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COMMENT **Open Access**

Raising awareness and addressing inequities for people with Down syndrome in South Africa

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Abstract

Globally, individuals with Down syndrome (DS) face profound inequities in social and health care access. These challenges are further compounded by racial disparities as well as a lack of awareness, research, and support, particularly in the Global South. This commentary discusses the multifaceted challenges and disparities encountered by people with DS in South Africa, highlighting the need for targeted interventions. The paper will summarise the proceedings and outcomes of an imbizo—a strategic gathering of stakeholders in South Africa. This event brought together a diverse group from the DS community, including individuals with DS, their families, healthcare providers, non-profit organizations, and representatives from the Gauteng Department of Health. The discussions at the imbizo were organized into five key thematic areas: Advocacy and Awareness, Inclusion and Engagement, Education, Data and Research, and Networking and Collaboration. Additionally, the paper will underscore the critical need for the establishment of a dedicated DS research network in South Africa. Such a network is envisioned to foster collaboration, facilitate knowledge sharing, and ensure that research initiatives are closely aligned with the needs of the DS community. Overcoming these inequities requires a holistic approach that encompasses policy reforms and the crafting of inclusive services. In its concluding sections, the paper will explore future avenues for creating a sustainable framework aimed at addressing the multifaceted needs of the DS community in South Africa. This initiative represents an effort towards amplifying the well-being, rights, and inclusion of people with DS. Highlighting the necessity of a collaborative and multifaceted approach, this paper proposes a path towards a more inclusive society, advocating for the mitigation of challenges faced by this marginalized community.

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Introduction

Down syndrome (DS) is the most frequent genetic cause of intellectual disability globally. Prevalence of DS is estimated at 6 million people worldwide with approximately 800,000 estimated in the US and Europe [1, 2]. Exact figures are unknown due to changing survival rates, trends in live births vs. terminations, and lack of data [3]. There is substantial variation in morbidity and level of intellectual disability among people with DS [4, 5], with particular impairment in expressive language, memory, executive function and motor coordination [6]. Manifestations of the DS phenotype prominently affect multiple bodily systems, particularly the musculoskeletal, neurological, and cardiovascular systems. Individuals with DS exhibit distinct disease risk profiles compared to the general population, including a heightened susceptibility to multimorbidity and specific conditions such as immunological dysfunctions, congenital heart defects, vision and hearing impairments, hypothyroidism, and mental health disorders like depression and anxiety [7–9]. A notable co-occurring condition is Alzheimer's disease (AD), which is the leading cause of mortality in adults with DS in the Global North [10]. Lack of knowledge among the medical community of age-specific risk for people with DS means that treatable conditions can go undetected and untreated, highlighting the need for improved education and knowledge of disease profiles in this population [3, 11].

While these disparities in health and healthcare access are evident globally, they are compounded when they intersect with demographics such as race, socioeconomic status and country of origin [12]. For example, the life expectancy for Black people with DS in the US, is much lower than that of their white counterparts across all age groups, and especially in the younger cohorts [10]. With the vast majority of research conducted in the Global North, little is known about the views, needs and health trajectories of people with DS in the Global South.

Down syndrome in South Africa

DS has a higher birth prevalence in low- and middle-income countries compared to high-income countries, with rates reaching up to 2–3 per 1,000 live births in the former compared with 1-1.5 per 1,000 live births in high-income countries [13]. Epidemiological data on DS prevalence and survival rates in South Africa are largely outdated and come predominantly from studies conducted in the early 2000s. During that period, it was estimated that approximately 2,300 infants with DS were born annually in South Africa, with survival rates remaining critically low. Only about one-third of these children survived beyond the age of two, primarily due to complications such as congenital heart disease and infections [14]. This significant disparity compared to high-income countries, where equitable access to healthcare has markedly improved life expectancy and quality of life for individuals with DS, highlights the urgent necessity for enhanced healthcare infrastructure and early intervention programs in South Africa [15]. The protection of the rights of persons with disabilities in South Africa is enshrined in the Constitution of the Republic of South Africa, 1996, which mandates equality and prohibits discrimination based on disability. The country's ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2007 underscores its commitment to promoting and safeguarding the dignity of persons with disabilities [16].

Social inequities and stigma worsen disparities for individuals with DS, beyond variability in intellectual disability and compounding the impact of (often untreated) co-occurring conditions. Globally, access to education and employment opportunities remain significantly lower for people with DS compared to the general population. The pervasive stigma experienced by individuals with intellectual disabilities throughout their lives is well-documented and has been linked to various adverse health outcomes [17]. This stigma not only affects their mental and emotional well-being but also contributes to physical health disparities by limiting access to quality healthcare and social services, ultimately exacerbating their overall health challenges. Raliphaswa et al. [18]noted that mothers in South Africa experience fear, embarrassment, and financial strain, exacerbated by healthcare professionals' lack of empathy and communication. This situation is compounded by societal negative attitudes towards DS and the lack of support systems. However, the cultural principles of ubuntu and collectivism in black African communities provide potential support structures that could be harnessed to improve care and reduce stigma [19].

Health inequities

Early diagnosis of DS is crucial for managing associated health conditions and improving life expectancy. In South Africa, diagnosis is often delayed with just over half of clinical diagnoses confirmed by cytogenetic testing, with an average age of diagnosis of over one year [20]. This significant delay hampers timely medical care, essential for addressing common health issues associated with DS, such as heart defects and thyroid dysfunction. The capacity of the South African health system faces significant challenges that exacerbate these delays. The public health sector contends with staff shortages, fragmentation of services, and financial constraints, all of which contribute to reduced efficiency in healthcare delivery [21]. Health services are heavily strained due to a high disease burden, a situation worsened by limited financial resources and ineffective human resource management. The cumulative impact of these systemic challenges underscores the need for strategic improvements, including better resource allocation and workforce training, to support early and accurate diagnosis and treatment.

Globally, people with intellectual disabilities face substantial challenges in acute healthcare settings, leading to negative experiences and poorer health outcomes [22–24]. Despite their significant health needs and frequent use of medical services [25], people with DS encounter considerable barriers. Proactive strategies are needed to ensure equitable healthcare access and quality [26, 27]. Additional barriers may be encountered in South Africa. Maphumulo et al. [28]reported that despite the high prevalence of thyroid dysfunction among children with DS only 7% of affected children with DS received appropriate care, indicative of broader issues within the healthcare system, including inadequate screening and follow-up. Similarly, access to necessary medical interventions, such as cardiac surgery, was limited for children with DS in South Africa with misconceptions about surgical outcomes and cost-saving measures as major barriers to accessing cardiac surgery [29]. A recent study conducted at a rural regional hospital in South Africa highlights substantial gaps between the American Academy of Paediatrics (AAP) guidelines and the actual practices observed in this setting. While the AAP guidelines serve as an intensive health supervision program aimed at enhancing the functioning and quality of life of children with Down syndrome through comprehensive screenings for prevalent co-morbid medical conditions, their implementation in South Africa faces significant challenges due to financial and health resource constraints. Despite efforts to adapt these guidelines, including screening for key conditions such as cardiac, thyroid, hearing, and haematological disorders, the study found these screenings were often delayed or inconsistently performed. This reflects the context-specific limitations faced by middle-income countries like South Africa, where logistical issues and a lack of specialized genetics services at regional hospitals impact service provision [30]. While guidelines such as those advocated by Tsou et al., [3] outline universal healthcare guidance for people with DS, the reality of significant disparities in healthcare highlight the urgent need for comprehensive and specific clinical guidelines tailored to the South African context. These guidelines must address the unique challenges of the healthcare system and advocate for better resource allocation and service provision, including early interventions and supports to improve outcomes, support independence, and reduce health inequities for individuals with DS.

With over 200,000 traditional healing practitioners (THPs) in South Africa, far exceeding the approximately 46,000 [31] Medical Doctors (MD), THPs are integral to the healthcare system, catering to 70–80% of the population [32, 33], particularly in rural and marginalized communities where access to healthcare may be limited [34]. They therefore play an important role in the care for people with DS in South Africa. Distrust or dissatisfaction with Western medical care, personal autonomy in choosing traditional medicine, philosophic congruence with cultural beliefs and practices, and costs are reasons given for seeking care from THPs [35]. As MDs and THPs often share patients, there is a need for improved communication and mutual understanding among all in the healthcare ecosystem to meet the needs of the DS population.

Research on DS in South Africa predominantly focuses on childhood, leaving a significant gap in understanding life expectancy and the ageing experience, including age-related co-occurring conditions. This lack of regions specific data add to the other systemic challenges within the health system, as unrecognized conditions cannot be effectively treated. To address this, it is essential first to identify the health needs of adults with DS in South Africa and to recognize and plan for their evolving health needs, ensuring timely diagnoses and treatments for age-related conditions. Raising awareness about DS, particularly concerning adults and older adults, is crucial in South Africa and across the African continent. Such efforts could improve overall quality of life for people with DS by reducing stigma, increasing opportunities for education and employment, and contributing to improvements in health outcomes and overall support for this population.

The atlantic institute

The Atlantic Institute is a global community of Atlantic Fellows focused on tackling persistent inequities across the globe through advocacy, awareness and research. Fellows and regional mentors across two programs at the Atlantic Institute; the Program for Health Equity based at Tekano in South Africa and the Program for Equity in Brain Health at the Global Brain Health Institute (GBHI) at Trinity College Dublin convened key stakeholders from South Africa's DS community including representatives from the Dept of Health, Down syndrome South Africa (DSSA) and its associations in Gauteng, service providers for people with DS, people with DS and their families. This Imbizo (a traditional meeting or gathering in the Zulu and broader Nguni cultures for community consultation and decision-making) was held on 22nd November 2023 in Johannesburg to identify key areas of inequity for the DS community and to foster collaborative solutions from the shared expertise. The Imbizo was conceptualized by Atlantic Fellows from both the Programs. These Atlantic Fellowship programs share a commitment to addressing inequities, and the participating fellows were actively engaged in the field of intellectual disability. This background laid the foundation for creating an event that prioritized a multidisciplinary and inclusive approach. The structure and agenda for the Imbizo were developed collaboratively in partnership with DSSA. The design aimed to balance structured presentations with open discussion, reflecting the traditional format of an imbizo, which emphasizes community consultation and shared decision-making. All participants were fully informed about the purpose of the gathering, which was to set priorities, and signed consent was obtained from all individuals, including self-advocates who spoke on behalf of themselves and their communities. The following section describes the proceedings and resulting themes that arose from the Imbizo.

Imbizo proceedings

The Imbizo began with facilitators from the Atlantic Institute outlining the event's goals, emphasizing collaborative efforts to support individuals with DS and the importance of inclusivity and diverse perspectives. They introduced the potential for establishing a dedicated research network focused on DS within South Africa and the broader African context.

Personal experiences

A self-advocate with DS shared her lived experience of growing up with DS in South Africa, detailing personal challenges, educational achievements, and her active role in raising awareness and contributing to research on Alzheimer's disease within the DS community. This was followed by a parent sharing their journey of raising a child with DS, emphasizing the critical need for accessible education, supportive communities, and sensitive communication during diagnoses.

Organizational insights

The Executive Director of Down syndrome South Africa highlighted systemic challenges such as delayed diagnoses, the lack of national data, and limited social interventions for adults. The need for inclusive education, expanded employment opportunities, and mental health policy reforms was emphasized. Additionally, a representative from The Living Link, a non-profit organization, discussed the significance of promoting independent living and meaningful employment, sharing success stories that illustrated the positive impact of training and job placements on individuals with DS.

Governmental perspectives

An official from the Department of Health addressed the gaps in service access and coordination, emphasizing the need for improved infrastructure and community-based healthcare initiatives. They also highlighted the importance of comprehensive data collection and better coordination among service providers to enhance the overall outcomes for the DS community.

The discussions underscored the importance of timely diagnoses, improved access to educational opportunities, comprehensive support services, and the removal of employment barriers. Integrating the voices of individuals with DS in decision-making processes was a recurring theme throughout the event. Discussions from the Imbizo were minuted and synthesised by EMG, and subsequently reviewed and agreed by all authors. These discussion points were analyzed and organised into five key thematic areas: Advocacy and Awareness, Inclusion and Engagement, Education, Data and Research, and Networking and Collaboration. Actionable steps identified by participants to address challenges are detailed in Table 1. These included enhancing collective advocacy efforts, and actively involving individuals with intellectual disabilities in decision-making roles. Emphasis was placed on prioritizing data collection to inform policy changes and illustrate community needs. The need for better coordination among government departments and across sectors was also stressed, as was the importance of expanding support networks and resources.

Advocacy and awareness

Discussion from the Imbizo highlighted the importance of advocacy and awareness efforts in addressing the disparities and health inequities faced by individuals with DS. Leveraging collective voices through political channels and social media is essential in advocating for the rights and needs of individuals with DS. The pervasive stigma experienced by individuals with intellectual disabilities, which exacerbates health challenges and limits access to quality healthcare and social services [17], underscores the importance of these advocacy efforts. Participants highlighted the role of support persons and advocating for their inclusion in all aspects of life and decision-making processes to help address the fear, embarrassment, and financial strain experienced by families, as noted by Raliphaswa et al. [18]. Providing advocacy training is also key to empowering individuals, equipping them with the necessary tools and knowledge to champion their own rights and the rights of others effectively.

More broadly, education and training across disciplines and sectors is vital for fostering a more inclusive and understanding environment for individuals with DS. Educating colleagues within schools and the broader education system about DS can help reduce stigma and raise awareness of people with DS. Education among health care professionals, including traditional healers, tailored to the South African context is needed as a fundamental step in overcoming health inequities, and lack of access

Table 1 List of Actionable steps identified by participants at the Imbizo

1. Utilise collective voices: Commit to raising awareness and advocating for the rights of individuals with Down syndrome through political channels and social media.	8. Consistency and advocacy training: Provide training to empower individuals to advocate for themselves and others.
2. Engage people with ID: Actively involve individuals with intellectual disabilities in decision-making processes and provide training programs.	9. Educate colleagues: Conduct training sessions for educators to promote inclusivity and understanding of individuals with Down syndrome.
3. Enhance inclusivity in gatherings: Ensure future meetings include accessible materials and active participation of individuals with intellectual disabilities.	10. Importance of support persons: Advocate for the inclusion of support persons for individuals with Down syndrome in various contexts.
4. Prioritise data collection: Focus on collecting data to advocate for policy changes and highlight the needs of the Down syndrome community.	11. Share data and resources: Promote the sharing of data and resources among stakeholders for evidence-based decision-making.
5. Build a database of employers: Create a database showcasing employers who hire individuals with intellectual disabilities to foster employment opportunities.	12. Involve multiple government departments: Engage various government departments to address the comprehensive needs of individuals with Down syndrome.
6. Network expansion: Encourage the nomination of new members to join networks for collaboration and shared insights.	13. Research and publish: Support research initiatives and disseminate findings to expand the knowledge base on Down syndrome.
7. Include indigenous knowledge: Integrate indigenous knowledge systems and traditional healers in initiatives related to Down syndrome.	

to timely healthcare for this population. Specifically, education on unique age-related disease trajectories in this population [3, 11] will help to improve health and quality of life across the lifespan. Such training efforts are needed across sectors, including government representatives, to equip them with the knowledge and sensitivity needed to make informed policy decisions that will impact individuals with ID.

Inclusion and engagement

Inclusive participation in decision-making processes was highlighted as imperative for addressing the unique challenges faced by individuals with DS. This involves actively engaging individuals with DS in decision-making processes, ensuring their voices are heard and valued, and prioritizing accessible information dissemination methods for individuals with ID. Incorporating indigenous knowledge systems into discussions can enrich the dialogue and understanding of DS, offering diverse perspectives and solutions, and respecting cultural heritage [19]. Better understanding in needed on how DS, and intellectual disability more broadly, is conceptualised within indigenous knowledge systems. Given that many people with DS consult THPs as part of their medical care, improved understanding, and communication between MDs and THPs could increase support for the DS population. This would also result in a more complete and comprehensive picture of how the whole healthcare ecosystem in South Africa (including biomedical and indigenous knowledge) conceptualizes DS and ID. This additional knowledge could additionally help to address the stigma around DS and support interventions to improve care, thus reducing health disparities.

Education and training

The Imbizo discussions emphasized the importance of education and the barriers faced by individuals with DS in accessing foundational and tertiary education. Participants highlighted that despite significant challenges, individuals with DS have the potential to achieve higher educational goals when provided with appropriate support. However, the current landscape of inclusive education remains complex, with systemic issues hindering full implementation. Research indicates that South African teachers often feel unprepared for inclusive practices due to inadequate training and resources [36]. This lack of preparation exacerbates delays in providing quality education and contributes to limited academic expectations for learners with disabilities.

In the post-apartheid era, the South African Department of Education's White Paper 6 [37] aimed to create a more inclusive education system that embodies human rights and equality. The discussions underscored that inclusive education is not only a fundamental right but also essential for fostering independence and well-being. Advocacy for comprehensive teacher training and resource allocation was seen as critical to support learners with DS in mainstream settings. The emphasis on creating an educational environment that values academic as well as social development was echoed, suggesting that improved training and exposure to learners with disabilities can shift teachers' attitudes positively [36].

Calls for inclusive reforms extended beyond primary education to tertiary levels, highlighting that systemic changes must encompass all educational stages to empower individuals with DS to achieve their full potential. The need for training healthcare and educational professionals to deliver sensitive and informed support was also emphasized, ensuring individuals with DS receive timely and adequate education that respects their rights and capabilities.

Data and research

Identifying research priorities is crucial for guiding efforts towards impactful advocacy and policy change. Collecting data, including epidemiological data on the prevalence and life expectancy of individuals with DS in South Africa, is vital for supporting resource allocation. Additionally, data on age-specific health conditions and barriers to healthcare are essential to effectively inform and shape policy decisions. Encouraging research initiatives and the publication of findings play a vital role in advancing understanding and developing effective strategies. Dissemination strategies, however, need to go beyond publications to ensure findings reach a diverse range of stakeholders. Additionally, promoting the sharing of data among stakeholders fosters a data-driven approach to addressing the needs of the community. The development of a DS specific research network dedicated to sharing insights and data would enhance the collective ability to advocate for meaningful change and support individuals more effectively. This approach addresses the significant gaps in understanding the life expectancy and aging experience of individuals with DS in South Africa, as highlighted by the lack of data on age-related co-occurring conditions.

Networking and collaboration

Networking and collaboration were identified as essential for a multidisciplinary approach to effectively advocate for and support individuals with DS. Strengthening these connections can bridge the significant gaps between established guidelines and the reality of practices in South Africa [30]. The Imbizo provided a pivotal platform for bringing together diverse stakeholders to set priorities and outline actionable plans aimed at addressing the unique needs of the DS community. An immediate outcome of this gathering was the formation of the South African Network of Intellectual Disability (SANID), which committed to maintaining dialogue and fostering collective action.

A key aspect of expanding these efforts involves broadening the network to incorporate a wider range of contributors, including healthcare professionals, educators, non-profit organizations, community leaders, and individuals with DS and their families. Establishing a comprehensive database of employers willing to employ individuals with intellectual disability, including people with Down syndrome, would play a crucial role in promoting economic independence and reducing barriers to meaningful employment. Resource-sharing among these stakeholders is also essential, as it can maximize the impact of available tools and knowledge, fostering a collaborative environment that enhances service delivery. By fostering partnerships rooted in shared objectives and mutual understanding, increasing collaboration among those across sectors, working to support people with DS could lead to a more cohesive and impactful response to the challenges faced by the DS community in South Africa, ultimately driving long-term improvements in care and support.

Future directions and conclusion

The landscape of DS in South Africa is marked by high birth prevalence, health and social care inequities including significant challenges in diagnosis and healthcare provision. Addressing these issues in South Africa requires comprehensive healthcare guidelines, improved access to medical interventions, and robust support systems for families. Enhancing early diagnosis, ongoing health monitoring, and caregiver support, coupled with culturally sensitive approaches, are crucial steps towards improving the health of people with DS in South Africa. Additionally social challenges such as addressing stigma and creating opportunities for employment and education would support improvement in overall quality of life for people with DS in South Africa. The ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2007 affirmed South Africa's commitment to protecting and promoting the rights and dignity of persons with disabilities. This, along with constitutional mandates, sets a strong foundation for continued advocacy and systemic change. Future steps should prioritize enhancing healthcare access, improving educational and employment opportunities, and fostering inclusive community support systems. A on comprehensive research and data collection to better understand the status of persons with DS will also guide both policy development and the allocation of resources effectively. The strength of the DS community in South Africa lies in its collective voice and diverse perspectives, which were instrumental in identifying key areas of inequity.

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Author contributions

All authors were involved in the development and running of the Imbizo. EMG wrote the first draft of the manuscript. All authors provided critical revisions.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Competing interests

The authors declare no competing interests.

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References

1. De Graaf G, Buckley F, Skotko BG. Estimation of the number of people with Down syndrome in the United States. Genet Sci. 2017;19(4):439–47.
2. de Graaf G, Buckley F, Skotko BG. Estimation of the number of people with Down syndrome in Europe. Eur J Hum Genet. 2021;29(3):402–10.
3. Tsou AY, Bulova P, Capone G, Chicoine B, Gelaro B, Harville TO, et al. Medical care of adults with Down syndrome: a clinical guideline. JAMA. 2020;324(15):1543–56.
4. Startin CM, D'Souza H, Ball G, Hamburg S, Hithersay R, Hughes KMO, et al. Health comorbidities and cognitive abilities across the lifespan in Down syndrome. J Neurodevelopmental Disorders. 2020;12(1):4.
5. Karmiloff-Smith A, Al-Janabi T, D'Souza H, Groet J, Massand E, Mok K et al. The importance of understanding individual differences in Down syndrome. F1000Research. 2016;5.
6. Hamburg S, Lowe B, Startin CM, Padilla C, Coppus A, Silverman W, et al. Assessing general cognitive and adaptive abilities in adults with Down syndrome: a systematic review. J Neurodevelopmental Disorders. 2019;11:1–16.
7. Antonarakis SE, Skotko BG, Rafii MS, Strydom A, Pape SE, Bianchi DW, et al. Down syndrome. Nat Reviews Disease Primers. 2020;6(1):9.
8. Tassé MJ, Navas Macho P, Havercamp SM, Benson BA, Allain DC, Manickam K, et al. Psychiatric conditions prevalent among adults with Down syndrome. J Policy Pract Intellect Disabil. 2016;13(2):173–80.
9. Landete P, Soriano JB, Aldave B, Zamora E, Acosta C, Erro M, et al. Obstructive sleep apnea in adults with Down syndrome. Am J Med Genet Part A. 2020;182(12):2832–40.
10. Iulita MF, Chavez DG, Christensen MK, Tamayo NV, Plana-Ripoll O, Rasmussen SA, et al. Association of Alzheimer disease with life expectancy in people with Down syndrome. JAMA Netw open. 2022;5(5):e2212910–e.
11. Baksh RA, Pape SE, Chan LF, Aslam AA, Gulliford MC, Strydom A. Multiple morbidity across the lifespan in people with Down syndrome or intellectual disabilities: a population-based cohort study using electronic health records. Lancet Public Health. 2023;8(6):e453–62.
12. McGlinchey E, Iulita MF, Fortea J. Compounded inequality: racial disparity and Down syndrome. Lancet Public Health. 2023;8(11):e836.
13. Christianson A, Howson CP, Modell B. March of Dimes: global report on birth defects, the hidden toll of dying and disabled children. 2005.
14. Christianson AL, Zwane ME, Manga P, Rosen E, Venter A, Downs D, et al. Children with intellectual disability in rural South Africa: prevalence and associated disability. J Intellect Disabil Res. 2002;46(2):179–86.
15. Karami Matin B, Kazemi Karyani A, Soltani S, Akbari S, Toloui Rakhshan S, Mohammadi Moghadam M. The relationship between health system functions and the prevalence of down syndrome on a global scale. Archives Rehabilitation. 2022;23(2):186–203.
16. Swanepoel M. Aspects of the impact of the United Nations convention on the rights of persons with disabilities on South African health law: Sect. 1. Forensic Sci International: Mind Law. 2020;1:100014.
17. Hotez E, Rava J, Russ S, Ware A, Halfon N. Using a life course health development framework to combat stigma-related health disparities for individuals with intellectual and/or developmental disability (I/DD). Curr Probl Pediatr Adolesc Health Care. 2023;53(1):101433.
18. Raliphaswa NS, Maluleke M, Netshikweta ML. Not my dream': Mother's challenge of raising intellectual disability child in Vhembe district. Health SA Gesondheid (Online). 2022;27:1–9.
19. Mathebane MS. Afrocentric Social Work Practice guidelines for assisting African clans raising children with congenital abnormalities. South Afr J Social Work Social Dev. 2021;33(2):20–pages.
20. Willoughby M, Aldous C, Patrick M, Kavonic S, Christianson A. Delay and poor diagnosis of Down syndrome in KwaZulu-Natal, South Africa: a retrospective review of postnatal cytogenetic testing. South Afr Med J. 2016;106(6):626–9.
21. Malakoane B, Heunis JC, Chikobvu P, Kigozi NG, Kruger WH. Public health system challenges in the Free State, South Africa: a situation appraisal to inform health system strengthening. BMC Health Serv Res. 2020;20:1–14.
22. Michael J, Richardson A. Healthcare for all: the independent inquiry into access to healthcare for people with learning disabilities. Tizard Learn Disabil Rev. 2008;13(4):28–34.
23. Phillips KG, Houtenville AJ, Reichard A. Using all-payer claims data for health surveillance of people with intellectual and developmental disabilities. J Intellect Disabil Res. 2019;63(4):327–37.
24. Iacono T, Bigby C, Douglas J, Spong J. A prospective study of hospital episodes of adults with intellectual disability. J Intellect Disabil Res. 2020;64(5):357–67.
25. McMahon MJ, O'Connor AM, Dunbar P, Delany A, Behan L, Grogan C, et al. Mortality in residential care facilities for people with disability: a descriptive cross-sectional analysis of statutory notifications in Ireland. BMJ open. 2023;13(5):e065745.
26. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet. 2014;383(9920):889–95.
27. Ramsey L, Albutt A, Perfetto K, Quinton N, Baker J, Louch G, et al. Systemic safety inequities for people with learning disabilities: a qualitative integrative analysis of the experiences of English health and social care for people with learning disabilities, their families and carers. Int J Equity Health. 2022;21(1):13.
28. Maphumulo SF, Honey EM, Abdelatif N, Karsas M. The prevalence and spectrum of thyroid dysfunction among children with Down syndrome attending the paediatric services at two tertiary hospitals in Pretoria, South Africa. South Afr J Child Health. 2023;17(4):192–5.
29. Lawrenson JB, Kalis NN, Pribut H, Shipton S, Stirling J, De Decker R. Why are some South African children with Down syndrome not being offered cardiac surgery? South Afr Med J. 2006;96(9):914–9.
30. Schoonraad L, Slogrove A, Engelbrecht A, Urban MF. A 5-Year retrospective review of the Health Supervision received by children with Down Syndrome at a South African Regional Hospital. J Trop Pediatr. 2020;66(4):441–7.
31. Tiwari SC, Tripathi RK, Kumar A. Applicability of the mini-mental state examination (MMSE) and the Hindi Mental State Examination (HMSE) to the urban elderly in India: a pilot study. Int Psychogeriatr. 2009;21(1):123–8.
32. Galvin M, Chiwaye L, Moolla A. Religious and medical pluralism among traditional healers in Johannesburg, South Africa. J Relig Health. 2024;63(2):907–23.
33. Mendu E, Ross E. Biomedical healthcare and African traditional healing in the management of HIV and AIDS: complimentary or competing cosmologies? Afr J AIDS Res. 2019;18(2):104–14.
34. Moeta M, Musie MR, Seretlo RJ, Ledimo M, Rasweswe MM, Makhavhu E, et al. Traditional health practitioners' training needs on biomedical knowledge and skills in a South African township. Afr J Prim Health Care Family Med. 2023;15(1):1–9.
35. Mpinga EK, Kandolo T, Verloo H, Zacharie Bukonda NK, Kandala N-B, Chastonay P. Traditional/alternative medicines and the right to health: key elements for a convention on global health. Health Hum Rts. 2013;15:44.
36. Donohue DK, Bornman J. South African teachers' attitudes toward the inclusion of learners with different abilities in mainstream classrooms. Int J Disabil Dev Educ. 2015;62(1):42–59.
37. South Africa. Department of E. Education white paper 6: Special needs education: building an inclusive education and training system. Department of Education Pretoria; 2001.

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