lusaka. In a report by Katongo and Chomba (2022), 11 self-help groups for parents of children with neurodevelopmental disabilities were mapped across Lusaka. All the self-help groups all had at least 10 members with an average membership of 20. Some groups contained parents that did not have children with neurodevelopmental disabilities (Katongo & Chomba, 2022).

The social context of the children with neurodevelopmental disabilities and their families was closely considered in this project. By the end of 2024, this project aims to increase the perceived quality of life of 1000 children with neurodevelopmental disorders and their families by 40%. In addition to training of community members in Ubuntu, a key tool in achieving this in the project is raising awareness to combat stigma. This project will be raising awareness through action days, media drives (TV, radio, social networks), distribution of informational material and partnerships with health centres in the community.

It is established that there is a high likelihood of undiagnosed neurodevelopmental disability within the target communities. This project will train 12 volunteers per year in each target district in early identification of neurodevelopmental disabilities. These volunteers will be mothers from the target group as well as community health workers/assistants. They will have the responsibility to identify children with neurodevelopmental disabilities in their communities, invite those children's caregivers to a peer-support self-help group and provide ongoing support/ mentorship to the caregivers as they settle into the group and its training programme.

TECHNOLOGICAL

Twenty percent of persons with disabilities in Zambia use assistive devices (Ministry of Community Development and Social Services, 2018). In the province of Lusaka, this proportion is higher with 22% of men with disabilities and 27% of women with disabilities using assistive devices (Ministry of Community Development and Social Services, 2018). Of these users, two thirds report the use of vision and hearing aids such as glasses, hearing aids and Braille; while one third report the use of mobility aids such as wheelchairs, crutches, walking sticks and/or standing frames (Ministry of Community Development and Social Services, 2018).

In Zambia and internationally, there is an increasing awareness, interest and use of assistive technology. Assistive technology and devices have been shown to increase inclusion, participation and access to opportunities for people with disabilities in Zambia. However, there is a significant shortfall between the need for and provision of assistive technology, and this is patterned by a range of social, demographic and structural factors (MacLachlan et al., 2018). In the National Disability Survey (Ministry of Community Development and Social Services, 2018), 58.8% of respondents reported a need for an assistive device, while only 16.5% of respondents reported this need being met.

The World Health Organization organised a Global Collaboration Summit on Assistive Technology (GATE) program to highlight and illustrate an example of good practice through a case study of assistive technology services in Norway. The Summit outlines some of the key principles that assistive technology polices should address such as the importance of active citizenship, the importance of advocacy, the need to find mechanisms to scale up good community practices to a higher level and the importance of political engagement (MacLachlan et al., 2018). The Summit acknowledged the challenges faced by resource-constrained countries such as Zambia and emphasised that policies should be practical, authentic and actionable with a view to enhancing sustainable development.

In 2018, Zambia with other African countries adopted the WHO Resolution EB142/ CONF./2 which outlined the various aspects of the need for improving access to assistive technology. It states the importance of assistive technology in the agenda for achieving the 2030 Sustainable Development Goals with its aim of 'leaving no one behind' (WHO, 2018). Following this Resolution, the included countries' governments are responsible for submitting reports every four years until 2030 on their progress in developing assistive technology (WHO, 2018). However, Zambia does not seem to be ready or getting prepared to embrace the fast-changing technological advancement to increase the knowledge, education, skill-development and inclusion of persons with disabilities (Chiluba et al., 2020).

In January 2022, 28.5% of the Zambian population were using the internet (Datareportal, 2022). Social media was used by 15.1% of the Zambian population, with the majority accessing Facebook (13.5% of the population), followed by Instagram (7.1%), LinkedIn (2.7%), Facebook Messenger (1.3%), and Twitter (0.6%). The number of mobile connections within the country equate to 91.4% of the population – although it should be noted that citizens may have more than one mobile connection (Datareportal, 2022).

Zambia has made some significant strides in its digital transformation (World Bank, 2020), in line with one of their key goals in the 7th National Development Plan (2017). With regards to digital infrastructure, all provincial centres are now linked to fibre internet, there is a national data centre, use of mobile phones has increased significantly and the affordability of broadband meets international benchmarks. However, last mile connectivity remains a shortfall preventing

digital systems being used in sparsely populated areas where access to services and markets is more limited. The cost of connectivity is reportedly also a barrier to persons and businesses due to low income levels (World Bank, 2020).

The 7th National Development Plan (2017) aims to have information and communications technologies (ICT) embedded into the school curriculum. However, in practice most schools are not connected to the internet, they do not have adequate access to devices and teachers have limited knowledge on how to use ICT in teaching and learning processes (World Bank, 2020). This was made evident during the COVID-19 pandemic where institutions experienced difficulty in delivering online lessons to learners. Students could not access e-learning facilities due to prohibitive costs, lack of access to devices, lack of teachers' digital literacy and inadequate e-learning platforms (Nkhowani, 2021). This lack of access, connectivity and skills was more prevalent in rural areas and in under-served populations such as persons with disabilities (Nkhowani, 2021).

Disadvantage and discrimination regarding access of information was experienced during the COVID-19 pandemic of 2019-2021. For example, the Zambian government developed radio and television messages primarily using the Zambian National Broadcasting Corporation (ZNBC) platform, but these were often not accessible to persons with visual and hearing impairment. The country was inadequately prepared and did not develop measures which included persons with disabilities (Chiluba et al., 2020). Persons with disabilities have to right to be included in all activities of health promotion, prevention of disease, treatment of disease and healthy living. This is the responsibility of local communities, as well as the international community and the Zambian government (Chiluba et al., 2020). Since the pandemic there has been significant national and international funding and initiative development within the e-learning space such as the Learning Passport which was released in partnership with UNICEF and the Zambian government (UNICEF, 2022a).

Another area of digital transformation in Zambia is the shift towards digital financial services (World Bank, 2020). Digital financial solutions have been utilised in the rolling out of the National Health Insurance Management Authority (NHIMA). NHIMA has partnered with Zambia Industrial Commercial Bank Limited (ZICB) to facilitate payment of National Health Insurance Scheme premiums using the ZICB digital banking platform, SmartPay. The NHIMA poses this as a solution for delivery of public services across the country, while making payment convenient and cost-effective (Njovu, 2021). However, as discussed earlier, this may limit the registration and access of the NHI by people in rural and/or low-income areas where there are low levels of access to technology and digital skills. Other major government payment flows have not yet been digitised such as the social cash transfer, taxes, school fees and licensing (World Bank, 2020).

When considering this project within the technological context of Zambia, two key factors have been considered. Firstly, the importance of assistive devices, accommodations and modifications for persons with disabilities. During the Ubuntu workshops, assistive devices such as support frames, positioning aids, wheelchairs and walkers will be demonstrated to healthcare workers and caregivers of children with neurodevelopmental disabilities. After being introduced to the assistive devices and how to use them correctly, healthcare workers and caregivers can more effectively advocate for a child to receive the assistive devices they may need via their local doctor/clinic. Accommodations and modifications for disabilities will also be considered in the development and production of information such as pamphlets with use of large legible fonts, pictures and keywords. The training venues will account for assistive devices, accommodations and modifications in that all venues used will be accessible via wheelchair and, where possible, content will be delivered in a quiet environment with visual supports to maximise access for caregivers and persons who may have disabilities. Accessing assistive devices, accommodations

and modifications for persons with disabilities can significantly increase their participation, inclusion and quality of life.

Secondly, in raising-awareness for these events, it is important to consider the digital landscape of Zambia, particularly the low proportion of internet and social media users, while a relatively high proportion of mobile cell phone users. To increase the size of the audience for awareness-raising campaigns, a range of platforms must be utilised including internet platforms, media platforms (TV, radio) and low-tech paper-based campaigns at high frequency locations such as clinics and shopping malls.

ENVIRONMENTAL

Access to health and education are basic rights of all persons in Zambia. However, there continue to be many access barriers, particularly for children and persons with disabilities. Barriers to health and education identified in Zambia include inaccessible buildings; the cost of schooling, transport and medication; a lack of special schools; inadequate funding; a lack of assistive technology; inappropriate equipment; a lack of inclusive education resources; and a lack of staff training on inclusion and disabilities (Scherer et al., 2022). Stigma can also be a barrier as it can result in families being embarrassed to take their child to school and/or health facilities (Scherer et al., 2022). Difficulties with accessing healthcare and schooling in Zambia are not isolated to persons with disabilities, although they are often the population that is most affected. For example, medication can often be out of stock at local pharmacies, clinics and/or health facilities. Although this affects all Zambians, it becomes a greater concern for persons with disabilities who require regular medication for management of their disability such as epilepsy (Scherer et al., 2022).

When considering the environment of this target group, climate and climate change is another significant variable. Zambia relies on rainfed, subsistence agriculture as a main source of food which is highly sensitive to changes in climate, as demonstrated by the failure of millet, maize and sorghum crops following the droughts of 2004-2005. Floods and droughts have increased in frequency and intensity over the past two decades which results in food and water insecurity as well as risks to established health systems, power production (hydropower), biodiversity and infrastructure such as roads and power supplies. Changes in climate pose challenges to Zambia's progress on reducing poverty, reducing food insecurity, developing infrastructure and managing its natural resources sustainably (Climatelinks, 2016).

In a report by Katongo & Chomba (2022), field visits to 14 health facilities were conducted in the parts of the Lusaka, Kafue and Chongwe districts of Lusaka province. This was conducted in order to better understand the resources and services available to children with neurodevelopmental disabilities at different health centres. These included primary health care facilities/clinics, as well as secondary health care facilities/hospitals. From this report, eight of the 14 health centres had no specialist staff to attend to children with neurodevelopmental disabilities. These health centres report referring children with neurodevelopmental disabilities to Beitcure, Kanyama Hospital, the University Teaching Hospital and Chongwe District Hospital. Six of the health centres had physiotherapists on staff to support children. Two health centres report providing some education on disabilities during their antenatal classes (Katongo, 2022). No other allied staff such as speech and language therapists and/or occupational therapists were reported (Katongo & Chomba, 2022). Scherer and colleagues (2022) note that in Zambia, persons with disabilities were frequently being referred from primary health facilities to secondary health facilities, regardless of their health complaint and symptoms, as clinic staff believed that it was only at district hospitals that persons with disabilities could be adequately treated. This was seen more regularly in the district of Lusaka, as primary clinics and district hospitals are in closer proximity in urban areas than rural areas (Scherer et al., 2022).

Although physiotherapy services were available at some of these health facilities in the Lusaka district, neurodevelopmental disabilities are not currently covered in the curriculum for physiotherapy and/or health care professionals at tertiary institutions (Scherer et al., 2022). Having a physiotherapist on site does not ensure that they are fully equipped or trained to provide specialist support to children with neurodevelopmental disabilities.

The government of Zambia has established some systems and procedures to try to increase access to healthcare for persons with disabilities. An example of this is the disability card, which entitles persons with disabilities to access benefits such as free bus rides and priority treatment at healthcare facilities. However, these systems are often under-utilised, not supported by policy and not well understood in the community (Scherer et al., 2022). All persons with disabilities should receive this card from the ZAPD when registering their disability, however many report not having one (Scherer et al., 2022). They report being unsure of the application process, finding it difficult to complete the application without support, and are deterred by the possibility of having to go to the city of Lusaka for an assessment as part of the application. Some out-patient departments have run registration drives in local communities with on-site health workers and forms to help persons with disabilities to register (Scherer et al., 2022).

Many of those who have the disability card, report that they do not receive any benefits from it such as priority service at healthcare clinics. Scherer et al. (2022) suggest that greater awareness of this card and the knowledge of what type of support can be provided to those who hold it is needed in healthcare facilities and the greater community. Scherer et al. (2022) also suggests that a standardized protocol and policy needs to be established in healthcare facilities to ensure consistency and fairness to persons with disability cards. A standardised policy may also help manage the stigmatization of other patients towards persons with disabilities who complain about others receiving 'special treatment' (Scherer et al., 2022).

In contrast to these challenges, innovative health care interventions are found across Zambia. These include clinics that are creating health hotspots in hard to reach communities where they provide testing of problem diseases, family planning awareness, education on supporting young children, antenatal care, and circumcision services. The ZAPD is also providing an array of awareness-raising campaigns and advocating for persons with disabilities on media platforms and at local council meetings. The ZAPD is also actively networking and connecting disability organisations with each other to better support each other initiate and achieve their goals (Scherer et al., 2022). More of these initiatives are needed to increase access to healthcare and education for under-served populations.

This project has considered the environmental context of Zambia in its design and goals. This project recognises that access to quality healthcare for children with neurodevelopmental disabilities cannot be achieved or sustained if healthcare workers are not adequately trained in neurodevelopmental disabilities. The project will conduct quarterly training in the three target districts to train health care workers on neurodevelopmental disabilities and child protection protocols. By 2024, this project aims for at least three out of five community health centres in the project area to provide rehabilitation services for children with neurodevelopmental disabilities; and for persons with disabilities and their families to have increased their access to appropriate rehabilitation and health services increased by 25%.

In addition to supporting healthcare workers within health facilities, this project aims to upskill physiotherapy students and healthcare worker students in neurodevelopmental disabilities prior to their graduation. Only two of the four specialist schools for health professionals teach the disabilities as a subject, but not none of the schools teach neurodevelopmental disabilities as a subject. This project aims for vocational schools to embed neurodevelopmental disabilities into their curriculum for physiotherapists and health professionals. Evelyn Home College has recently implemented a new curriculum and is unable to incorporate the Ubuntu program currently, but will make Ubuntu available online for distance learning. Once changes can be made to their curriculum, Evelyn Home College plans to incorporate neurodevelopmental disabilities into the curriculum of final year of physiotherapy students. For official approval of the curricula at the vocational schools and Evelyn Home College, a basic understanding

of the relevance of the project by the school authorities is essential. The project staff will visit the Ministry of Health, Ministry of Community Development and Social Services, Ministry of Vocational Education and Training and Evelyn Home College regularly to advocate for this target population and to update them on the progress of the project. By 2024, this project aims for four vocational schools to have incorporated neurodevelopmental disorders in their curricula for health professionals; and for at least 60 physiotherapists and health professionals to have been trained in the Ubuntu programme.

In order to address the challenge of transport faced by the target group, the project design has also considered the creation of new parent support groups that will enable an increase in the accessibility of the project activities across different geographic locations.

LEGAL

Zambia's laws support effective protection of children's rights. However, the implementation of these laws can be poor and leads to weak child protection systems in Zambia. The first challenge in the protection of children in Zambia is the lack of uniformity on the definition of a child. Traditionally, one becomes an adult at puberty, while constitutionally one becomes an adult at 18 years. For entering marriage, traditionally, puberty is the minimum criterion for girls to get married, while according to statutory law, the minimum criterion is 16 years (with parental consent) and 21 years (without parental consent). These inconsistencies in the legal system and its definition of a child hinder child protection practices in Zambia and contribute to the high prevalence of child marriages and teenage pregnancies (Pellser Mungu, 2018). The second challenge is that in many rural areas, no formal structures or institutions are actively engaged in fighting injustices against children. There are low levels of awareness of child rights and poor enforcement of consequences for offenders (Pellser Mungu, 2018). Thirdly, the justice system infrastructure does not take into account the needs of children. The age for criminal responsibility is as young as eight years old in Zambia. However, Juvenile court is only at subordinate court level despite it being required at all court levels (Pellser Mungu, 2018). Finally, there is no explicit rights education policy in schools. Children need to know their rights in order to defend themselves, advocate for themselves and report rights violations to trusted adults (Pellser Mungu, 2018).

More positively, there are policies and departments of government in place to respond to crimes and injustices and these have met some success. For example: the Zambia Police Act No14 (1991) mandates Victim Support Unit officers to provide professional counselling to victims of crime & to offenders. In 2021, 73.5% of the reported cases received professional counselling (Zambia Police, 2022).

There are a range of laws and policies protecting the rights or persons with disabilities in Zambia. The first policy for persons with disabilities in Zambia was enacted in 1968 (Handicapped Persons Act of 1968). This law focused on establishing 17 employment centres with sheltered employment for persons with disabilities across Zambia. This was replaced with the Disabilities Act No. 33 (1996) which brought about the establishment of the Zambia Agency for Persons with Disabilities (ZAPD) and the National Trust Fund for the Disabled (NTD) to provide micro-credit to persons with disabilities. In 2010, Zambia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as a commitment to improving the welfare of persons with disabilities. In order to meet the goals of the UNCRPD, the Persons with Disabilities Act No.6 (2012) was enacted to provide for the elimination of all forms of discrimination on the grounds of disability. This Act provides grounds for legal action against persons and/or agencies who engage in discriminatory practices with possible consequences of monetary fines and/or imprisonment. In 2015, the National Policy on Disability was launched to provide guidance and support for Government and stakeholders on disability and development in line with international standards with the vision of equal opportunities for persons with disabilities by 2030.

Despite these acts and policies in place, there has been a lack of enforcement of the Persons with Disabilities Act and a lack of inclusion of persons with disabilities in Zambia's key policies. Reasons for poor enforcement include lack of enforcing penalties, lack of funding and resources, negative attitudes, low sensitisation of the Act and lack of coordinating mechanisms (Scherer et al., 2022). This is evident across all sectors of the economy. Bwalya (2017) conducted a policy analysis on the inclusion of persons with disabilities in key employment, social protection, health and disability-specific policies. The results show all policies ranged from questionable to

medium in their inclusion. Notably the Mental Health Act did not comply with the UNCRPD treaty as it predates it. Although the Mental Health Act is under review, it has not been updated in the past decade.

Within education, the scoping review by Scherer et al. (2022) reports that inclusive policies, strategies and implementation plans are lacking within the education sector. For example persons with disabilities and their families report that some schools have rejected applications from children with disabilities, despite legal grounds for admission (Scherer et al., 2022). In addition, the government is unable to sufficiently fund specialist education for children with disabilities and there continues to be a high reliance on donor funding for special education programmes (Scherer et al., 2022).

Within the healthcare system, persons with disabilities continue to experience lack of access to services and information. In the World Report on Disability (World Health Organization & World Bank, 2011), 62.6% of persons with disabilities in Zambia reported needing medical rehabilitation services, while only 37.5% report accessing this. This gap pervades medical services including social benefits (62.6% in need, 8.4% received support), counselling for parents (47.3% in need, 21.9% received support), mobility aids (57.3% in need, 18.4% received support) and advice (51.2% in need, 14.3% received support).

Within the justice system, persons with disabilities are not sufficiently catered for, despite legal grounds for this under the Persons with Disabilities Act (2012). In the scoping review of the experiences of persons with disabilities in the justice system, they report negative experiences at police stations, in court and in prison. Experiences were reported as negative, and many of the persons with disabilities reported often being unsure of what was happening. Reports of physical abuse, poor physical conditions, and mistreatment by staff were also reported (Scherer et al., 2022).

This project has considered Zambia's legal context and accommodated for this in its planning and implementation. The project's advocacy and awareness-raising efforts will not be limited to caregivers and healthcare workers, but also policy makers, ministers, NGOs, government officials and municipalities. The project staff will visit the Ministry of Health, Ministry of Community Development and Social Services, Ministry of Vocational Education and Training and the Evelyn Home College throughout the project's lifespan. The project has also set up workshops for representatives from organisations supporting persons with disabilities in Zambia to develop their advocacy skills and fundraising abilities. This project aims for children with neurodevelopmental disabilities and their families to be regularly on the agenda of the local development committees and budget planning meetings. In addition, this project aims for at least 200 members of development committees at the district and country level be better informed of the rights of persons with neurodevelopmental disorders and disabilities.

CONCLUSION

This situational analysis employed the PESTEL framework as a tool to understand the context of the general environment of Zambia as a nation and the experiences of children with neurodevelopmental disorders and their families in the three target districts (Chongwe, Lusaka and Kafue). The PESTEL framework also enabled the analysis of the state and condition of children with neurodevelopmental disorders, their families and ecosystem. Using factors such as the political, economic, social, technological, environmental, and legal context of Zambia, it is evident that there is an urgent need for raising awareness about barriers and misinformation around children with neurodevelopmental disorders in schools, health facilities, society and politics to increase the quality of life of children with disabilities and their families. Further, there is a need to develop support strategies for the families of children with neurodevelopmental disorders. The most effective tool for combating these barriers, misinformation and creating support strategies is through training and education, which will be utilised across multiple community stakeholders in this project.

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