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Community inclusion, participation and support for people with disabilities in Zambia: a qualitative study

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ABSTRACT

Background: Recent reports, including recommendations from the United Nations Committee on the Rights of Persons with Disabilities, have highlighted failings in disability inclusion in Zambia. A recent scoping review identified need for up-to-date evidence to inform disability-inclusive policy and practice.

Objective: To generate new evidence on community inclusion, participation and support for people with disabilities in Zambia.

Methods: In-depth interviews were held with 36 participants, including 16 adults with disabilities, 16 caregivers of a child with disabilities, and four key informants from government and civil society. Participants were recruited from three districts in Lusaka Province - Lusaka, Chongwe and Kafue. Participants were purposively sampled to maximise variation by sex, age, impairment type, district and locality (rural, urban, peri-urban). Data collection was completed in November 2022.

Results: Key themes from the study identified stigma and discrimination towards people with disabilities, the exclusion of people with disabilities from community life, limited available support and inadequate government action on disability inclusion. There were examples of positive action on disability support, such as the Social Cash Transfer, but implementation needed improvement. Disability-awareness campaigns are widely needed across government and communities, as is funding for organisations such as the Zambia Agency For Persons With Disabilities.

Conclusions: Action is needed to improve disability inclusion and implementation of the United Nations Convention on the Rights of Persons with Disabilities in Zambia. This includes appropriate funding, capacity-development and meaningful engagement with people with disabilities and their representative organisations.

1. Introduction

Of the 1.3 billion people with disabilities worldwide, approximately 80% live in low- and middle-income countries.[1,2] Signatories of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) commit to promote the rights of people with disabilities, to adopt appropriate legislature, to eliminate discrimination, to ensure equal access to justice, healthcare and education, to provide accessible information and environments, and to promote participation in political and community life.[3] Although most countries have ratified the UNCRPD, people with disabilities remain one of the world's most marginalised and disadvantaged groups.[2,4,5,6,7]

Zambia has an estimated all-age disability prevalence of 7.7 %; approximately 1.5 million people.[8] The country has a history of disability legislation, including the Persons with Disabilities Act 1996, from which formed the Zambia Agency For Persons with Disabilities

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(ZAPD), a quasi-government institution, developed to promote disability inclusion.[9] More recently, the country ratified the UNCRPD in 2010 and enacted the Persons with Disabilities Act 2012, which updated the role and functions of ZAPD.[9,10] People with "severe" disabilities qualify for the government Social Cash Transfer programme, if they live in a household that meets welfare criteria.[9,10] Eligible households with disability receive double the standard cash transfer amount. Despite action for disability inclusion in Zambia, recent reports demonstrate failings in implementing the UNCRPD.[10,11,12,13] People with disabilities in Zambia experience stigma and discrimination, inaccessible environments, and exclusion from education and employment.[11,12,13] The government spends just 0.03 % of the national budget on disability inclusion.[10,14] In 2024, the Committee on the Rights of Persons with Disabilities recommended that Zambia take action to improve implementation of the UNCRPD and the Persons with Disabilities Act 2012.[15] Recommendations included revision of national legislation and policy, improved participation of people with disabilities in planning and implementation, and national disability-awareness campaigns.[15] Recent scoping review of disability research in Zambia identified the need for up-to-date, peer-reviewed research to inform disability-inclusive policy and practice.[12]

This study aims to provide further evidence on the situation of people with disabilities and caregivers in Zambia, specifically community inclusion, participation, and support available from non-governmental organisations (NGOs), organisations of persons with disabilities (OPDs) and government.

2. Methods

This qualitative study included in-depth interviews with 36 participants, including 16 adults with disabilities, 16 caregivers of a child with disabilities, and four key informants from government and civil society.

2.1. Study setting

The study was conducted across three districts in Lusaka Province. The three districts (Lusaka, Chongwe, Kafue) were selected to provide urban, peri-urban and rural settings. Lusaka district is largely urban and holds Lusaka, the capital and largest city of Zambia. Chongwe district, approximately 40 km from Lusaka, is a mix of rural and peri-urban settings. Kafue district, approximately 50 km from Lusaka, is similarly a mix of rural and peri-urban settings.

2.2. Participants

Participants were recruited with the support of OPDs, NGOs and disability focal points in the community. We used Patton's maximum variation sampling to purposively select participants.[16] For adults and children with disabilities, we sought variation across age, sex, type of impairment, district and locality (urban, peri-urban, rural). We segmented the target group by these criteria, aiming for equal representation across each category. Using this method, we sought 16 adults with disabilities and 16 caregivers of children with disabilities. Key informants selected had expertise on disability and government support in Zambia and Lusaka Province. They included government officials working on disability and representatives from OPDs. We did not aim for a minimum sample size for key informants and recruited until saturation. Participant characteristics are available in Table 1.

2.3. Data collection

In-depth interviews were conducted between May–November 2022 by lead author (NS), a disability researcher from the UK, and second author (RC), a qualitative researcher from Zambia. RC received a three-day training from NS on disability, research ethics, informed consent, the interview guides, and interviewing people with disabilities (e.g. working with a sign language interpreter). Specific training was provided on interviewing people with intellectual disabilities and/or communication difficulties, including responsive interviewing techniques, such as adapting the depth of questioning based an individual's capacity and preference. In addition, RC provided NS with guidance for culturally appropriate research in Zambia. Following training, we conducted four pilot interviews, refining interview guides and interview technique. These interviews were included in the final analysis.

Interview guides included questions on the experiences of people with disabilities and caregivers in the community, community attitudes, and support available from government and third sector organisations. NS conducted interviews in English (his native language). RC conducted interviews in Cinyanja (her native language) and English (her fluent second language). Cinyanja is the most widely spoken language in Lusaka Province. English is the most commonly used second language. Interviews with deaf and hard of hearing participants were conducted via a sign language interpreter. Interviews were conducted in a participant's home. Key informants were interviewed in private offices at their place of work. One key informant was interviewed remotely via Zoom. Adult participants with an intellectual disability were given the choice to interview alone or with a caregiver. If they preferred or if they did not have capacity, a caregiver was interviewed as proxy. One adult with an intellectual disability interviewed alone, one interviewed alongside a caregiver, and two were interviews with a caregiver providing a proxy response. During proxy interviews, we encouraged caregivers to reflect not on their experience, but to represent the experience of their relative. Proxy response enabled us to capture experiences of people who have

Table 1
Sample characteristics.

Variable	Criteria	N	%
People with disabilities			
Total		16	
Age	18–30	5	31 %
	30–60	6	38 %
	60+	5	31 %
Sex	Male	8	50 %
	Female	8	50 %
Impairment type	Physical	4	25 %
	Hearing	4	25 %
	Visual	4	25 %
	Intellectual	4	25 %
District	Lusaka	6	38 %
	Chongwe	5	31 %
	Kafue	5	31 %
Locality	Urban	6	38 %
	Peri-urban	6	38 %
	Rural	4	25 %
Caregivers			
Total		16	
Child age	0–6	4	25 %
	7–10	5	31 %
	11–14	7	44 %
Child sex	Male	7	44 %
	Female	9	56 %
Parent sex[a]	Male	4	22 %
	Female	14	78 %
Impairment type[b]	Physical	7	44 %
	Hearing	5	31 %
	Visual	4	25 %
	Intellectual	5	31 %
District	Lusaka	6	38 %
	Chongwe	5	31 %
	Kafue	5	31 %
Locality	Urban	6	38 %
	Peri-urban	6	38 %
	Rural	4	25 %

[a] In some instances, interviews were conducted with two caregivers at one time and the total is thus greater than the sample size.

[b] Participants may have a condition resulting in more than one disability/ impairment type and the total may be greater than the sample size.

difficulty communicating and who may experience unique challenges in day-to-day life.

Interviews lasted 30–80 min and were audio-recorded. Responses from sign language users were reported orally by the sign language interpreter for the interviewer and audio-recording. Audio-recordings were transcribed verbatim. Interviews conducted in Cinyanja were transcribed and translated into English by an independent transcriber and checked by the interviewer (RC). Transcripts were anonymised and stored on a secure server.

2.4. Data analysis

Data was analysed using thematic analysis.[17] The analysis included six steps: (1) authors familiarised themselves with the data, noting initial codes; (2) authors developed a coding framework and NS coded transcripts in NVivo 12; (3) NS identified emerging themes, comparing relationships across codes and participant groups; (4) themes were reviewed by all authors and mapped against the data; (5) themes were refined and narrative developed; (6) participant quotes and case studies were extracted for presentation.

2.5. Reflexivity

Our research team comprised diverse perspectives, including disability researchers from the UK, Zambia, Zimbabwe, Ghana and South Africa. One of the researchers is a person with a disability and one is a caregiver of a child with a disability. Diversity aided interpretation but also necessitated reflection to limit biases. NS, the lead author, has lived in and worked on disability research across East and Southern Africa, but his interpretation of findings may be impacted by limited first-hand experience of systems and communities in Zambia. Discussion and reflection with co-authors from Zambia and other African countries, and with lived experience of disability, mitigated this risk.

The authors further reflect that they are active in advocacy for disability rights, including government policies and service provision that support realisation of the UNCRPD. We recognise that this ideological commitment may have influenced interpretation of results, although we have strived to limit the impact of this potential bias on the presentation of results.

2.6. Reliability and validity

We adopted a number of strategies to promote reliability and validity of this qualitative research.[18,19,20] To promote credibility of the research, we discussed research aims, methodology and data collection tools with an OPD in Zambia. To validate findings, authors discussed themes in a multi-day workshop and with leaders at OPDs and NGOs in Zambia. We did not complete respondent validation as many participants did not have access to technology to review transcripts. To ensure reliability and transparency, we documented all steps and procedures in a data audit trail to identify potential bias.

2.7. Ethical considerations

Ethical approval was obtained from the Research Ethics Committee at the London School of Hygiene & Tropical Medicine (26568) and the University of Zambia Directorate of Research and Graduate Studies (HSSREC-2022-APR-009).

Before starting each interview, researchers sought written or verbal informed consent from participants. Verbal consent was audio-recorded. People with communication or intellectual disabilities were provided a simplified information sheet, with caregiver consent and participant assent obtained when required. Informed consent was given from participants to publish anonymised quotations.

3. Results

Key themes from the study included: (a) stigma and discrimination towards people with disabilities; (b) exclusion experienced by people with disabilities; (c) limited support available in the community; and (d) inadequate government action on disability inclusion.

3.1. Disability stigma and discrimination

Many participants reported experiences of stigma and discrimination. Experiences can be categorised as public and internalised-stigma.

> *"I'm being mistreated. Sometimes I'm insulted. I'm being mocked."*
>
> *(Adult with an intellectual disability, Kafue)*

Regarding public stigma and discrimination, people with disabilities reported negative stereotypes and prejudice towards disability in society. This manifested in derogatory comments, mocking and ridicule. For example, a mother overheard her neighbours saying it is better to be dead than to have a disability, a deaf man was laughed at on the bus when he could not hear the bus conductor, and a parent was told that she had neglected her child to cause their disability.

> *"… there's no love in the community. They always just stigmatise and laugh at disabled people. They turn them into a laughing stock, which is not good, because we are also people and I don't think this will end, no. We are being marginalised left, right …"*
>
> *(Adult with a visual impairment, Chongwe)*

These negative experiences were not isolated incidents. They were described as part of a broader negative societal attitude toward people with disabilities. In many cases, stigma was evident as misplaced sympathy and pity, which left people with disabilities feeling "othered", rather than valued and empowered. People with disabilities and caregivers felt that communities and the government viewed people with disabilities as useless and unable to contribute to society. Negative attitudes resulted from a lack of information and knowledge about disability.

People with disabilities expressed opinions consistent with internalised-stigma and caregivers appeared to internalise societal prejudices because of affiliate and associate stigma. People with disabilities reported reduced self-esteem and self-worth and many caregivers did not leave their house with their child because of discrimination. Some caregivers were in denial about their child's disability, believing that their impairment would improve in time. Some showed reluctance to support their child, their development and their inclusion, and had limited aspirations for their child's future.

Participants described positive examples of advocacy and awareness raising, but these were often small, siloed efforts by OPDs, NGOs, and groups of people with disabilities and caregivers. To improve reach, participants called for nationwide disability awareness campaigns. Participants pointed to the success of HIV/AIDS awareness campaigns, which reduced stigma. They wanted disability to be talked about as openly and with as much knowledge.

> *"So the community, whenever they see a persons with disabilities, they curse us, they oppress us. That's very bad and it really depresses me and I feel lonely […] If the Government or some other national or international organisation can create awareness about us persons with disabilities, I know society and attitudes can change. If people continue being in the dark, then society will not change their perspectives."*
>
> *(Deaf adult, Lusaka)*

People with disabilities, including young people with disabilities, wanted to be involved in raising awareness. One caregiver's teenage son had received disability-awareness training from an OPD and he was excited to start campaigns on social media. Parents also wanted training and empowerment to help with advocacy and sensitisation. They wanted to be connected with other parents of children with disabilities to do this. Some parents in this study were involved in informal parent and caregiver groups that engaged in advocacy in communities and on the radio.

The majority of participants said that government personnel needed better knowledge on disability rights to promote awareness through government ministries and agencies, including police, healthcare settings and schools. Participants further encouraged government to support and finance OPDs to sensitise nationally, and encouraged community action to improve disability attitudes. Churches, religious groups and village headman, who are influential in the community, could be trained as focal points to spread disability awareness.

3.2. Exclusion from community life

People with disabilities, including children with disabilities, were marginalised and isolated. People with disabilities faced physical and social barriers that prevented them from fully participating in community activities and accessing essential services, including school, healthcare and employment. Exclusion occurred within public spaces and within their own families, and led to fewer social interactions and reduced opportunities for meaningful engagement. Exclusion from employment and higher disability-related costs resulted in financial difficulties for many.

Barriers to participation included discrimination, inaccessibility of buildings, transport and the wider environment (e.g. sidewalks), inaccessible information (e.g. public health campaigns), and limited service provision (e.g. sign language training), to name a few.

Exclusion caused people with disabilities to feel lonely and isolated. Social isolation was exacerbated by discrimination, leading to internalised stigma, emotional distress and mental health issues such as anger, anxiety and depression.

> *“Everything which was running through my mind was negative. There was nothing that was positive, because people had different … told their children not to be playing around with me thinking that I will … that my disability may be contagious. So I was a loner, anger was just too much in me. That time around I suffered a lot and I tried to take my life four times …”*
>
> *(Adult with a visual impairment, Lusaka)*

Caregivers were also abandoned by their family. Some mothers were left by their husband. Caregivers did not have the information on supporting a child with a disability and found providing care extremely challenging, especially when family abandoned them. Caregivers reported feelings of stress and mental health issues. Many requested support.

> *“It’s a big impact [having a child with a disability], because when she was born, I was working […] I had to quit the job and it was so hard […] Life became so hard, so hard […] All my relatives suddenly stopped visiting and I could feel lonely […] I wished I had my mother to help me. There was no one elderly to help me and show me how to handle this thing. I had to learn everything for myself from scratch [participant started to cry].”*
>
> *(Caregiver of a child with a visual impairment, Kafue)*

3.3. Support for people with disabilities and caregivers

Support for people with disabilities and caregivers was limited. Many participants were not aware of available support and were not able to utilise what was available. Some had registered for support with government and other organisations but had not heard anything further.

> *“Interviewer: How would you describe the support that’s available to people with disabilities in the community?*
>
> *Participant: I haven’t seen any […] Nothing, nothing, nothing, nothing […] we haven’t … we haven’t seen anything […] I think you are the first one who has come here.”*
>
> *(Caregiver of a child with an intellectual disability, Lusaka)*

The Social Cash Transfer was noted the most prominent support for people with disabilities and families. People with disabilities that accessed the scheme reported positive benefits. It helped families buy food and clothing, as well as chickens, charcoal and other goods to start small businesses for sustainable income. However, many did not access the scheme. To access the scheme, people with disabilities require a disability card from ZAPD to prove their disability status, but there was a low proportion registered. Assessment for the card was often conducted in the capital Lusaka, which was difficult for many to access because of distance, inaccessible transport and cost. Others were simply unaware that the card was available. Even when approved and registered for the Social Cash Transfer, some never received money. Key informants in government reported problems with cash flow. Overall, the scheme was largely well-perceived, but participants recognised the need for improvement in implementation.

NGOs and OPDs have provided support, in the form of cash-transfers, provision of assistive devices, and training for caregivers. These were often beneficial. However, this support was rare and small-scale. NGOs and OPDs had limited funding to provide long-term support at scale. Participants called for additional funding and capacity-development for OPDs who provided essential advocacy and support to people with disabilities and their families.

With limited formal support available, some people with disabilities and families relied on informal support. This included support from friends and family, who provided financial support or childcare. Informal networks included informal community groups. These were often groups of caregivers or cooperatives of people with disabilities. These groups often made products for sale together. Caregivers especially valued these informal groups, as they alleviated isolation, helped generate income and improved their knowledge on disability.

> *“[…] when I meet such parents I feel very much connected, because it’s like you are in the same boat, passing through the same things and you are speaking one language.”*
>
> *(Caregiver of a child with physical and intellectual disabilities, Lusaka)*

Although informal groups were valued, the majority of caregivers and people with disabilities were unaware that groups existed. Formal caregiver groups were occasionally available (for example, from Zambia Association of Parents for Children with Disabilities), but the frequency of these had reduced in recent years due to limited funding. Community and family action was viewed as essential for fostering disability inclusion, promoting support networks, and enhancing understanding and accessibility at grassroots level.

3.4. Government action on disability inclusion

Participants noted that government action on disability inclusion was limited. People with disabilities and caregivers felt neglected by government. They felt that the government often made empty promises that went undelivered. They called on them to take more responsibility for disability inclusion. Participants noted that the UNCRPD had been a force for positive action but government implementation was hindered by limited funding. In particular, ZAPD received too little funding to achieve its mandate.

Implementation was further restricted by limited sensitisation and awareness on disability among key stakeholders in government and across key sectors, including education and healthcare. Thus, disability inclusion schemes, including the Social Cash Transfer, were limited in scale.

> *“Without planning for them [people with disabilities], there will be nothing for them and it will be the same old usual story where on one side we are saying ‘leave no one behind’ on paper, but in the actual reality, we are leaving a lot of those people behind [...] So I think the biggest gap has to do with sensitisation and awareness. A lot of stakeholders are still in the ignorance cocoon to say, ‘We didn’t know we were supposed to provide for this.’ So every time you ... you take an institution to task, the only excuse they have is, ‘Sorry, we didn’t know, we didn’t know we needed to do this.’”*
>
> *(Key informant in government disability role)*

In some instances, participants reported concerns that government corruption limited efforts towards disability inclusion and support for people with disabilities, including the Social Cash Transfer.

> *“You know, this issue of corruption ... they would rather put some others, even if they’re not disabled, in with who they want to access the Social Cash Transfer, as long as they’re ... they’re relatives. You see what I mean?”*
>
> *(Caregiver of a child with physical and intellectual disabilities, Lusaka)*

Government commitment to disability inclusion was said to be improving, with ZAPD developing initiatives to improve engagement with disability organisations and people with disabilities. For example, ZAPD was working with ministries to have people with disabilities in high-level government positions and there were initiatives to improve sensitisation across public institutions. However, ZAPD needed more funding and support to substantially improve action on disability inclusion and OPDs called for improved involvement of persons with disabilities in planning and implementation of national disability strategy.

Although numerous participants called for disability policy reform and improved support, not all understood existing support structures, the mandate of organisations such as ZAPD and where to go for specific needs. For example, ZAPD no longer provided direct services to people with disabilities and instead coordinated and promoted support across stakeholders and service providers. However, many people with disabilities continued to seek direct support from the agency (such as assistive devices), leaving them with negative views when rejected, that may be unwarranted.

> *“But if you go there [ZAPD] it’s as dry as a desert, you get nothing. But why? These people, they are supposed to be there for us [...] we get nothing, literally nothing from them [...] They promise this but haven’t been funded by the Government. You go there, [and they say], ‘We haven’t been funded.’”.*
>
> *(Adult with a visual impairment, Chongwe)*

There is therefore need to improve knowledge and awareness on the disability support available, from whom it is provided and the rights of people with disabilities to available services.

4. Discussion

People with disabilities and their families in Zambia experience stigma, discrimination and exclusion. Support from government is limited. People with disabilities and caregivers rely on NGOs and OPDs who have limited funds, leading to small-scale, short-term support. There is urgent need for action from the government to increase funding for disability inclusion. While government action is crucial for systemic change, families and communities play a vital role in advocating for and implementing disability inclusion, although limited resources hinder their capacity to take meaningful action. Government support can help alleviate these barriers by providing the necessary funding, resources and training to empower community and family initiatives.

Stigma and discrimination towards people with disabilities remain a major challenge in Zambia, as across many countries in sub-Saharan Africa.[5] Improving awareness on disability and reducing stigma was a key recommendation to the Government of Zambia by the United Nations Committee on the Rights of Persons with Disabilities and it requires immediate attention.[15] As identified in this study, action to improve disability-awareness should engage people with disabilities and community leaders. Evidence on interventions to reduce disability stigma in low- and middle-income countries demonstrates potential strategies, but the quality of research is poor, often looking at short-term outcomes, rather than long-term impact.[21] There is need for higher quality research that evaluates the effectiveness and sustainability of stigma-reduction strategies over extended periods of time. Research into the mechanisms of disability stigma and how stigma operates in contexts of poverty will aid development of contextually appropriate intervention strategies.

The findings in this study support previous evidence on the exclusion of people with disabilities and limited disability inclusion in Zambia.[10,12,13,15,22] Limited implementation of the UNCRPD appears to result from a lack of funding, including a lack of funding for ZAPD. Government spending just 0.03 % of the national budget on disability inclusion and the proportion of the Ministry of Community Development and Social Services budget towards disability inclusion has reduced since 2019, from 3.05 % to 0.54 %.[14] This is a worrying trend. Research shows that for every dollar invested into disability inclusion, economies see a ten dollar gain.[2] Whereas exclusion from participation in employment and the economy costs countries 3–7 % of Gross Domestic Product (GDP).[23] Budgeting for disability inclusion should be seen by the Government of Zambia as an economic investment, as well as a human rights obligation. In their assessment of disability spending in Zambia, UNICEF called on the government to seek additional funding from overseas donors, such as the United Nations Development Programme. Just 0.82 % of government funds for disability inclusion programmes are financed by overseas donors and increased funding from external partners is recommended to promote implementation of the UNCRPD.[14]

Although government support was limited, the Social Cash Transfer was recognised as a positive scheme. However, there are failings in implementation. A 2019 report on social protection and disability in Zambia made several recommendations to improve access and increase impact of the scheme.[24] Recommendations include movement to a universal benefit rather than affluence test, movement to individual entitlements rather than household benefits and improvement to registration procedures. The report also corroborates findings of this study with regards to the limited funding for the scheme. Only 0.12 % of GDP is allocated for the Social Cash Transfer scheme, a small amount by international standards. Authors recommend increasing investment to 1 %, which would support expanded coverage.

As well as limited government support, this study highlights limited community support for people with disabilities in Zambia, consistent with a recent scoping review in LMICs.[25] OPDs and NGOs often play a vital role in Zambia, providing advocacy, raising awareness and directly supporting people with disabilities. However, support they can provide is often small-scale and short-term. Evidence suggests that NGOs can in fact act as a barrier to disability inclusion when they lack disability awareness, lack motivation and lack funding.[26] OPDs and NGOs need funding, resources and capacity-development to scale interventions. Engaging people with disabilities is vital in this process of scale-up.[27] Scaling disability inclusive programmes is further limited by a lack of high-quality impact evaluation on the effectiveness of interventions.[25,27,28,29] Research is needed in Zambia to evaluate community support and interventions for people with disabilities, in order to stimulate funding and to inform implementation.

Overall, action to improve disability inclusion is needed in Zambia, in order to alleviate stigma, discrimination and barriers to community life and services for people with disabilities, reduce social isolation, improve access to employment opportunities and education, and improve quality of life and wellbeing. To achieve this, the Government of Zambia needs to fully implement the UNCRPD. This includes improved funding, appropriate governance and accountability systems, up-to-date research and data, disability awareness across private and public sectors, and support to OPDs and NGOs. Meaningful change requires the government to act on all of the recent recommendations from the United Nations Committee on the Rights of Persons with Disabilities.[15]

4.1. *Limitations*

There are limitations to consider when interpreting findings. The research was conducted in Lusaka Province and the findings may not reflect the situation across the country. This is an issue across disability research in Zambia.[12] The funding for this study contributed to work in Lusaka Province and it was not within our scope to conduct research in other areas of the country. It is important that additional research be conducted across the country to inform appropriate government action. Further, more female caregivers were interviewed than male. In Zambia, female caregivers are typically the primary caregiver of children with disabilities, and we were often asked to speak to the female caregiver, even if the male caregiver was available. The challenges that male caregivers experience may be underrepresented in the findings and we encourage additional research with this group. Given the findings emerging regarding stigma and discrimination, it may have been beneficial to conduct additional research with community members and people without disabilities in order to better understand their views on disability.

5. Conclusion

This study highlights the pervasive stigma, discrimination, and exclusion faced by people with disabilities in Zambia, resulting in marginalisation and limited access to services and support. There is a critical need for funding and government commitment to disability inclusion, improved implementation of existing schemes, such as the Social Cash Transfer programme, and comprehensive disability awareness campaigns. To drive meaningful change, there is need for increased funding and capacity-development for OPDs and NGOs, as well as further research into effective inclusion strategies.

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CRediT authorship contribution statement

Nathaniel Scherer: Writing – original draft, Visualization, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Rhoda Chabaputa:** Writing – review & editing, Visualization, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Tamara Chansa-Kabali:** Writing – review & editing, Visualization, Resources, Project administration, Formal analysis, Conceptualization. **Kofi Nseibo:** Writing – review & editing, Visualization, Formal analysis, Conceptualization. **Judith McKenzie:** Writing – review & editing, Visualization, Formal analysis, Conceptualization. **Martha Banda-Chalwe:** Writing – review & editing, Visualization, Resources, Formal analysis, Conceptualization. **Tracey Smythe:** Writing – review & editing, Visualization, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare no conflict of interest.

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