

Barriers to employment for people with intellectual disabilities in low- and middle-income countries: Self-advocate and family perspectives

Kimber Bialik  | Manel Mhiri

Inclusion International, London, UK

Correspondence

Kimber Bialik, Inclusion International, The Foundry, 17 Oval Way, London SE115RR, UK.
Email: kimber@inclusion-international.org

Funding information

Foreign, Commonwealth and Development Office

Abstract

Despite a growing focus on disability-inclusive employment and livelihoods, people with intellectual disabilities and their families remain underrepresented in both the literature and in employment programming. This paper identifies key barriers to inclusive employment collected through six (6) focus groups made up of people with intellectual disabilities (N:54) and their family members (N:45) in Kenya, Uganda, Nigeria, and Bangladesh. Self-advocates and families report stigma, denial of access to education, safety and security concerns, pressure to engage in self-employment, and discrimination as key barriers. Their experiences can contribute to more inclusive cross-disability perspectives on employment and provide guidance for practitioners aiming to design responsive disability-inclusive employment programmes.

KEYWORDS

disability-inclusive employment, employment, families, intellectual disability, self-advocacy

1 | INTRODUCTION

Disability-inclusive employment has been a growing area of interest for funders, international organisations, the development sector and organisations of persons with disabilities (OPDs). There is a growing recognition that although people with disabilities represent an estimated 15% of the global population (World Health Organization & World Bank, 2011), they remain significantly less likely to be participating in paid formal sector employment than the

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2022 Inclusion International. *Journal of International Development* published by John Wiley & Sons Ltd.

general population (Colella & Bruyère, 2011). Among people with disabilities, people with intellectual disabilities are among the most marginalised and have the lowest rate of participation in the labour force as compared to other impairment groups (Khayat-zadeh-Mahani et al., 2020). While the introduction of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) affirmed the right of all people with disabilities to access open, inclusive and accessible workplaces as outlined in its Article 27, this is not yet a reality for people with intellectual disabilities.

Despite the systemic exclusion that people with intellectual disabilities continue to face, cross-disability perspectives on disability-inclusive employment often exclude the specific barriers that people with intellectual disabilities encounter when trying to access employment, which can result in policies and programmes that are unresponsive to the unique needs of different impairment groups. While some of the key elements for fostering inclusive employment for people with intellectual disabilities have been identified in the literature—namely, ensuring employment based in the local community, securing fair pay, the individual having the freedom to choose their own job and access to support at work being available (Bond, 2004)—these analyses tend to be rooted in a broader cross-disability perspective and not in the experiences of people with intellectual disabilities and their families. This paper aims to respond to this gap in the literature by presenting the perspectives of people with intellectual disabilities and their families on access to employment.

Clear presentation of the voices of people with intellectual disabilities and their families is a necessary addition to the literature as people with intellectual disabilities still face significant barriers to accessing inclusive employment around the world. While there are little reliable data on the employment rates of people with intellectual disabilities in low- and middle-income countries (LMICs), exclusion from employment is a phenomenon consistent across countries and regions. Data on the employment rates of people with intellectual disabilities in high-income countries are indicative of the scale of the problem—only 7.1% of people with intellectual disabilities in Ireland (National Disability Authority, 2005), 4.2% of people with intellectual disabilities known to their local authority in Scotland (Scottish Commission for Learning Disability, 2018) and 25% of people with an intellectual disability in Canada (Inclusion Canada et al., 2021) have a job in the open labour market. In LMICs, people with intellectual disabilities are even less likely to have access to education (Inclusion International, 2009), and the significant stigma pervasive in these regions (Inclusion International, 2006) creates additional barriers to employment that amplify the exclusion experienced in higher income countries. Sheltered workshops for people with intellectual disabilities remain prevalent around the world, people with intellectual disabilities continue to be discriminated against by employers and colleagues, and people with intellectual disabilities are expected to accept unfair and unequal wages for performing the same work as their colleagues without disabilities (Inclusion International, 2021), despite these realities being in violation of Article 27 of the CRPD (United Nations General Assembly, 2006).

However, when the barriers to inclusive employment for people with intellectual disabilities are reflected in the literature, they are commonly reported through the perspectives of employers (Kocman et al., 2017; Morgan & Alexander, 2005; Zappella, 2015) or through the perspectives of academics, disability service providers and professionals (Khayat-zadeh-Mahani et al., 2020). The studies that do collect data about lived experience directly from people with intellectual disabilities themselves tend to be based in the global north (Cheng et al., 2018; Lysaght et al., 2012), leaving a gap in the literature for disability-inclusive employment rooted in the experience of persons with intellectual disabilities from LMICs. The current gap in knowledge risks disability-inclusive employment programming failing to understand and appropriately respond to diverse contexts and the needs of communities in LMICs.

Although parents and social networks of families play a key role in facilitating employment opportunities for people with intellectual disabilities (Petner-Arrey et al., 2016), the perspectives of family members are also not often reflected in the literature on disability-inclusive employment. Some family members have been included in studies as a proxy participant for their family member with an intellectual disability (Khayat-zadeh-Mahani et al., 2020), although in these instances they were speaking on their family member's behalf and not speaking to their own unique role and experiences as a family member. As key supporters of family members with an intellectual disability, who are often instrumental in supporting their access to employment, the lack of representation of the voices of family members of people with intellectual disabilities is similarly a key gap in the literature.

A related issue alongside representation are the principles of disability-inclusive employment reflected in the literature. The metrics used to measure successful inclusive employment rarely measure genuine inclusion, with few studies attempting to understand belonging, reciprocity or fulfilment in the workplace as reported by employees with intellectual disabilities (Lysaght et al., 2012). Where case studies exist, they tend to focus on strategies that will maximise efficiency for people with intellectual disabilities in the workplace (Moore et al., 2017) but are less likely to address ideas of belonging and inclusion at work. The lack of focus on inclusion as a value and the lack of grounding in the CRPD creates a risk that methodologies may be promoted which are not contributing to genuinely inclusive workplaces and communities.

This paper aims to address these gaps by identifying structural and institutional barriers to accessing inclusive employment and the strategies that successfully facilitate inclusive employment in LMICs, as reported by people with intellectual disabilities and their families from Kenya, Uganda, Nigeria and Bangladesh. Promoting the voices of people with intellectual disabilities and their families in LMICs contributes to richer learning based on their direct experiences of employment and exclusion from employment. This can help researchers and practitioners ensure that the methodologies and programming developed to create disability-inclusive employment are responsive to and directed by the experiences of people with intellectual disabilities and their families, in line with the 'nothing about us without us' ethos of the disability movement.

2 | METHODOLOGY

Qualitative data on barriers to employment were collected from people with intellectual disabilities and their families through focus groups in Kenya, Uganda, Nigeria and Bangladesh. The focus groups were conducted through Inclusive Futures, a UK Aid-funded project running from July 2019 through June 2022 that works to identify pathways for disability-inclusive employment. The selection of countries for collecting data on perspectives of people with intellectual disabilities and their families was limited to the eligible countries for the Inclusion Works project, namely, Kenya, Uganda, Nigeria and Bangladesh.

Questions and activities during the focus group sessions were designed to address two key questions—what barriers do people with intellectual disabilities face, and how well are the unique experiences of people with intellectual disabilities captured in understandings of disability-inclusive employment for the cross-disability community. To identify whether people with intellectual disabilities and their families agreed that their experiences were reflected in cross-disability statements, participants analysed and discussed statements about barriers to employment for people with disabilities from the Situational Analyses for Kenya, Uganda, Nigeria and Bangladesh produced as guiding documents for the Inclusion Works project. Data from the focus groups were collected by the authors and coded across key themes.

2.1 | Participants

Six focus group interviews were conducted during 2019 that included a total of 54 participants with intellectual disabilities and 45 participants who are family members of people with intellectual disabilities. All focus group participants were members of a local organisation of persons with disabilities (OPDs) which belong to the Inclusion International network, and the participants were identified for participation in the focus groups by their local OPD. Focus groups of people with intellectual disabilities and focus groups of family members of people with intellectual disabilities were conducted separately, with three focus groups conducted for people with intellectual disabilities (one each in Bangladesh, Nigeria and Kenya) and three focus groups conducted for family members of people with intellectual disabilities (one each in Uganda, Nigeria and Bangladesh), as detailed in Table 1.

TABLE 1 Breakdown of participants

Focus group	Location	Demographic	Nationality	Number of participants
1	Dhaka, Bangladesh	People with intellectual disabilities	Bangladeshi	26
2	Nairobi, Kenya	People with intellectual disabilities	Kenyan and Ugandan	8
3	Lagos, Nigeria	People with intellectual disabilities	Nigerian	20
4	Kampala, Uganda	Family members of people with intellectual disabilities	Ugandan	16
5	Lagos, Nigeria	Family members of people with intellectual disabilities	Nigerian	13
6	Dhaka, Bangladesh	Family members of people with intellectual disabilities	Bangladeshi	16

A total of 54 people with intellectual disabilities participated in the three focus groups of self-advocates. Participants in these three focus groups are referred to both as ‘people with intellectual disabilities’ and as ‘self-advocates’ throughout this article. These focus groups included individuals over the age of 18 who had an intellectual disability, most of whom had some experience with formally organised self-advocacy, either through participating in previous self-advocacy training or participation in a local self-advocacy group through their OPD. Within each focus group, participants had a diverse array of work statuses, with each group including individuals who were unemployed, self-employed, working without pay and working with pay in a formal sector job. Participants primarily lived in urban centres. Participants in the Nigerian and Bangladeshi focus groups had more male than female participants, whereas the participants in the Kenyan focus group were primarily female. The focus groups of people with intellectual disabilities took place over 2 days, with a variety of open-ended questions and group activities used to prompt discussion about disability-inclusive employment and barriers to employment among the participants.

The focus groups composed of family members of people with intellectual disabilities included 45 participants across the three groups. The researchers used a broad definition of family which included blood relatives, non-blood relatives and other primary caregivers; however, despite the wide eligibility, all family members who chose to participate in the focus groups were blood relatives. Participants were primarily parents of people with intellectual disabilities but also included some siblings, grandparents and other extended family members. All three family focus groups skewed significantly female, which is reflective of the disproportionate responsibility of care that falls on female family members (Moreira da Silva, 2019). The participants primarily lived in urban areas. The focus groups of family members took place in 1 day over two 3-h sessions, with a variety of open-ended questions used to prompt discussion about disability-inclusive employment and barriers to employment among the participants.

2.2 | Ethics and positionality

Both participants with intellectual disabilities (or their guardian in the case of participants under the age of 18) and participants who are family members of persons with intellectual disability gave consent to participate. Information about the focus group was shared in local languages, and informed consent was obtained by the local OPD supporting the focus groups. Participants with intellectual disabilities participated in focus groups alongside a support person of their choice.

Regarding researcher positionality, the focus groups and data analysis was conducted by a Uganda-based researcher from Canada and a Tunisia-based Tunisian researcher. The researchers did not have experience with the local context in all of the focus group locations, but to ensure appropriateness for the diversity of local contexts, focus groups were co-facilitated alongside local staff of the OPD supporting the focus groups. Additionally, both

authors are siblings of people with intellectual disabilities and are working in the field of advocacy and rights promotion for people with intellectual disabilities. This positionality informed the research team's data analysis and understanding of both family and self-advocate perspectives.

This research was conducted with funding from the United Kingdom's Foreign, Commonwealth and Development Office (FCDO) as part of the Inclusion Works project. Ethical approval was sought for the Inclusion Works project in each of its four implementation countries—Kenya, Uganda, Nigeria and Bangladesh.

3 | RESULTS

Throughout the six focus groups, both people with intellectual disabilities and their family members shared experiences that were relatively consistent across countries and contexts. Stigma against people with intellectual disabilities by employers, the importance of education, concerns about self-employment, experiences of exploitation and abuse in the workplace, the essential role of families and increased barriers for women with intellectual disabilities were the key themes discussed in all six focus groups. Focus groups of family members of people with intellectual disabilities also raised additional themes of security and workplace safeguarding.

3.1 | Stigma from and discrimination by employers

Stigma and negative attitudes towards people with intellectual disabilities emerged as the most common barrier raised by the participants across the three focus groups of self-advocates, both during the hiring process and when in employment. Self-advocate participants argued that unlike other disabilities, employers lack an understanding of what intellectual disability is, which makes them less likely to hire someone with an intellectual disability as compared to a person with a physical or sensory disability, which the participants felt were more widely understood. In Nigeria and Bangladesh, participants also made a point to note that negative attitudes are not limited to employers—they felt that customers and co-workers they may encounter at work also hold negative attitudes towards people with intellectual disabilities. A self-advocate participant in Bangladesh reported that he had noticed that employers have a belief that all people with intellectual disabilities are 'not of sound mind', and for that reason are unwilling to hire them for any job that would require decision making. Similarly, another self-advocate participant in Bangladesh expressed that in his experience employers are concerned that people with intellectual disabilities will be 'a disturbance' to the workplace and that employers are unwilling to hire them for that reason. These experiences are consistent with the negative attitudes towards people with intellectual disabilities held by employers and others in the workplace documented in the literature (Schur et al., 2005; Scior, 2011). Participants in Bangladesh emphasised the key role of parents, siblings and other family members in helping employers to understand their potential and skills and correct their misconceptions.

Perceptions of value also emerged as a key theme across both the self-advocate and family focus groups. Participants with intellectual disabilities reported that they felt that employers fail to see the value of potential employees with intellectual disabilities. Across all three self-advocate focus groups, they reported that they believe employers do not want to hire them because employers feel that their value or productivity would not be worth more than their wages would cost the employer. Similarly, family members reported that when people with intellectual disabilities are hired, the belief that they are likely to be unproductive employees impacts how their employer interacts with them. While the literature reflects concerns by employers about job performance and absenteeism (Kaye et al., 2011), participants in the three self-advocate focus groups in Kenya, Nigeria and Bangladesh reported that they believe their experience was different from people with disabilities in other impairment groups, for whom the participants do not believe employers have the same hesitancy about inherent value.

Linked to this devaluation, work culture and disrespect were also key themes that emerged through discussion in the Kenyan and Bangladeshi focus groups. These insights from self-advocates are significant as treatment of people with disabilities by colleagues is a key ingredient in creating inclusive workplaces (Colella & Bruyère, 2011). Participants with previous work experience shared stories of experiencing ridicule and harassment by co-workers, physical and verbal abuse in the workplace and consistently dismissive attitudes from supervisors and co-workers. One participant in Bangladesh expressed that many employers treat the people with intellectual disabilities that they have hired 'like servants'. Family members in Bangladesh shared that employees with an intellectual disability are often treated as scapegoats and reported their children being blamed for workplace incidents unrelated to them, as well as not being forgiven for errors that other employees without disability would not be criticised for. Negative attitudes by colleagues are documented as a limiting factor for goal achievement and inclusion in the workplace for people with disabilities (Akrami et al., 2006), but the experiences reported by self-advocates go well beyond negative attitudes and constitute clear instances of abuse. The issue of workplace discrimination and abuse was not discussed or identified in the Nigerian focus group, where few participants had previous paid work experience outside of their OPD, which could account for the lack of shared experience. Participants across all countries noted that they do not experience discrimination in workplaces when the employer is an OPD representing people with intellectual disabilities. Many of the self-advocate participants had gained their first work experience through their local OPD, and some of the participants continued to work for their local OPD at the time of the focus group. Self-advocate participants identified OPDs as employers who can see their value and who are more willing to provide them with jobs suited to their skills.

Self-advocate participants in Nigeria, Bangladesh and Kenya all pointed to the denial of reasonable accommodation in the workplace as another common instance of discrimination they face. They identified a wide range of accommodations that would support them in the workplace—flexible working hours or shorter shifts where appropriate were raised by participants in all three focus groups, as was clear communication from employers and the use of plain language. Transportation to work was raised as an important accommodation in Kenya and Bangladesh, as participants raised that public transit is often unsafe or difficult to navigate. While extensive research has been conducted on reasonable accommodations in the workplace for people with physical disabilities (Padkapayeva et al., 2017), literature on reasonable accommodation for people with intellectual disabilities in their own words is much less prominent. Self-advocate participants in Bangladesh also raised that sensitivity training for co-workers in their workplace was an essential ingredient for a successful work experience. Self-advocate participants also raised the need for equal pay, standard benefits and having the terms of their contract respected as an important part of the employment package for people with intellectual disabilities. Self-advocates in Kenya collectively agreed that the most important accommodation an employer can offer them is flexibility, which includes supporting them when they ask for help and making adjustments to their role where they need more support.

3.2 | Denial of fair pay

Self-advocates reported that the perception that employees with intellectual disabilities are inherently less valuable often manifests as denial of fair pay. Evidence of wage discrimination and unequal pay have been documented in the literature in higher income countries (Gunderson & Lee, 2016; O'Reilly, 2003), and various models to estimate wage differentials between people with disabilities and people without disabilities exist (Baldwin & Choe, 2014), but little of these data reflects the reality in LMICs. Self-advocates in Kenya shared that it is common practice for employers to ask people with intellectual disabilities to work unpaid for a period of time to 'prove themselves' before the employer would make a decision about whether or not it would be worth it to pay them for their work. Self-advocates in all three countries also reported that they are offered lower wages for the same work that an employee without a disability would be paid a full wage for. Participants said that because they have fewer employment options, people with intellectual disabilities are often willing to accept lower wages and that employers are aware of

and take advantage of this situation. Self-advocates also reported that in their experience, employers also have low expectations of the agency of people with intellectual disabilities, and as a result, they believe that an employee with an intellectual disability would not challenge the unfair wages.

Participants in the Kenyan focus group reported being paid anywhere from a quarter of the standard wage to one-tenth of the standard wage in their previous work experience. Participants in Bangladesh reported that employers in Dhaka often place people with intellectual disabilities in a different category from the employees that they see as 'normal' for wage purposes and that they typically would pay an employee with an intellectual disability one-quarter of the standard wage. Similarly, family members shared stories consistent with the theme of unfair pay in their focus groups. One family member in Bangladesh shared that her son was made to work unpaid trial shifts for an employer, and after passing the trial and being hired with pay, his wage was significantly lower than his colleagues who performed the same role. One parent in Nigeria shared that her daughter is paid one-tenth of the standard wage for her work in a hair salon. Parents in Uganda also reported that this was the case for their family members with intellectual disabilities who work in the informal sector—one family member shared an anecdote about his daughter's work producing and selling bags. Although her materials cost 30 000 Ugandan shillings and she sells the bag at a price of 50 000 shillings, customers regularly approach her and attempt to buy her products at a cost of 1000 or 2000 shillings because they believe that because she has an intellectual disability, her product does not have full value and should not be sold at full price.

3.3 | Access to education

Educational barriers also came up in all six focus groups as a key impediment to employment. In LMICs, including Kenya, Uganda, Nigeria and Bangladesh, people with intellectual disabilities are typically excluded from mainstream schools and are commonly either out of school or isolated in segregated schools (Inclusion International, 2009). Self-advocate participants expressed that their exclusion from the mainstream education system prevents them from accessing certificates, and participants emphasised that employers tended to be unwilling to consider them as candidates for jobs because they do not have certificates. They reported that they identify the segregated education system for people with intellectual disabilities in Kenya to be part of the problem, sharing that segregated schools do not provide any kind of certificate for proof that the individual attended school, which puts them at a disadvantage in the job market. A lack of school completion certificates as a result of marginalisation from mainstream education for people with disabilities has been documented in the literature in other contexts (Wehbi & El-Lahib, 2007), but there is little documentation of how this challenge manifests for people with intellectual disabilities specifically.

Family members in all three family focus groups echoed these concerns, highlighting access to education as a key challenge they had faced in attempting to access employment for their family member. Family members in Nigeria shared anecdotes about connecting with business owners to seek employment for their family member with an intellectual disability and being denied because they could not provide any certificates or other proof of school attendance. Families in Uganda shared that even in instances where the segregated schools their children attended did produce a certificate, employers would not accept these certificates because they were not from a mainstream school. Families in Nigeria also noted that the expectations of education levels and specific certificates varied from employer to employer, with some employers asking for secondary school certificates and others looking for candidates with vocational training certificates. Family members reported that because the expectations for specific certification or training are not consistent across sectors, it is difficult to identify employers who may be a good fit for their family member. Similarly, on the theme of documentation, families in Uganda shared that they have been asked by employers to provide a letter of recommendation from their local authority before their family member with an intellectual disability can be hired but that the local authorities were unwilling to produce this kind of letter for a person with an intellectual disability.

3.4 | Gender

Gender was also a key theme that was discussed by self-advocates primarily in the Kenyan and Bangladeshi self-advocate focus groups. This theme is consistent with the evidence base on gender in the literature, which reflects that women with disabilities face more significant discrimination in accessing and maintaining employment than men with disabilities (International Labour Organization, 2004). Traditional gender roles were raised by self-advocates in Bangladesh as a key barrier to employment for women with intellectual disabilities. Women with intellectual disabilities in the Bangladeshi focus group raised that family expectations of marriage and child-rearing took precedence over preparing them for work and that their family members are often not supportive of them seeking work, instead pressuring them to marry and have children. Participants in Kenya shared that manual labour jobs are often the only roles for which employers are willing to hire people with intellectual disabilities but that it would be difficult for a woman to be considered or hired for a manual labour job. Bangladeshi focus group participants also shared that they believe women are paid less than men for the same role, while the Nigerian and Kenyan focus groups did not raise this concern. While many of the other experiences that were raised during the focus group were unique to people with intellectual disabilities seeking employment, this point of discussion was one of the only instances raised of a more widely applicable barrier, to both women with other disabilities and women without disabilities. Experiences raised by self-advocates aligned with the reality of gender discrimination in higher income countries, whereby women with disabilities are less likely to be hired, less likely to be promoted and typically paid less (International Labour Organization, 2004; O'Reilly, 2003). While self-advocates in Kenya also voiced that they felt paid jobs were more difficult to access for women with intellectual disabilities than men with intellectual disabilities, their discussion about gender as a barrier instead focused on safety concerns from family members about women in the workplace.

3.5 | Safety and security

The most pervasive theme raised by family members in the three focus groups in Uganda, Nigeria and Bangladesh was safety and security for their family member with an intellectual disability at work. Presently, there is little documentation in the literature about the increased risk of abuse in the workplace for people with intellectual disabilities, particularly in LMICs, although the literature does document that people with intellectual disabilities do experience varying types of abuse throughout their lives (Hewitt, 2014). Many family members shared stories of both verbal and physical abuse and harassment on the job by co-workers and supervisors. Anecdotes from families in Bangladesh ranged from colleagues refusing to eat lunch with an employee with an intellectual disability to life-threatening physical violence on the job. Family members in Nigeria shared stories of their family member experiencing physical or sexual assault in the workplace and while travelling to work and shared their hesitancy to support their family member to access employment outside the home in the aftermath of the abuse. Family members in all three countries raised concerns about the safety of people with intellectual disabilities accessing inclusive workplaces, particularly with concerns about independent transportation to work. Family members in Bangladesh shared that in their communities, it is common for people to work outside of their communities and travel long distances to work—family members reported that they want to accompany their family member to work but do not have the time or resources to do this, and private vehicle transportation is cost prohibitive. Financial security was also a key safety and security concern flagged by family members in Uganda, Nigeria and Bangladesh—they noted that financial autonomy was a barrier for their family members, who they were concerned bore a risk of financial exploitation by employers and colleagues. Although the evidence base on financial abuse and financial control of people with intellectual disabilities is limited, this concern of family members is reflected in the literature in higher income countries (Buhagiar & Azzopardi Lane, 2020).

Safety and security did not emerge as a key theme or concern in the self-advocate focus groups, although self-advocates in Kenya reported that they were aware safety was a big concern of their family members. Families in Uganda and Nigeria recognised the challenging balance between the desire of their family member with an

intellectual to disability to work 'out there' and their concerns about their safety when they are working in inclusive employment. Families in Bangladesh were more likely to be optimistic about their family member's opportunities to work in the formal sector and shared that they did not feel like their concerns and hopes were in conflict with that of their family member with an intellectual disability.

3.6 | Overemphasis on self-employment

At least one participant in each self-advocate focus group was self-employed, and although self-employment was not a primary focus of any of the discussions, it was addressed in each focus group. Self-advocates in Kenya, Nigeria and Bangladesh all reported that they are often pushed into self-employment as an alternative to formal sector work experience. This pressure for people with disabilities to engage in self-employment is consistent with the narrative on self-employment reflected in the literature, which tends to present self-employment as a flexible, satisfying and effective way to ensure accommodation in employment (Jones & Latreille, 2011; Pagán, 2009). Participants in Bangladesh were emphatic about the barriers in place to self-employment, noting that people with intellectual disabilities do not get financial support to start a small business and they lack access to the training and support they would need to make their business successful. A participant from Uganda who is self-employed as a tailor shared experiences of discrimination from customers and attempts to take advantage of him by attempting to negotiate lower prices. In Bangladesh and Kenya, participants emphasised the role of family for people who are self-employed, noting that support from families is the best way to make self-employment successful for people with intellectual disabilities. Similar barriers to self-employment for people with intellectual disabilities have been documented in higher income countries—a study of business owners with cognitive disabilities found that an array of labour-intensive supports are required to support with business management and that business owners were not able to earn an adequate amount of money to live on through self-employment initiatives (Hagner & Davies, 2002). Self-advocate focus group participants in Kenya affirmed that while some individuals may want opportunities for self-employment, their broader goal for people with intellectual disabilities was that everyone has access to a job in an inclusive formal sector workplace. Participants in Kenya shared that inclusive work environments are empowering, because it gives them an opportunity both to learn from others and to teach others, which they identify as important for their self-esteem. This reflection from the participants is consistent with findings in the literature which indicate that jobs in the competitive labour market yield higher job satisfaction for people with intellectual disabilities than alternatives (Jiraneck & Kirby, 1990).

Concerns about security and safety shaped the perspectives of family members on self-employment, which they perceived more favourably as a viable option than the self-advocates. Family members in Uganda shared that they considered self-employment ideal because it reduces the risk that comes with working in an external workplace—they can be assured that their family member is safe because they are working from home, and they do not need to manage the added cost or added danger of public transport. Families in Nigeria emphasised that they felt like they needed to be engaged in every aspect of their family member's work to ensure that they were safe, which is an easier task when their family member is self-employed.

3.7 | The role of families

The role of families was also raised by self-advocates with respect to formal employment. Adults with intellectual disabilities are less likely to leave their family home as an adult (Wehman, 2006), resulting in the family continuing to play a significant role throughout adulthood. Self-advocate focus group participants discussed the role of their families in helping them identify and apply for work opportunities, which was consistent with reflections in the literature about the positive impact of family engagement in workplace transitions (Kohler & Field, 2003). Self-advocates in

Kenya, Nigeria and Bangladesh agreed that for people with intellectual disabilities, their families are their key supporters and are typically the ones who help them to get jobs. All participants who had previous work experience stated that their family members played a role in helping them to secure that job. However, participants in Kenya and Bangladesh also raised that family can also be a barrier to work, particularly in cases where their families are concerned about safety and security outside of the home. This reflection on family concerns and potential for overprotection has also been documented in the literature in higher income countries (Callus et al., 2019).

The family member focus groups in Uganda, Nigeria and Bangladesh also discussed what they saw as the role of the family in supporting access employment. While the majority of the family members consulted reported that their family member with an intellectual disability was unemployed, for those who were employed, the family member noted that they or another family member had been instrumental in helping them access that job. Family members in all three focus groups affirmed that supporting their family member to access employment was a key part of their familial role. Family members in Uganda reported that as their family member's primary supporter, they are best suited to help them access a role that is a good fit for their strengths and weaknesses. Family members in Nigeria raised that it typically is only the immediate family—parents or siblings—who take on this role, noting that they lack support from extended family members, even when those extended family members have their own businesses or connections with employers. These results affirm that the documented key role families play in supporting access to employment for people with intellectual disabilities in higher income countries (Kohler & Field, 2003; Petner-Arrey et al., 2016) also hold true in LMICs.

3.8 | Other economic barriers

Both self-advocate participants and family member participants reported economic barriers impacting access to employment, although self-advocates spoke about economic barriers at the individual level while family members spoke about economic barriers at the systemic level.

Self-advocate participants discussed how family wealth may be a barrier for some people with intellectual disabilities trying to access employment, with participants in Kenya and Bangladesh pointing out that for people with intellectual disabilities whose families are not well connected or who do not have any family members who own businesses, their path to employment is more difficult. Participants in Bangladesh also emphasised that wealthy families are the most likely to have access to the government jobs that people with intellectual disabilities see as most desirable, as these families are most likely to have connections to political leadership. Self-advocate participants in Kenya also noted that people with intellectual disabilities from wealthy families are more able to get jobs outside of their immediate neighbourhood because their family is able to afford private transportation for them to and from work, which increases their opportunities for work locations.

In contrast, families raised the broader economic situation of their countries as a barrier for employment. This theme was particularly significant in the Nigerian focus group, where family members reported that high unemployment rates across Nigeria made access to employment even less likely, because people with university degrees are currently unemployed and seeking roles where they would be underemployed, which creates even less availability in the job market for someone with an intellectual disability who has not had access to education. During economic downturns, people with disabilities also face an increased likelihood of job loss as compared to people without disabilities during cutbacks, which has been documented in higher income countries (Mitra & Kruse, 2016).

4 | DISCUSSION

The barriers raised by people with intellectual disabilities and their families in the focus groups addressed primarily areas where they felt that the narrative about disability-inclusive employment was not fully reflective of their

experiences and areas where programmatic work on disability-inclusive employment is failing to address the key issues that they face. Based on these reflections, this section identifies recommendations for disability-inclusive employment programming that is responsive to the needs and concerns of people with intellectual disabilities and their families.

Self-advocates and their families pointed to a number of instances where they felt that their experience of barriers to employment and experiences in work differed from people with disabilities with other impairments—they feel that employers see them as less valuable than other people with disabilities, they feel that segregated schools being the only education they have access to puts them at a disadvantage, they feel that they are often pressured into self-employment out of the assumption that inclusive workplaces are not right for them, and they feel they are most likely to be mistreated in the workplace. They also carved out a unique role for families that differs from other groups of people with disabilities, and they have unique safeguarding concerns. While some of these barriers also impact other people with disabilities, people with intellectual disabilities and their families report being more affected by these barriers and instances of discrimination or facing heightened negative impacts. As one of the most marginalised groups among people with disabilities (Khayatzadeh-Mahani et al., 2020), the unique experiences of people with intellectual disabilities in their own voices should be better represented in cross-disability employment literature to ensure all experiences and barriers are reflected.

A number of the points raised by people with intellectual disabilities and their families have direct implications for disability-inclusive employment practice, particularly for cross-disability programming that aims to be inclusive of all people with disabilities. The concerns raised by self-advocates and their family members about ongoing discrimination in the workplace perhaps has the most significant implications for future practice. While the literature discusses barriers to accessing employment (Kocman et al., 2017; Morgan & Alexander, 2005; Zappella, 2015) and much of employment programming similarly looks at strategies for breaking down barriers, the reflections shared by self-advocates about discrimination in the workplace suggest that methodologies that focus primarily on barriers are not fully addressing the issue of exclusion from employment. Self-advocates shared experiences in the focus groups of workplace bullying, mistreatment by supervisors and colleagues and exploitation in the workplace which indicates that supporting people to overcome barriers and get into a job is insufficient for ensuring inclusion. The experience shared by self-advocates and their families suggests that to be responsive to the continued barriers to inclusion that a person faces once in a workplace, programming must be designed not only to place people in jobs, but to create environments within workplaces where employees with intellectual disabilities can be fully included, valued and treated as an equal. Ongoing disability sensitivity training and support from colleagues were identified as strategies to achieve this by self-advocate participants.

The narrative about families developed both by people with intellectual disabilities and their family members in the focus groups also has significant implications for programme design for disability-inclusive employment work. The focus groups indicate that self-advocates and their family members have a clearly aligned understanding of the role of family members in their search for employment—families are their key supporters, can support self-advocates with making decisions about the employment that may be a best fit for them and are instrumental in helping them with outreach to employers and securing a job. These insights are also consistent with discussions about families of people with intellectual disabilities in the employment literature (Kohler & Field, 2003; Petner-Arrey et al., 2016). As family members of people with intellectual disabilities play a different and more comprehensive role in the journey to accessing inclusive employment compared to the family members of other people with disabilities, this unique role for family members of people with intellectual disabilities should inform the design of programming. Cross-disability inclusive employment programming rarely builds in a substantial role for family members, which both people with intellectual disabilities and their family members identify as a key ingredient for their success in employment. This newly articulated role for families also indicates that additional research on the role and needs of family members of people with intellectual disabilities is needed to ensure that programme methodologies are informed by their expertise and the additional barriers they face as family members.

Commentary about the viability of self-employment also has significant implications for the design and delivery of disability-inclusive employment work. Self-advocates report pressure for them to be self-employed, despite a consensus among the self-advocate focus group members that inclusive employment in formal sector workplaces alongside their peers with and without disabilities is the form of employment they want to be accessing. As development programming pivots towards a great focus on livelihoods and informal sector work for people with disabilities, the will and preferences of people with intellectual disabilities must be taken into consideration, and options for programming that supports access to formal sector work environments should be retained and prioritised.

The concerns of family members raised during the discussion about safety and security also indicate the need to rethink safeguarding practice in employment programming. Families raised two major sources of risk for people with intellectual disabilities in accessing employment—the risk of abuse or exploitation while travelling to and from work and the risk of exploitation in the workplace by colleagues, customers, supervisors and others at work. While safeguarding practices within programmatic work often create robust structures for safety monitoring, these issues identified by families can be best responded to through programme interventions as opposed to monitoring and evaluation. Safe transportation to work as a form of reasonable accommodation for people with intellectual disabilities can be incorporated into the design of programmes, and interventions for employers that often focus on top-level leadership or human resources managers can be expanded to employees at all levels to ensure that all colleagues have a basic understanding of what it means to work in an inclusive workplace. While self-advocates identified additional risks in the workplace that they face, they also reported feeling othered and isolated by their colleagues in the workplace. Disability-inclusive programming must ensure that safeguarding systems being created for programme work transition from the lens of ‘vulnerability’ which contributes to othering people with intellectual disabilities and framing them as in need of protection. Instead, programmes can balance the need for safeguarding with the need to prevent ‘othering’ people with disabilities by creating safeguarding systems that are human rights based and that aim to protect everyone equally, not only ‘vulnerable’ employees.

Another key lesson that emerges from the focus groups of both self-advocates and their family members is the need to ensure that employment programming is not executed in isolation. Many of the barriers that people with intellectual disabilities and their families identified were not solely employment related and cut across other themes such as access to education, access to public transportation and broader stigma in the community. Employment programming must reflect these barriers that occur at different points across the life span and aim to create interventions that are responsive to these cross-cutting issues that impact employment. Employment programming should aim to be holistic and address other barriers to fully inclusive communities.

5 | CONCLUSION

The calls for inclusive employment from people with intellectual disabilities and their families are clear—self-advocates and their families are calling for more support to access formal sector employment (Inclusion International, 2021) and for these methodologies for supporting them to be designed in a way that is responsive to their specific needs as a marginalised group of people with disabilities. Self-advocates and their families have identified a variety of barriers that continue to impact their access to employment—these include stigma and discrimination from employers and colleagues, denial of reasonable accommodation, lack of access to education, perceptions of low value, gender barriers, unsafe workplaces and other barriers.

To create a shift in the conversation about disability-inclusive employment towards the genuine inclusion of people with intellectual disabilities, there is a need to ensure that these voices are reflected in research and writing about disability-inclusive employment from a cross-disability perspective. Future research that centres the voices of people with intellectual disabilities and their families would be welcomed, and the findings suggest a need for additional research into the unique role of families for supporting access to inclusive employment. Similarly, the field would benefit from future research that looks specifically at disability-inclusive employment models and whether or

not they are genuinely inclusive of people with intellectual disabilities and other marginalised groups, to ensure methodologies are creating workplaces where people with intellectual disabilities are valued equally.

ACKNOWLEDGEMENT

This work is funded by the Foreign, Commonwealth and Development Office.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Kimber Bialik  <https://orcid.org/0000-0002-8387-4824>

REFERENCES

- Akrami, N., Ekehammar, B., Claesson, M., & Sonnander, K. (2006). Classical and modern prejudice: Attitudes toward people with intellectual disabilities. *Research in Developmental Disabilities, 27*, 605–617.
- Baldwin, M. L., & Choe, C. (2014). Re-examining the models used to estimate disability-related wage discrimination. *Applied Economics, 46*(12), 1393–1408. <https://doi.org/10.1080/00036846.2013.872762>
- Bond, G. R. (2004). Supported employment: evidence for an evidence-based practice. *Psychiatric Rehabilitation Journal, 27*(4), 345–359. <https://doi.org/10.2975/27.2004.345.359>
- Buhagiar, S., & Azzopardi Lane, C. (2020). Freedom from financial abuse: Persons with intellectual disability discuss protective strategies aimed at empowerment and supported decision-making. *Disability & Society, 37*(3), 361–385. <https://doi.org/10.1080/09687599.2020.1833312>
- Callus, A., Bonello, I., Mifsud, C., & Fenech, R. (2019). Overprotection in the lives of people with intellectual disability in Malta: knowing what is control and what is enabling support. *Disability & Society, 34*(3), 345–367. <https://doi.org/10.1080/09687599.2018.1547186>
- Cheng, C., Oakman, J., Bigby, C., Fossey, E., Cavanagh, J., Meacham, H., & Bartram, T. (2018). What constitutes effective support in obtaining and maintaining employment for individuals with intellectual disability? A scoping review. *Journal of Intellectual & Developmental Disability, 43*(3), 317–327. <https://doi.org/10.3109/13668250.2017.1327040>
- Colella, A., & Bruyère, S. (2011). Disability and employment. In E. Zedeck (Ed.), *APA handbook of industrial and organizational psychology* (pp. 473–504). American Psychological Association.
- Gunderson, M., & Lee, B. Y. (2016). Pay discrimination against persons with disabilities: Canadian evidence from PALS. *International Journal of Human Resource Management, 27*(14), 1531–1549.
- Hagner, D., & Davies, T. (2002). “Doing my own thing”: Supported self-employment for individuals with cognitive disabilities. *Journal of Vocational Rehabilitation, 17*, 65–74.
- Hewitt, O. (2014). A survey of experiences of abuse. *Tizard Learning Disability Review, 19*(3), 122–129. <https://doi.org/10.1108/TLDR-06-2013-0031>
- Inclusion Canada, People First of Canada, UBC Canadian Institute for Inclusion and Citizenship. (2021). Response to draft general comment no. 8, article 27: The right to work & employment.
- Inclusion International. (2006). Hear our voices: People with an intellectual disability and their families speak out on poverty and exclusion. Inclusion International: London, UK.
- Inclusion International. (2009). Better education for all: When we're included too. Inclusion International: Salamanca, Spain.
- Inclusion International. (2021). Submission to the CRPD committee – General comment 8: The right to work and employment. Inclusion International: London, UK.
- International Labour Organization. (2004). Global employment trends for women 2004. Geneva: International Labour Organization.
- Jiranek, D., & Kirby, N. (1990). The job satisfaction and/or psychological well being of young adults with an intellectual disability and nondisabled young adults in either sheltered employment, competitive employment of unemployment. *Australia and New Zealand Journal of Developmental Disabilities, 16*(2), 133–148. <https://doi.org/10.1080/07263869000033951>
- Jones, M. K., & Latreille, P. L. (2011). Disability and self-employment: evidence for the UK. *Applied Economics, 43*(27), 4161–4178. <https://doi.org/10.1080/00036846.2010.489816>
- Kaye, H. S., Jans, L. H., & Jones, E. C. (2011). Why don't employers hire and retain workers with disabilities? *Journal of Occupational Rehabilitation, 21*, 526–536. <https://doi.org/10.1007/s10926-011-9302-8>

- Khayatzadeh-Mahani, A., Wittevrongel, K., Nicholas, B., & Zwicker, J. D. (2020). Prioritizing barriers and solutions to improve employment for persons with developmental disabilities. *Disability and Rehabilitation*, 42(19), 2696–2706. <https://doi.org/10.1080/09638288.2019.1570356>
- Kocman, A., Fischer, L., & Weber, G. (2017). The Employers' perspective on barriers and facilitators to employment of people with intellectual disability: a differential mixed-method approach. *Journal of Applied Research in Intellectual Disability*, 31(1), 120–131. <https://doi.org/10.1111/jar.12375>
- Kohler, P. D., & Field, S. (2003). Transition-focused education: Foundation for the future. *The Journal of Special Education*, 37, 174–183. <https://doi.org/10.1177/00224669030370030701>
- Lysaght, R., Cobigo, V., & Hamilton, K. (2012). Inclusion as a focus of employment-related research in intellectual disability from 2000 to 2010: a scoping review. *Disability and Rehabilitation*, 34(16), 1339–1350. <https://doi.org/10.3109/09638288.2011.644023>
- Mitra, S., & Kruse, D. (2016). Are workers with disabilities more likely to be displaced? *International Journal of Human Resource Management*, 27(14), 1550–1579.
- Moore, K., McDonald, P., & Bartlett, J. (2017). Emerging trends affecting future employment opportunities for people with intellectual disability: the case of a large retail organization. *Journal of Intellectual & Developmental Disability*, 43(3), 328–338. <https://doi.org/10.3109/13668250.2017.1379250>
- Moreira da Silva, J. (2019). Why you should care about unpaid care work. OECD Development Matters. March 18. <https://oecd-development-matters.org/2019/03/18/why-you-should-care-about-unpaid-care-work>
- Morgan, R. L., & Alexander, M. (2005). The employer's perception: employment of individuals with developmental disabilities. *Journal of Vocational Rehabilitation*, 23, 39–49.
- National Disability Authority. (2005). Disability and work: The picture we learn from official statistics. National Disability Authority: Dublin, Ireland.
- O'Reilly, A. (2003). The right to decent work of persons with disabilities. International Labour Organization, Geneva.
- Padkapayeva, K., Posen, A., Yazdani, A., Buettgen, A., Mahood, Q., & Tompa, E. (2017). Workplace accommodations for persons with physical disabilities: Evidence synthesis of the peer-reviewed literature. *Disability and Rehabilitation*, 39(21), 2134–2147. <https://doi.org/10.1080/09638288.2016.1224276>
- Pagán, R. (2009). Self-employment among people with disabilities: Evidence for Europe. *Disability & Society*, 24(2), 217–229. <https://doi.org/10.1080/09687590802652504>
- Petner-Arrey, J., Howell-Moneta, A., & Lysaght, R. (2016). Facilitating employment opportunities for adults with intellectual and developmental disability through parents and social networks. *Disability and Rehabilitation*, 38(8), 789–795. <https://doi.org/10.3109/09638288.2015.1061605>
- Schur, L., Kruse, D., & Blanck, P. (2005). Corporate culture and the employment of persons with disabilities. *Behavioral Sciences & the Law*, 23, 3–20. <https://doi.org/10.1002/bsl.624>
- Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Research in Developmental Disabilities*, 32, 2164–2182. <https://doi.org/10.1016/j.ridd.2011.07.005>
- Scottish Commission for Learning Disability. (2018). Learning disability statistics Scotland, provisional statistics. Scottish Commission for Learning Disability: Glasgow, Scotland.
- United Nations General Assembly. (2006). Convention on the rights of persons with disabilities. 13 December 2006. A/RES/61/106.
- Wehbi, S., & El-Lahib, Y. (2007). The employment situation of people with disabilities in Lebanon: Challenges and opportunities. *Disability & Society*, 22(4), 371–382. <https://doi.org/10.1080/09687590701337736>
- Wehman, P. (2006). Transition: The bridge from youth to adulthood. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (4th ed., pp. 3–39). Brookes.
- World Health Organization, & World Bank. (2011). World report on disability. World Health Organization: Geneva, Switzerland.
- Zappella, E. (2015). Employers' attitudes on hiring workers with intellectual disabilities in small and medium enterprises: an Italian research. *Journal of Intellectual Disabilities*, 19(4), 381–392. <https://doi.org/10.1177/1744629515580883>

How to cite this article: Bialik, K., & Mhiri, M. (2022). Barriers to employment for people with intellectual disabilities in low- and middle-income countries: Self-advocate and family perspectives. *Journal of International Development*, 1–14. <https://doi.org/10.1002/jid.3659>