

Review

A Scoping Review of Empirical Literature on People with Intellectual Disability in Nigeria

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Abstract: Intellectual disability (ID) is an emerging field of research in Nigeria. This review seeks to identify what has been published in order to describe the evidence and to identify the major gaps in knowledge and practice. A systematic search of five databases and an African disability journal yielded 15 papers that reported on empirical studies related to people with ID in Nigeria. Fifteen studies across the databases and journal searched met the inclusion criteria. The participants included adults and children with ID and their families. Twelve of the papers employed quantitative methods, two were qualitative and one was a mixed methods study. There is a paucity of empirical research on people with ID in Nigeria, thus emphasising the need for more primary research about people with ID living in Nigeria. Nigeria is estimated to have the largest population of people with disabilities in Africa; however, this review found limited empirical work regarding their lives, prevalence and care. This limited evidence hinders the understanding of the challenges people with an intellectual disability face and potentially inhibit the creation of policy-oriented solutions to their plights in a globalised world.

Keywords: intellectual disability; Nigeria; family; parents; scoping review



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1. Introduction

According to Maulik et al. [1], the highest prevalence of people with an intellectual disability (ID) are seen in low- and middle-income countries (LMIC). Authors and researchers have continuously noted the scarcity of research on the African continent about people with ID compared to Western countries, e.g., [2–4]. This dearth in research can be argued to be one of the sources of continued neglect, stigmatisation and limited care service provision for people with ID and their families (see [3]). It has also been suggested that research on ID has enabled Western governments to create systems and structures that enable both government and private-funded social care provisions and improvements on the inclusion of people with ID in different parts of society, such as health, education, employment and housing [3]. Some African countries such as South Africa seem to be carrying out more research about people with ID than other African countries such as Nigeria, which is the country of focus in the current scoping review. This was evidenced in a scoping review by Ngenga [2], which found two out of the three papers to have met the criteria set in relation to people with ID to stem from South Africa and the third from Nigeria. Moreover, Capri et al. [5] recently carried out a scoping review on the rights and citizenship of people with ID in South Africa and found 59 papers to be relevant.

In the absence of research on the prevalence of ID in Nigeria (see [6]), it is not possible, other than through extrapolations from other countries, to estimate the overall number of people with ID [4] (p. 88), [6]. In 2018, the World Health Organization estimated that 29 million people in Nigeria were living with a disability [7]. The lack of information, poverty, inconsistent assessment methods and possibly the desire of some families to hide

such disabilities due to stigma and negative attitudes toward disabled people, e.g., [4,8–10], are likely to contribute to the continued neglect of issues affecting people with ID and their families. Nigeria is located in Western Africa, bordering the Gulf of Guinea, and is estimated to have a population of 219,460,000 people [11]. The country is often described as the “Giant of Africa” due to having the largest economy in Sub-Saharan Africa, and it has a growing, relatively youthful population, where 62% are between the ages of 0 and 24 years [11,12]. Nigeria is ethnically and culturally diverse, with over 250 ethnic groups speaking over 500 languages [10]; the main languages include English, Hausa, Yoruba and Igbo (Ibo), with Islam, Christianity and other religions being practiced in the country [4,11]. Although the country relies heavily on oil as its main source of foreign exchange earnings and government revenues, its economic growth has also been driven by growth in agriculture, telecommunications and services [11].

Notwithstanding the country’s economic potential, the Nigerian National Bureau of Statistics’ “Poverty and Inequality in Nigeria 2019” report highlighted that 40% of the total population (almost 83 million people) live below the country’s poverty line of 137,430 naira (381.75 USD) per year [8]. The association between poverty and disability has been repeatedly shown [13–15], and Nigeria’s poorly funded, almost absent social welfare system means that most support for people with a range of disabilities is provided by families, the community or religious sources [4].

Nigeria signed the United Convention on the Rights of Persons with Disabilities (UNCRPD) and ratified its optional Protocol in 2010—an attempt to protect the rights of disabled people [16] and, in January 2019, passed the Discrimination Against Persons with Disabilities (Prohibition) Act 2018 [17]. However, Nigeria has yet to implement the adequate measures required to promote the legal rights of disabled people in all aspects of society [16]. It has been argued, e.g., [4,18,19], that stigma and negative attitudes towards disabled people in countries such as Nigeria are often due to a public lack of awareness and understanding of the causes of disabilities. This lack of understanding and awareness affects the treatment and care of people with disabilities in Nigeria. As a signatory of the UNCRPD, the country is obliged to maintain the rights and dignity of its disabled citizens, including those with ID, and therefore, it is crucial for more ID-focused research to inform and guide transformative interventions needed to improve the lives of people with ID in the country.

Within the range of disabilities (e.g., physical, sensory and intellectual), ID appears to be particularly “hidden” in communities, policies and research. Scior et al. [20] argued that, globally, people with ID are the most abused, stigmatised, marginalised and socially excluded (also see [21]). For example, a recent survey conducted in Northern Nigeria [22] used local community-based and disabled people’s organisations in five administrative regions to contact disabled people in their communities. The majority of the 1067 respondents reported that they had physical, hearing or visual disabilities, and only 0.3% of the respondents were identified as having the characteristics of ID using the Washington Group Extended Set on Functioning questionnaire [23].

The literature has consistently acknowledged the scarcity of information and empirical research about people with ID in developing countries such as Nigeria, e.g., [2,4,24]. For example, a recent meta-synthesis [6] of disability research in Western Africa revealed that, of the 223 disability articles from West Africa reviewed, only 24 were papers related to people with ID in the whole of West Africa; however, there was no information from the meta-synthesis on how many of these 24 ID studies were specifically derived from Nigeria [6]. To our knowledge, there has been no published scoping review on ID research in Nigeria.

Research Question and Objectives

The present study describes a scoping review of empirical research about people with ID in Nigeria to explore evidence about their lives and identify gaps in their knowledge and/or practice. The following research question was formulated: What is known from

empirical studies (published between January 2007 and March 2021) about the lives of people with ID in Nigeria?

2. Materials and Methods

2.1. Methods

This review was guided by Arksey and O'Malley's [25] first framework for a scoping review and further informed by a more recent adaptation by Peters et al. [26] using the following 5 stages:

- identification of the research question;
- identification of relevant studies;
- selection of studies to be included;
- charting the data;
- collating, summarising and reporting the results of the articles included for review.

2.2. Identifying Relevant Studies—Search Strategy

During February and March 2021, electronic searches were conducted of the following databases and journal: Web of Science, MEDLINE, Scopus and the *African Journal of Disability (AJOD)*, Vol. 1 (1) 2012—Vol. 10, 2021) and the first twenty pages (due to its inclusive nature) of Google Scholar. Each of the keywords (see Table 1) were searched alongside "Nigeria". The *African Journal of Disability (AJOD)* was selected as it publishes studies on disabled (including ID) people in Africa, and the databases enabled us to access papers not already found in *AJOD*. Saturation was reached when further systematic searching of the databases and *AJOD* revealed only previously located articles. The reference lists of potentially relevant papers identified through the databases were also checked, but no additional relevant papers were found.

Table 1. Keywords used in the systematic search of the databases and *AJOD*.

Intellectual Disability	Nigeria
Disab *, autism *, mental retard * developmental disorder * and special educational need. * The last three keywords incorporated the following terms: Down's Syndrome, fragile X, learning disability, intellectual disability, learning difficulty and foetal alcohol syndrome	Nigeria

Mental retard *: considered derogatory but was included as a keyword so that any paper that may have used this term between 2007 and 2021 was not missed out.

2.3. Selection of Studies—Applying Inclusion and Exclusion Criteria

The review was also guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR—<http://www.prisma-statement.org/Extensions/ScopingReviews>, accessed on 2 January 2021) [27].

2.4. Inclusion Criteria

To be included in the review, the papers had to be:

- Study—peer-reviewed articles reporting on empirical studies, qualitative or quantitative and/or mixed method research;
- Population—include people with ID alone or with a comparison group or people with ID and their families and teachers as research participants or solely include parents and siblings of people with ID;
- Language and year—written in the English language and published between January 2007 and March 2021. The year 2007 was selected because that was the year when Nigeria ratified the UNCRPD, and the subsequent years potentially covered disability-related policy changes in Nigeria that may have impacted the lives of people with disabilities. Additionally, a review carried out by Ngenga [2] of previous years yielded

only 3 empirical research articles on ID in Africa: 1 was from Nigeria and 2 from South Africa.

2.5. Exclusion

- Nonempirical papers;
- articles not reporting data specifically identifying the lived experiences of people with ID or their families and teachers;
- Grey literature was excluded—prior to deciding to exclude the grey literature, the keywords presented in Table 1 were used to search three grey databases (i.e., www.opengrey.eu; www.isrctn.com, accessed on 5 February 2021, as well as the World Health Organization database via the African Index Medicus), and the searches yielded no relevant results in the context of ID research in Nigeria.

As illustrated in Figure 1 below, a total of 279 papers were identified through Web of Science, MEDLINE, *AJOD*, Scopus and Google Scholar. The grey databases were initially searched to explore the breadth of research via these routes that may be relevant to our topic—ID and Nigeria, in order to decide if the grey literature should be included or not; however, no relevant literature was identified through the grey databases. Figure 1 summarises the identification and selection of the studies. The search generated a lot of discussion papers, opinion pieces and reviews commenting on disability policies in Nigeria and the general barriers experienced by disabled people there. Of the 279 papers located, 210 were removed based on the title, abstracts and duplicates, leaving 69 potentially relevant articles for further eligibility assessment. The titles and abstracts of these 69 papers were screened, and 48 were removed, as they focused on conditions other than ID or were not empirical. The remaining 21 papers were read in full, and 6 of those papers were excluded, leaving a total of 15 papers that met the inclusion criteria. Both authors independently reviewed the titles, abstracts and full texts of the potentially relevant papers. Both authors resolved disagreements on study selection and data extraction through discussion to reach a consensus in line with the inclusion criteria.

2.6. Charting the Data

The data abstracted from the 15 included studies were organised into two formats: firstly, via a Microsoft Excel spreadsheet with information such as authors, year of publication, study population, aim, methodology and general findings presented in the Supplementary File. In a few instances, it was not possible to extract information due to lack of clarity in the methods used or data presented, e.g., [28]. The second format for organising and presenting abstracted data is a thematic content analysis (TAC) [29], which is a descriptive presentation of qualitative data by identifying and grouping common categories (themes) from the findings of each included article. The process involved saving electronic copies of each included article in a shared folder, then highlighting the findings relevant to this scoping review within each article. Each highlighted finding was treated as a distinct unit of meaning. These units were then copied and pasted into a word document together with units of similar meaning from other articles. Once all units of similar meaning were congregated, they were coded and labelled with the initial categories (themes) using phrases copied from the highlighted texts, and these categories revised as coding continued. Copies of all the included articles were reviewed again, and more units of meaning were identified and added to the relevant similar Word documents; there was also some re-labelling of the categories. All meaning units per category were read again and redistributed accordingly, and the relabelling of categories was as appropriate; the categories were also either collapsed or subdivided into subthemes as applicable. A few days after, copies of the included articles were reread without looking at the units of meaning or categories. A further review of the units and categories took place, and some remained unchanged whilst others were either redistributed, collapsed or subdivided as appropriate. These were continuously reviewed according to the TCA process following a few days' intervals until it was clear that categories (themes) reflected the findings from

the included articles (see [29]) (pp. 2–3). The authors undertook a final reading of the units of meaning, categories and themes separately, and any disagreement or uncertainty was discussed until agreement was reached.

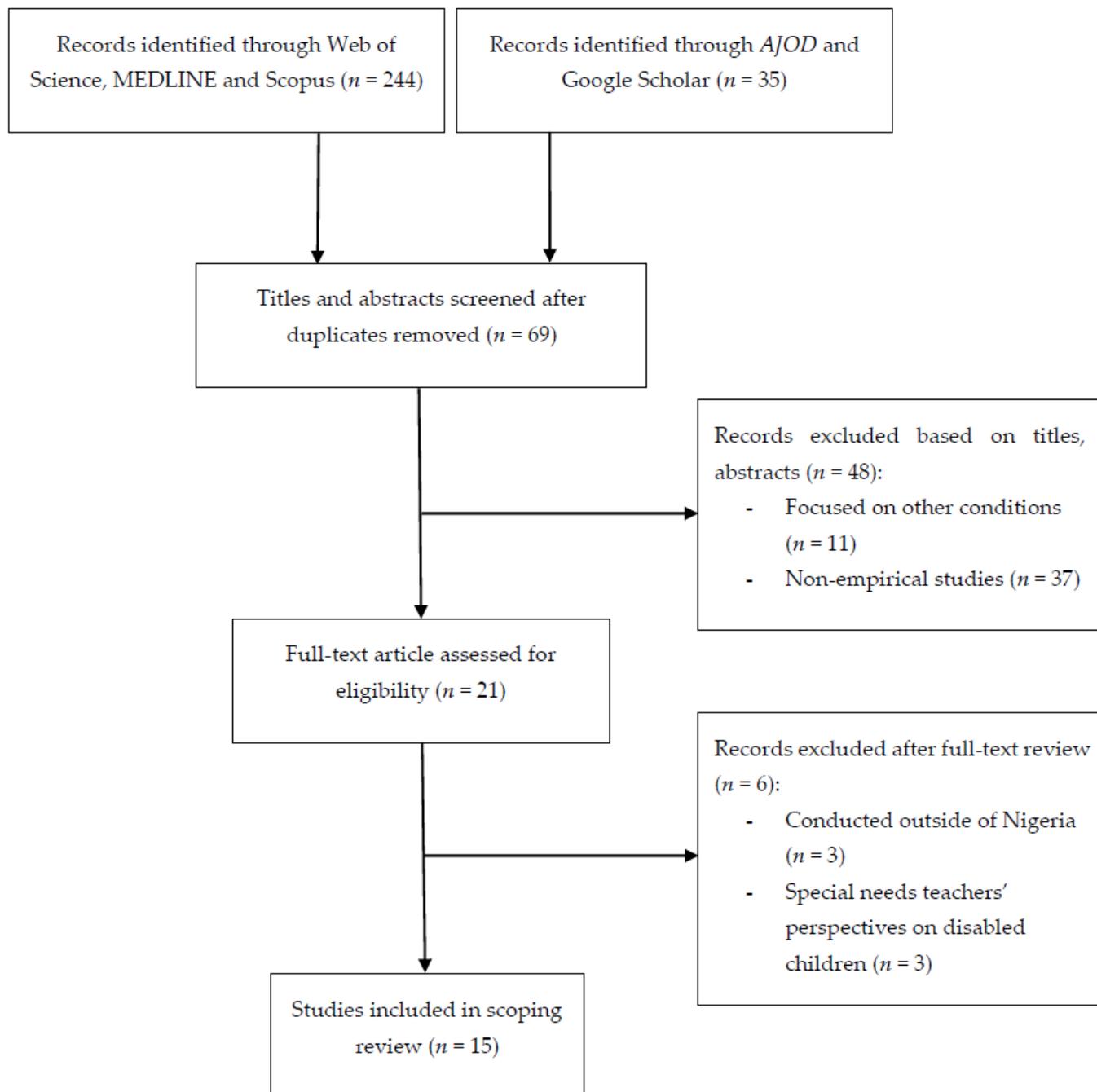


Figure 1. Flow chart of studies included in the review.

3. Results

A summary of the characteristics of the included papers and a thematic content analysis addresses the scoping review question of: What is known from the existing empirical studies (2007–March 2021) about the lives of people with ID in Nigeria?

3.1. Study Characteristics—Description of the Articles Included

As shown in the Supplementary File:

- Five of the papers, i.e., [28,30–33], focused on family experiences and people with ID, where some of these papers explored the influence of a child with ID on family experiences such as marital stability or family quality of life;
- Three articles [34–36] explored sexual practices and knowledge of pupils with ID;
- Three papers [37–39] investigated the prevalence of autism spectrum disorder and behavioural patterns in children with ID;
- Four papers [40–43] examined the social, school environment factors contributing to social development and language comprehension, as well as entrepreneurship training of people with ID.

The sample participants included parents and siblings of people with ID, i.e., [28,30–33]. Eight papers [34–41] included children and young people with ID, and the remaining two papers [42,43] included teachers without ID. Two [28; 33] of the fifteen included studies utilised qualitative methods but Ajuwon [28] did not clearly describe the method used. One of the 15 included papers employed both qualitative and quantitative methods [34] and the remaining twelve employed quantitative methods (see Supplementary File). Three different articles, i.e., [34–36], reported on different aspects of one main study by Aderemi and Pillay [34]; a similar approach was also seen in [37,38].

3.2. Themes

Four main themes from the included papers were identified: Caregiving experiences—this theme consisted of four subthemes: Interpersonal and emotional support, Marital experiences, Concerns related to the future of family members with ID and coping with a child with ID. Other themes were: Prevalence of neurodevelopmental and behavioural conditions in children and young people with ID; Sexual experiences of people with ID and Language comprehension, social and entrepreneurship skills and people with ID.

3.3. Theme I: Caregiving Experiences

This theme relates to the experiences of caregivers (parents and siblings) in the context of supporting a family member with ID. Five papers that met the inclusion criteria contained findings related to this theme [28,30–33]. Ajuwon [28] found that over one-third of respondents identified caregiver burden of a child with ID as the primary stressor in their lives. A majority of the parent participants of children with Down’s Syndrome (DS) in Ajuwon [28] experienced physical and financial burdens as stressful, and no “home care assistance” was available. Parents also reported negative attitudes from community members, which limited their access to social, community and economic resources [28]. Fifty-five percent of participants [28] reported problems with healthcare, accessibility and affordability being the primary issues. Participants reported resorting to unregulated herbal remedies from traditional healers for many ailments. Financial well-being was impacted by aging and retirement issues for older carers, such as poor-quality pensions that are not paid on a regular schedule, as well as the poor state of the Nigerian economy: unemployment and poor earnings. The stress experienced resulted in the loss of social activities, loss of employment and loss of independence for mothers who, were often the primary caregivers. Similarly, Oyedibe et al. [30] also found that mothers showed more caring responsibility of their child with ID compared to fathers, reflecting traditional Nigerian cultures.

3.3.1. Interpersonal and Emotional Support

The findings of four papers, i.e., [28,30,32,33], included results related to this subtheme. Family care burdens were reported to be alleviated by positive family attitudes, a caring experience, social support and resilience, e.g., [28,30]. Participants [28,30] reported strong, positive social and emotional relationships with nuclear and extended family members. A majority (79.0%) of the respondents in Eni-Olorunda, Ariyo and Lasode [32] said their parent-in-laws did not blame them for their child’s disability, and 81.0% also reported that their parent-in-laws did not ask the spouses to separate or divorce, with 54.3% saying their parent-in-laws supported them psychologically and emotionally. Participants in

Ajuwon [28] reported that family QoL was improved by factors such as the growing independence of the disabled family member, improvement in their financial situation, good financial management and good-performing investments, as well as job promotions or new business opportunities. Moreover, having young family members without a disability in employment also enhanced the family finances. Onyedibe et al. [30] found that perceived social support was negatively associated with parenting stress; that is, the more social support parents had, the less parenting stress they reported. Personal resilience also negatively predicted parenting stress; therefore, the more resilience parents reported, the less stress they reported. Low resilience and high social support were associated with higher parenting stress, as was low reported resilience and low social support. Chukwu et al. [33] found that female participants reported that social support from friends and professionals helped in finding someone to listen to them and give them encouragement.

3.3.2. Marital Experiences

Only one paper revealed findings related to this subtheme. According to Eni-Olorunda et al. [32], a little over half of the parents (55.2%) said that their homes were like “heaven on Earth”, and 72.4% said that their families were closely knitted together, with a similar proportion of 70.5% saying that their spouses loved them unreservedly. More than half (65.7%) of the respondents said that the presence of a child with ID brought the family closer together, and 72.4% reported that it did not cause any rift between them and their spouses, with a large majority (79.0%) saying their spouses did not blame them for the birth [32]. Just under half of the respondents said that spending on the child with ID had worsened their finances, leading to friction in the marriage, while 55.2% said that this does not cause any friction [32]. Eni-Olorunda et al. [32] found no significant relationship between the educational status of respondents and marital stability after the discovery of the child with ID. Around one-fifth reported that their parent-in-laws said that the presence of the disabled child should lead spouses to separate or divorce [32]. However, three-quarters of parents [32] reported that siblings of children with ID love and accept them fully and were not in any way hostile to the child, and this further strengthened the marital relationship.

3.3.3. Concerns Related to the Future of Family Members with ID

Concerns expressed about the future well-being of family members with DS were rooted in the lack of support services and the increasing burden with aging, as services for people with disability were less available to adults, with limited access to vocational education and self-help training to promote independence. One mother of a teenage girl with DS in [28] (p. 38) remarked “I’m not sure what will become of my daughter now that she is getting to that age, when other teenage girls without disability are doing some type of work, or engaging in social activities with boys, and looking ahead to possible relationship and marriage. Frankly speaking, I do not know how to handle the situation, and I am not going to be around forever to look after her!” According to Ajuwon [28], although most of the parents have low incomes, their attitudes, as seen in their efforts to keep their children in special education centres, can be seen as positive; they are eager to give their children vocational training, as their main concern is their child’s survival and welfare when they, as the main carers, die. Services such as schools and private special education schools are costly in Nigeria, and finances are a major concern to parents.

3.3.4. Coping with a Child with ID

Three papers [28,31,33] reported findings related to this theme. For example, Chukwu et al. [33] found that parents reported different coping strategies. Some adopted a problem-focused coping strategy by seeking information from professionals, online and television programmes, and such knowledge on the different aspects of ID helped counter superstitious beliefs relating to the causes of ID. These participants were from educated backgrounds, with access to modern communication facilities. Other participants [33] used emotion-focused strategies; they became emotional during discussions about the causes of ID, sometimes “letting off steam” through suspicions and blaming

others—especially marital partners—with spouses accusing each other of infidelity or curses due to the spouse’s previous wrongdoings. Feelings of resentment, bitterness and fear of the unknown had negative effects on the marital relationship. Siblings felt their family member with ID received preferential treatment from their mother. Other strategies found [33] included pretending the person with ID does not exist; keeping away from other people and “locking” away or “keeping” the child “out of public view” due to stigma, shame and negative attitudes and comments from the public.

Ajuwon and Brown [31] found that some parents held superstitious beliefs about disabilities. For example, parents commented that they associated their child’s disability with evil spirits, initiation into cults or family curses. Most of the parents, especially those with superstitious beliefs, reported that they had engaged in “shopping for a cure” via teaching hospitals, native doctors, churches or Imams. Ajuwon [28] further found family relationships were enhanced when they followed traditional, cultural values and actively practiced their religious faith. Caregivers received support from adult children without a disability, extended family and their religious communities. Participants [28] reported that receiving emotional and practical support, having religious faith, personal effort and a positive attitude that “things will get better” were associated with their current and perceived future well-being. Some parents [28] indicated that traditional superstitions associated with forms of disability were problematic and must be replaced with the modern understanding of disabilities. They identified religious and cultural leaders as the key to this shift in knowledge and practices. Other parents viewed education as a means of raising awareness of disabilities and eradicating misconceptions [28].

Chukwu et al. [33] found that some parents reported using spiritual- and religious-focused coping strategies, especially those with strong religious beliefs. These parents were active in a church, receiving ministration from the church to help them cope with stress and have a positive outlook for their child. Spiritual and religious coping strategies included: seeking help from their religious and spiritual community, counselling and referrals to institutions for the care of the child with ID. Spirituality and religious-based coping strategies were not all positive ones; others reported feelings of being punished, abandoned or resigned to the will of God, sometimes searching for spiritual cleansing. Other spiritual and religious coping strategies included seeking a native (traditional) doctor if they believed ID is caused by witchcraft and believing that a native doctor was helpful in calming hyperactivity and other behaviours of concern shown by the person with ID.

3.4. Theme II: Prevalence of Neurodevelopmental and Behavioural Conditions in Children and Young People with ID

This theme outlines the findings related to other neurodevelopmental and behavioural conditions commonly exhibited by children and young participants with ID. Three papers, i.e., [37–39], included findings related to this theme. Atilola et al. [39] reported a significantly higher prevalence of neurological conditions (including epilepsy, slurred speech, dyskinesia; hemiparesis and quadriparesis) and ID in adolescents residing in a social welfare juvenile justice institution than in those who went to schools. Epilepsy was more prevalent in adolescents admitted to an institution due to neglect compared with those admitted due to offending behaviours. Bakare et al. [38] found that, of 44 children with ID, 21 were classified as having behavioural problems on the clinical scale of Strengths and Difficulties Questionnaire (SDQ). The SDQ employed [38] uses five clinical subscales (emotional symptoms, conduct problem, hyperactivity, peer problem, total difficulties and prosocial scales) to measure behaviour problems. Mild ID rather than more severe ID was associated with higher total difficulties scores, with males more likely to show hyperactivity behavioural problems compared to female participants. Bakare et al. [37] found that the prevalence of childhood autism among children with ID was 11.4% of the 44 children studied, with a male/female ratio of 4:1.

3.5. Theme III: Sexual Experiences of People with ID

This theme includes findings related to the sexual activities of participants with ID. Three papers, i.e., [34–36], included findings related to this theme. These papers appeared to be reporting findings from one large study involving 300 pupils (123 female, 177 male) from an ID special needs school and 300 mainstream learners (154 female, 146 male) aged 12–19 years and 12 teachers each from the ID school and mainstream school in Oyo State, Nigeria.

Aderemi and Pillay [34] found that one-quarter (26%) of the students with ID were engaging in sexual activity more frequently than students without ID—20% of the students with ID reported having multiple sexual partners. Female students with ID were shown to be at greater risk of sexual abuse than students without ID, and condom use with the last sexual activity was reported significantly less by students with ID and could be due to the reported lower availability of condoms to students with ID [34]. Aderemi and Pillay [35] reported that learners with ID abstained from sex less than their peers without ID, and girls with ID were almost four times more likely to report a history of rape than nondisabled girls. Aderemi, Pillay and Esterhuizen [36] found that significantly more learners with ID than nondisabled learners (62.2% versus 37.8%) reported having sexual experiences. Of the sexually experienced female ID participants, 28 (68.3%) reported a history of rape compared with 9 (2.9%) of the female participants without ID. Intellectual disability was significantly associated with lower HIV transmission knowledge involving casual sexual partners and the non-use of condoms during the last sexual activity.

3.6. Theme IV: Language Comprehension, Social and Entrepreneurship Skills and People with ID

This theme reports on findings related to aspects of young peoples' education for adult living: improving English language comprehension, social skills and the need for entrepreneurship skills for people with ID in Nigeria. Four papers, i.e., [40–43], included findings related to this theme. Eni-Olorunda and Adediran [40] compared two experimental interventions (audio-taped and individualised instruction and a control group receiving education as usual) for improvement in English language comprehension in pupils with ID. Both experimental groups showed significantly higher English comprehension scores than the control group. The individualised instruction group showed the highest performance, followed by the audio-taped instruction group and the control group. The mean scores of the students with a low socioeconomic status were better than those with a high and medium socioeconomic status. Pre-test data were not reported in the paper.

Adeniyi and Omigbodun [41] reported improvement in the social skills of pupils with ID using an adapted version of the “Explore” social skills curriculum. Participants whose mothers had no formal education had lower mean social skills scores than those whose mothers had either a primary or post-primary education. No significant mean difference was found across the other demographic variables, such as age and gender. Isawumi and Oyundoyin [42] found a wide variety of independent variables, such as “parental educational qualification, parent employment, attitude of fellow students, teacher’s attitude, school library and sport facilities”, that correlated significantly with social skill deficits among students with ID. The participants in Olufemi et al. [43] found that students with ID and/or their teachers thought that persons with ID needed education in entrepreneurship skills and, following such education, that jobs needed to be provided for persons with ID. The sample [43] also thought that the facilities, infrastructure and financial support from the government were not adequate at schools for pupils with ID.

4. Discussion

This scoping review aimed to locate articles reporting empirical research about people with ID in Nigeria in order to explore evidence about their lives and identify gaps in knowledge and/or practice. Fifteen studies met the inclusion criteria. The findings from the fifteen included studies reported the experiences and living conditions of people with

ID and their families in Nigeria. Four themes were found from the papers that met the inclusion criteria of this scoping review. These themes related to:

- the experiences of caregivers supporting a family member with ID;
- the presence of additional neurodevelopmental and behavioural difficulties displayed by children and young participants with ID;
- the sexual activities of participants with ID;
- English language comprehension, social skills and the need for entrepreneurial skills of young people with ID in Nigeria.

Personal accounts indicated that the negative experiences of families and people with ID are due to stigma, as well as a lack of public awareness and understanding of the causes of intellectual disability [28,30,31]. These findings corroborated previous works on disabilities in lower- and middle-income countries, e.g., [4,9,18–20]. The consequences associated with these negative experiences and attitudes regarding persons with ID and their families, e.g., [28,30,31], include exclusion from various aspects of society, limited access to economic resources and inadequate, unaffordable health and social care. For example, Adeniyi and Adeniyi [44] reported a scarcity of services for children with developmental disorders in African countries such as Nigeria and that the few available services are limited to the capital cities, provided by the private sector, expensive and beyond the affordability of most families.

The following [28,30,32] found that parents adopted either “problem-focused or emotion-focused” coping mechanisms; with some parents acting as if the child with ID does not exist and hiding family members with ID from the public due to stigma, shame and negative attitudes from others [32]. These findings support those of McConkey et al. [9] that shame is often associated with ID in developing countries where families may hide their family member with ID due to physical impairments or behavioural challenges. These actions, according to McConkey et al. [9], support the negative perceptions and misunderstandings of disabilities in societies. Therefore, families can play a key role in countering negative attitudes towards persons with ID through the “nurturing development” of their family member with ID and participating in family and community events. This places a significant burden upon families to “shoulder” the criticism from others, to bolster opportunities for contact and to establish relationships for people with ID within communities. Moreover, the suggestion that parents should be provided with “information” about what “causes” ID [9] is supported by findings from this scoping review and could play a useful role in challenging the negative ideas of people with ID, as parents pass this information to others, especially in relation to their own family member with ID.

Other findings from this scoping review, e.g., [28,30,32], reported families “accepting” their child with Down’s Syndrome and receiving support from other family members and being part of religious communities. Receiving such support was reported to protect parents of young people with ID from parenting stress.

This and other factors such as an emphasis on entrepreneurial skills suggest that, rather than be advised to repeat the services structure and interventions found in the Global North, countries such as Nigeria should look to the strengths of local spiritual and religious communities and traditional stakeholders, as well as disabled people and their families, for guidance on developing support services and interventions geared towards eradicating the stigma attached to people with a disability and their relatives. Despite Nigeria signing the UNRPD and passing the Discrimination Against Persons with Disabilities (Prohibition) Act 2018 in 2019 [17], people with ID and their families continue to be disadvantaged, marginalised and “left behind” in government planning, with limited unaffordable services adding to parental anxiety related to the current and future prospects of family members with ID, e.g., [28,30,31]. As discussed in Mostert [45] and Scior et al. [20], it is difficult, in practice, to implement the UNCRPD (or any laws) if the disability stigma in society is not addressed; it is therefore crucial for the government to work with national, regional, spiritual and religious, as well as local and traditional, groups; research centres

and non-governmental disability organisations to counter the stigma towards people with ID (see [10,46]).

Although Nigeria is often described as the “Giant of Africa” due to having the largest economy in Sub-Saharan Africa, the included studies show that people with ID and their families continue to live in poverty and lack adequate health and social care services, along with resources to cater to their needs, e.g., [37–39]. The association between poverty and disability is illustrated in people with a disability often being excluded from social, economic and political opportunities and bearing increased financial burdens related to their impairments. Poverty also means people experience limited access to adequate services, which comes with an added risk of illness, injury and impairment, leading to various disabilities, e.g., [13–15,47].

Other findings from this review, i.e., [40–43], reported that personalised learning strategies supported people with ID in gaining social and comprehension skills despite their parents’ economic and social status. In addition, entrepreneurial training and education was thought to improve the future economic prospects of people with ID [43]. Therefore, these findings from this review suggest that skills training such as entrepreneurship would be helpful for people with ID, thus reflecting a source of self-employment and skills development that is rarely suggested in the Global North context, which tends to focus on people with ID being provided with support or access to existing work. The self-sufficiency implied by entrepreneurship presents a further potential strength of countries in the Global South.

This scoping review also reported research showing that people with ID were more sexually active, with multiple sex partners, have less knowledge of HIV and are less likely to practice safe sex (e.g., using condoms) than their peers without ID, which could be due to the lower availability of condoms and/or lack of sex education for people with ID, i.e., [34–36]. These findings substantiate similar studies with disabled people that found that participants struggled to access sexual and reproductive health services due to cultural beliefs that they are not sexually active, e.g., [21,48,49], despite being more likely to be a victim of sexual abuse [22,50] than their nondisabled peers.

The papers in this review mostly reported data from parents and siblings of people with ID as the participants; therefore, future research would need to include the voices of people with ID, who will be able to provide a more personal insight into their lived experiences in Nigeria. There also exists gaps in the topics studied, as seen by the current findings from this review. For example, there is a paucity of research about the social lives, sexuality and entrepreneurship training or ventures of people, especially adults, with ID. As a signatory of the UNCRPD, Nigeria has an obligation to encourage the rights and dignity of its citizens with disabilities, including those with ID, and it is important for the government to invest and fund disability research that will inform transformative change. A lack of such research limits the nation, as there is no reference point from which to develop the necessary services and interventions.

Limitations

A limitation of this review is the lack of quality appraisal of the papers included. Although scoping reviews do not aim to assess the quality of the evidence (see [24]), in light of the emerging nature of ID research in Nigeria, we did not carry out one, because we wanted to be able to access the available studies relevant for this scoping review notwithstanding their methodological strength and rigor. We acknowledge and corroborate McKenzie, McConkey and Adnams’ [3] recommendation that there is a need for improvement in “disability data collection” in Africa in the context of reporting, methodological rigor and robustness. The findings from the included literature that met the inclusion criteria for this review are not readily generalisable to the circumstances of all people with ID in Nigeria, as the studies are localised within single states and rarely include voices of children, young people and adults with ID.

The limited scientific quality of the research and reporting found in some of the papers included in this review suggests that additional support and resources need to be found to develop the potential for research to illuminate the living experiences and extent of these in the Global South, including Nigeria. For example, in Olufemi, Favour and Olaosebikan [43], it is unclear which aspect of their findings derive from pupils with ID or their teachers, as one sentence says the “respondents are students with intellectual disability” (pp. 666), yet the survey instrument shown (incompletely) asks for marital status, and on page 668, it is suggested that teachers and pupils provide the data. This study, i.e., [43], is unclear in other aspects as well. One potential support for African researchers to improve the research base to aid policy development and service development could consist of a mentorship scheme between more established academics and upcoming academics in African universities and/or knowledge exchange programmes using a partnership model between African, American, United Kingdom and European universities.

5. Conclusions

The findings of this scoping review support other work across Africa that highlight the need for more rigorous research toward people with ID and their families in Nigeria. The focus upon parents should be balanced with a greater focus upon the experiences and voices of people with ID. This should include people with ID (and nondisabled people) from the many different cultures; communities and educational, economic and political groups in Nigeria in order to understand the reasons for the negative perceptions of people with ID, not only the reasons provided by the family members of people with ID, e.g., [45]. The findings from such robust research will help to better inform policies and interventions aimed towards achieving long-term change in the stigma, negative perceptions and attitudes towards people with ID. These initiatives should focus on combining and employing both personal, organisational and governmental policies and interventions to change attitudes towards people with ID and their families (see [10,46]). There is also a need for evidence-based interventions and policies impacting all areas of the lives of people with ID (e.g., schooling, housing, leisure, employment and relationships), thus being recognised as citizens with rights similar to everyone else in society.

Supplementary Materials: The following supporting information can be downloaded at: <https://www.mdpi.com/article/10.3390/disabilities2030034/s1>, Table S1: Studies included in the scoping review. References [28,30–43] are cited in the Supplementary Materials.

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