REVIEW

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Improving the health of children and adults with intellectual disability in South Africa: legislative, policy and service development

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Poor understanding of the field of intellectual disability, limited teaching and training of service providers, and gaps in legislative reform and funding mechanisms have led to the slow translation of policy gains into improved quality of life for persons with intellectual disability.

This chapter provides a critique of current legislation, public policy, service development and civil society action to promote the health, wellbeing and social integration of persons with intellectual disability in South Africa.

The chapter reports on the findings of a scoping review of grey literature and peer-reviewed studies published between 2009 and 2019. It considers the implication of the United Nation's Sustainable Development Goals (SDGs) for the health and wellbeing of persons with intellectual disability, and addresses key issues, role-players, sectors and settings that impact on the lives of persons with intellectual disability.

The review found that strides have been made toward inclusion of persons with intellectual disability in policy directives to alleviate poverty and hunger, promote inclusive education, and improve the (mental) health status of persons with intellectual disability within the health, social services, justice and education sectors. Poor understanding of the field of intellectual disability by policy makers and implementers, limited teaching and training of healthcare and other service providers, and gaps in legislative reform and funding mechanisms have led to slow translation of policy gains into improved quality of life for persons with intellectual disability. In the past decade, peer-reviewed published literature on intellectual disability in South Africa has increased in response to emergent human rights issues, but research that informs strategies and interventions to promote the health and wellbeing of persons with intellectual disability has been limited.

Recommendations are made on further policy, legislative and service reform, research and training, and stakeholder roles in fully realising the SDGs for persons with intellectual disability in South Africa.

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Introduction

Persons with intellectual disabilities (ID) comprise an estimated 1-2% of the world's population, most of whom live in low-and middle-income countries (LMICs) and are among the most vulnerable and marginalised.[1] A review of the global burden of disease estimated that persons with ID worldwide increased from 118.2 million in 1990 to 154 million in 2013. Around 104.9 million have borderline and mild ID, and about 49.1 million have moderate to profound ID.[2] Nationally, accurate collection and interpretation of epidemiological ID data is hindered by lack of consensus on definitions and terminology, and varied data-collection methods. A country-level review of public policy and services for persons with ID in South Africa published in 2010 reported that while no reliable data on aetiology of ID in the country are available, the prevalence rate may be higher than in other LMICs due to high rates of preventable causative conditions, such as nutritional deficiencies, tuberculosis meningitis, foetal alcohol spectrum disorder and trauma. The review noted that ID remained a low public health priority, with persons with ID experiencing significant unmet social, health and educational needs.[3]

The aim of this review is to provide a country-level overview of current health-related research published subsequent to the 2010 review, focusing on legislation, public policy, services and advocacy to promote the health and wellbeing of persons with ID in South Africa. Scoping reviews are appropriate to provide an overview of current evidence and to identify knowledge gaps in an area of inquiry.[4]

The United Nations (UN) Sustainable Development Goals (SDGs) provide a useful framework for review, having clear links to the UN Convention on Rights of Persons with Disabilities (UN CRPD).[5,6] The term 'Health and Wellbeing' is used, as conceptualised in SDG3, which recognises that health is influenced by SDGs other than SDG 3. The review was guided by the following question: What does current research on legislation and policy, services, training and capacity development, and advocacy reveal regarding what is needed to support the health and wellbeing of persons with ID in South Africa?

Methods

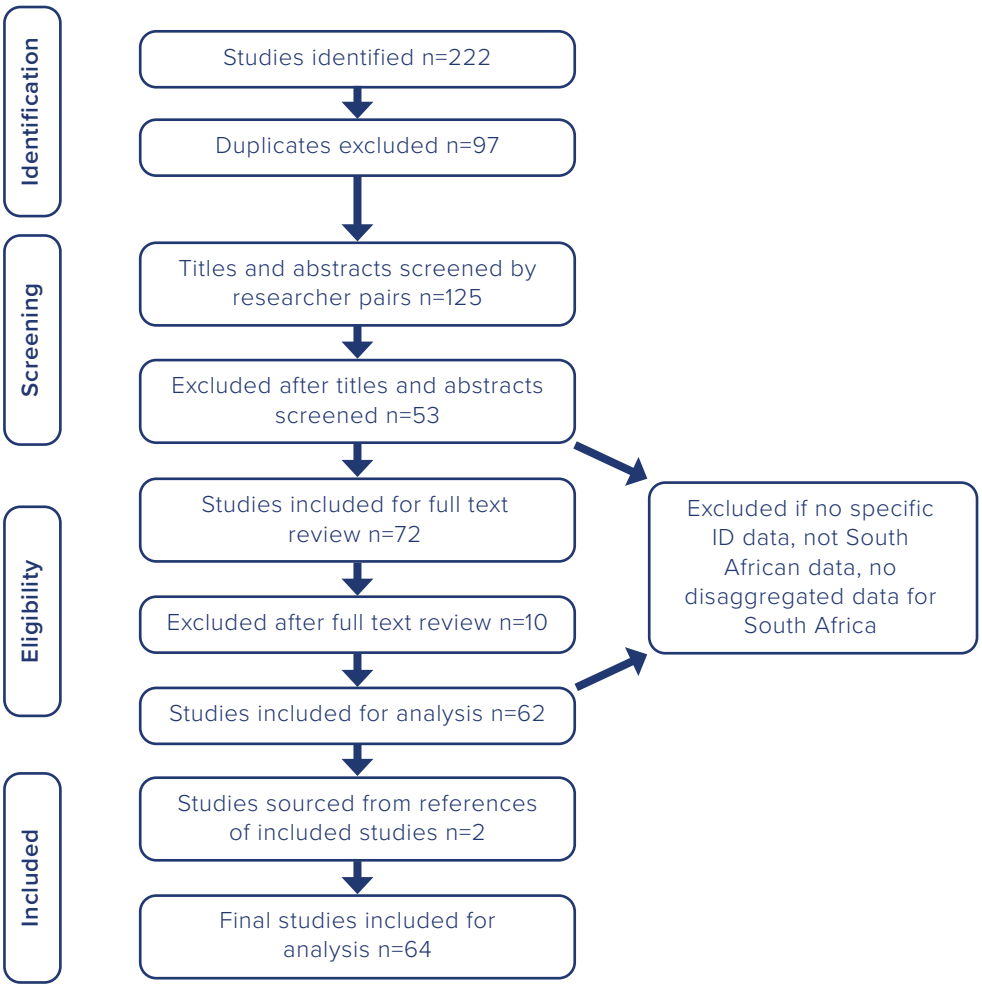
A search was done of government websites as well as the following electronic databases: PubMed, Scopus, and Ebscohost (Africa-wide CINAHL, CINAHL Complete, Medline, Medline Complete, Academic Search Premier, Africa Wide Info, SocINDEX, APA PsycInfo and APA PsycArticles) using appropriately developed search terms. Retrieved documents were analysed thematically for ID, and included six Acts[7-12] and two national policies[13,14] that directly reference ID. The PRISMA-ScR guidelines (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) were followed.[15] Table 1 below outlines criteria for sourcing studies and selecting studies.

Table 1: Eligibility criteria for inclusion in the scoping review

Inclusion	Exclusion
Children and adults with ID	• Disability but not ID • Developmental disabilities but not ID • Conditions in which ID is not always present
• Research in South Africa • International studies that include disaggregated data for South Africa	Studies outside South Africa
Published in peer-reviewed journals	Not published in peer-reviewed journals
English	Not English
Published January 2009-March 2020	Studies published outside the timeframe

Figure 1 summarises the selection process for included studies. Author pairs screened the retrieved records for eligibility, first by title and abstract, then by full text, after which selection decisions were finalised by all authors. Quality assessment of the included papers was not conducted as the aim of the review was to provide a comprehensive overview of the limited available literature.[4] All records were available electronically. The review did not require ethical approval.

Figure 1: Flow diagram of the search, screening, selection and inclusion of studies



A data extraction sheet was used to capture data inductively, based on selected SDGs: 1 (No poverty), 2 (No hunger), 3 (Good health and well-being), 4 (Quality education), 5 (Gender equality), 8 (Work and economic growth), 10 (Reduced inequalities), 16 (Peace, justice and strong institutions), and 17 (Partnerships for the goals). Data were also synthesised, where available, under the themes: legislation and policy, services, training and capacity development, and advocacy.

Key findings

Characteristics of included studies

Table 2 summarises characteristics of included studies (n=64) by author(s), date, topic, SDGs and findings on the themes noted above. Studies used quantitative (n=26), qualitative (n=33), and mixed-method (n=5) designs.

Table 2: Characteristics of included studies

Author, year	Topic	Services	Legislation and policy	Capacity development	Advocacy
Adnams, 2010[3]	ID in SA	**SDG 3**: Low priority impacts service implementation.			**SDG 16**: Address preventable causes: high burden of disability.
Berry et al., 2011[16]	Social assistance eligibility assessment	**SDG 3**: Assessment tool required for social grants.			**SDG 1**: Improve access of children with IDD to poverty-alleviation initiatives.
Brown et al., 2009[17]	Teacher resources and coping orientation	**SDG 4**: Educator stress in managing challenges of learners with ID can erode motivation to teach learners with complex needs.		**SDG 4**: Offer interventions that promote positive self-regard and build strengths-based orientation to learners' capabilities so as to enhance educator resilience.	
Calitz, 2011[18]	Psycho-legal challenges			**SDG 10**: Rape victims in court need mediators.	
Capri et al., 2018[19]	Rights and citizenship	**SDG 3, 11 & 16**: Health rights to be observed.		**SDG 5**: Individuals require support during legal procedures.	
Capri et al., 2018[20]	Esidimeni	**SDG 3**: Poor service decisions result from lack of understanding of ID.		**SDG 11**: Improve remuneration and training of carers and multidisciplinary professionals.	
Coetzee et al., 2019[21]	Family intervention for challenging behaviours	**SDG 3**: International service guidelines adapted for SA.			
Combrinck, 2017[22]	UN CRPD and GBV		**SDG 16**: Legislation to protect against exploitation, GBV and abuse not sufficiently aligned with UN CRPD.		
Donohue et al., 2014[23]	Children's perspective of rights	**SDG 3 & 4**: Low priority, service barriers impair rights-based access.			
Dreyer, 2017[24]	Education and support	**SDG 3**: Negative educator attitudes towards inclusive education.			

Author, year	Topic	Services	Legislation and policy	Capacity development	Advocacy
Engelbrecht, 2019[25]	Inclusive education	**SDG 3**: Understand cultural and socio-economic context when implementing inclusive education.			
Erasmus et al., 2016[26]	Parent's perception of children's rights				**SDG 4**: Address parent's prioritisation of children's right to education and safety.
Freeman, 2018[27]	Deinstitutionalisation		**SDG 3**: Strict principles for (de-) institutionalisation not motivated by cost saving.		**SDG 3 & 17**: Lobby for the right to community living: improve investment in community living and build capacity to live in communities.
Fujiura et al., 2010[28]	National monitoring of the status of persons with ID required				**SDG 10**: Improve national information systems and statistics collected for ID.
Giarelli et al, 2009[29]	DD and behaviour problems in school children	**SDG 4**: Remedial education and behavioural support services needed at schools.		**SDG 4**: Provide teachers with classroom-based behaviour-management skills.	**SDG 4**: Advocate for adaptation to curricula and teaching practice to support learners with ID and behavioural challenges.
Goga et al., 2019[30]	Health programmes to prevent HIV needed				**SDG 3 & 17**: Address shortage of trained healthcare staff, devices.
Hanass-Hancock et al., 2018[31]	Sexuality education	**SDG 4**: Challenge of untrained staff, lack of attention to socio-cultural context.		**SDG 3**: Trainers need assistance to manage difficulties in delivering sexuality education.	
Janse van Rensburg et al., 2015[32]	Mental health of student nurses			**SDG 3**: Practical and coping skills training needed to reduce distress.	
Knox et al., 2018[33]	Screening for DD in HIV-positive/ negative children	**SDG 3**: Need developmental screening of HIV-positive children.			
Kramers-Olen, 2017[34]	Sexual knowledge and consent capacity	**SDG 3 & 16**: Importance of assessing sexual consent capacity.	**SDG 3 & 5**: Policy to uphold sexuality rights.		**SDG 3 & 5**: Reinforce right to consensual sexual expression.

Author, year	Topic	Services	Legislation and policy	Capacity development	Advocacy
Kruger, 2015[35]	Right to education court ruling		**SDG 10**: Education policy insufficient for substantive equality.		**SDG 10**: Address separation of students due to ableism.
Lorenzo et al., 2012[36]	Access to livelihood assets among youth				**SDG 1, 2, 3 & 8**: Include disabled youth in employment opportunities.
Lygnegård, 2013[37]	Generic and special needs of children with disabilities				**SDG 3 & 10**: Include the voices of disabled children in research.
Maddocks et al., 2020[38]	Caregiver perceptions of caring and rehabilitation	**SDG 10**: Care constrained by lack of finance, poor access to rehabilitation, special school placement, and lack of support networks.		**SDG 17**: Strengthen community care systems.	
Manaka et al., 2018[39]	Nurse carer experiences			**SDG 3**: Person-centred therapeutic relationship between nurse carers and persons with ID is key.	
Marlow et al., 2019[40]	Screening tools for ASD and DD	**SDG 3**: Identified 10 screening tools.			
McKenzie et al., 2012[41]	Rights discourses in education	**SDG 10 & 16**: Ethics of care approach recommended.			**SDG 3, 10 & 16**: Recognise complexity of rights claims made by/on behalf of persons with ID.
McKenzie et al., 2013[42]	Research and service development on ID in an African context	**SDG 1, 2, 3, 4, 5, 8 & 10**: Include lifespan supports such as self-advocacy, sexuality education, supports for aged and families. Mainstream ID in disability programmes.	**SDG 3 & 17**: Include individuals with ID in policy development.		**SDG 10**: Improve African understanding of ID.

Author, year	Topic	Services	Legislation and policy	Capacity development	Advocacy
McKenzie et al., 2013[43]	Health conditions and support needs in residential facilities	**SDG 3, 5, 8, 10 & 11**: Limited access to healthcare and rehabilitation for mental health, challenging behaviours, medication and family support. Limited economic inclusion, community-based services and living.		**SDG 3**: Staff in-service training can support staff to innovate, share practices.	
McKenzie et al., 2014[44]	Residential facilities	**SDG 3, 10 & 16**: Human-rights based service evaluation needed.		**SDG 3**: Ensure that residents retain contact with local community and have opportunity for vocational and life skills development.	
McKenzie & McConkey, 2016[45]	Family carers	**SDG 3, 4 & 5**: Support future planning. Prioritise community-based education, training and leisure options.		**SDG 4 & 8**: Develop community-based education and training for competence.	**SDG 3, 4 & 17**: Promote collective action and conversation among caregivers.
McKenzie et al., 2017[46]	Inclusive education for children with ID		**SDG 4**: Shift to systemic inclusion to aid inclusive learning environments.	**SDG 4**: Train teachers, build caregiver skills, accredit training.	**SDG 4 & 17**: Promote community involvement to destigmatise.
McKenzie et al., 2019[47]	Democratic rights				**SDG 10 & 16**: Include persons with ID in gains achieved for disability rights.
McKenzie, 2020[48]	Curriculum challenges		**SDG 4**: Insufficient attention to inclusive education policy implementation.		
Meer & Combrinck, 2017[49]	Families and GBV	**SDG 1, 3, 4, 5, 8 & 16**: Lack of GBV action due to poverty, reliance on DG or perpetrator, stigma. Provide sexuality rights education, socioeconomic empowerment.			

Author, year	Topic	Services	Legislation and policy	Capacity development	Advocacy
Mkabile & Swartz, 2020[50]	Caregiver explanatory models	**SDG 3 & 5**: Accessible services for low-resourced carers, children. Women affected by patriarchal attitudes.	**SDG 3**: Integrate traditional and alternative healers.		**SDG 3**: Recognise alternative healthcare practitioners in health system.
Molteno et al., 2011[51]	Psychiatry sub-specialities	**SDG 3**: Need evidence-based community-based, primary and tertiary care.		**SDG 3**: Postgraduate training and ID sub-specialists needed.	**SDG 3**: Provide consultation support for integrated policy implementation in service delivery across levels of care.
Nqcobo et al., 2012[52]	Dental caries prevalence	**SDG 1 & 3**: Targeted use of scarce resources. High unmet treatment needs due to inaccessible services.			**SDG 16**: Promote interdisciplinary collaboration.
Nqcobo et al., 2019[53]	Caregiver perceptions of oral health	**SDG 3 & 4**: Expand caregiver and teacher oral health education for early detection.			
Olusanya et al., 2018[54]	DD in under 5s	**SDG 1, 2, 3, 4 & 8**: Identification of cause, early detection and intervention needed. Due to poverty in LMICs, children not reaching potential.	**SDG 3 & 4**: Use WHO ECD Nurturing Care Framework.		**SDG 10**: Prioritise developmental potential of young children
Phasha, 2009[55]	Responses to sexual abuse of teenagers	**SDG 3 & 4**: Appropriate health and education to support children.	**SDG 16**: National DoE procedures should be revisited to better align organisational protocols with legislation.	**SDG 4**: Educators must be trained to deliver content.	
Phasha & Nyokangi, 2012[56]	School-based sexual violence	**SDG 4 & 5**: Clear policies, reporting procedures, developmentally appropriate sex education to combat exploitative behaviour		**SDG 4 & 5**: Empower learners with self-protection skills and information on acceptable forms of sexual behaviour for young adults with disabilities.	**SDG 4 & 5**: Address the culture of concealment of sexual abuse.

Author, year	Topic	Services	Legislation and policy	Capacity development	Advocacy
Phasha & Nyokangi, 2013[57]	GBV in schools	**SDG 4 & 5**: Supervision, school prefects, support staff, clear procedures needed on GBV.		**SDG 4 & 5**: Education and teacher training to address GBV.	
Phaswana et al., 2013[58]	Clinical factors and ability to testify	**SDG 3 & 16**: Early referral to mental health services, improve referral pathway.	**SDG 3 & 16**: Health and legal system to collaborate in care.		
Pillay, 2012[59]	Challenges for children in legal system	**SDG 16**: Collaboration between legal and mental health professions.			
Pillay et al., 2011[60]	Examinations and social context variables	**SDG 1, 2, 4 & 8**: High poverty, hunger, unemployment. Grants, work, income generation, workshops, special schools essential.		**SDG 17**: Address lack of ID knowledge among families, practitioners, sectors.	
Potterton et al., 2010[61]	Home stimulation programmes	**SDG 3**: Home stimulation programmes can improve development.		**SDG 4**: Improve parent skills to support child's development.	
Rasdien et al., 2019[62]	Developmental clinic patients	**SDG 3**: Early identification, assessment and intervention challenging.		**SDG 3 & 4**: Develop capacity for early detection, intervention.	
Roberts et al., 2016[63]	Dental needs of children	**SDG 3**: Optimal dental care possible. Parental role important.		**SDG 3 & 4**: Include skills to treat persons with ID in dental training.	
Rohleder, 2010[64]	Educators ambivalence about sex education	**SDG 3 & 4**: Educator anxiety can limit sexuality education.		**SDG 4**: Change attitudes that hamper education.	
Sandy et al., 2013[65]	Support needs of caregivers	**SDG 3 & 4**: Limited education, health services, respite, decision-making and supervision causes caregiver stress.	**SDG 3**: Deinstitutionalisation has taken place without resources to families, community.	**SDG 3 & 4**: Reduce caregiver stress via health literacy, knowledge and skills.	**SDG 3**: Provide information to empower parents to advocate.
Savolainen et al., 2012[66]	Teachers' attitudes and self-efficacy in inclusive education			**SDG 4**: Build practical skills, address contextual influencers on training receptivity.	

Author, year	Topic	Services	Legislation and policy	Capacity development	Advocacy
Schoeman et al., 2017[67]	Developmental screening: follow-up adherence predictors	**SDG 3**: Parents defaulting on referrals for early intervention due to lack of information on child's development, employment concerns, other responsibilities.			
Spangenberg et al., 2016[68]	Validation of education database	**SDG 4**: Few children under 4 attended centres, lack of access to care for young adults.	**SDG 16**: Information systems can inform service planning.		**SDG 17**: Multi-sector input needed.
Stein et al., 2018[69]	Mental health services	**SDG 3**: Insufficient funding for mental health, ID services. Develop community services.		**SDG 3 & 4**: Cross-disciplinary sub-specialisation needed.	
Struthers, 2011[70]	Health-promoting schools and sport to address community conflict	**SDG 1, 4 & 10**: Health-promoting schools can be a vehicle for social inclusion of ID learners.			
Swanepoel & Haw, 2018[71]	Maternal depression	**SDG 1 & 3**: 60% of mothers received care dependency grants, 33.3% screened positive for depression.			
Temane, 2016[72]	Student nurses experience of placements	**SDG 3 & 4**: Training in inhumane ID settings distress student nurses.		**SDG 4**: Student nurses require ongoing tutor support.	
Tomlinson et al., 2014[73]	Global research priorities	**SDG 3**: Prevalence, biomarkers, risk/ protective factors; early identification, screening, intervention; awareness, prevention and promotion; health system access.		**SDG 3**: Human resource capacity; include NPOs, persons with ID in research; support for families.	
Van der Linde, 2014[74]	Nursing auxiliaries' job satisfaction			**SDG 3 & 4**: Improve ID specific skills, provide mentoring to reduce stress and improve job satisfaction.	

Author, year	Topic	Services	Legislation and policy	Capacity development	Advocacy
Van der Linde & Casteleijn, 2016[75]	Comparison of assessments of functioning	**SDG 3**: OT and nurse assessments valuable for intervention development.			
Van Niekerk et al., 2015[76]	Time utilisation trends of supported employment services	**SDG 1, 3, 8 & 16**: No sustainable funding for open labour work support. Supported employment feasible if adapted to ID service utilisation patterns.		**SDG 3 & 4**: Include supported employment in OT training standards, job coaching, and development of supported employment programmes.	
Van Wieringen & Ditlopo, 2015[77]	Medical student training			**SDG 4**: Medical students need in-depth teaching, clinical exposure to manage ID patients confidently.	
Wedderburn et al., 2019[78]	Neurodevelopment of HIV-exposed uninfected children	**SDG 3**: Uninfected children exposed to maternal HIV infection and ARVs may have language delays at 2 years.			

ARV = antiretroviral; ASD = autism spectrum disorder; DD = developmental disability; DG = disability grant; ECD = early childhood development; GBV = gender-based violence; IDD = intellectual and developmental disabilities; NDoE = National Department of Education; NPO = non-profit organisation; UN CRPD = United Nations Convention on the Rights of Persons with Disabilities.

Legislation and policy

Data illustrated how outdated legislation can impact on the rights of persons with ID.[18] For example, political equality (SDG 10) is denied under the Electoral Act (No. 73 of 1998), which regulates that citizens declared "of unsound mind" may not be registered as voters. SDG 16 calls for non-discriminatory laws and policies.[7] The Mental Health Care Act (No. 17 of 2002) lists severe and profound ID in its definitions, which has at times excluded persons with mild and moderate ID from mental health-related services.[8]

Abusive terminology has changed in South African law, with terms such as 'idiot', 'moron' and 'imbecile' replaced with 'mental handicap', 'mental retardation', and more recently, 'intellectual disability', although not uniformly. An amendment is underway of section 77 of the Criminal Procedures Act (No. 51 of 1977) (assessment of capacity to understand proceedings) and section 78 (mental illness or mental defect and criminal capacity) to replace the term "mentally defective" with "intellectual disability".[9] The 2020 Sexual Offences and Related Matters Amendment Bill retains the term "mentally disabled",[79] and does not distinguish between persons with psychosocial disability and ID.[18]

SDG 5, gender equality, calls for elimination of violence against girls and women, including sexual exploitation. Gender-based violence (GBV) is rife in South Africa, including sexual abuse of girls and women with ID.[22,49,55] Section 194 of the Criminal Procedures Act (No. 51 of 1977) provides that persons affected by "mental illness or … any imbecility of mind … thereby deprived of the proper use of his reason … cannot be deemed competent to give evidence".[9] Lack of legislated reasonable accommodation for survivors of sexual crimes in understanding court proceedings and providing credible witness, can result in non-conviction of perpetrators.[9] The Sterilisation Act (No. 44 of 1998) recognises the right to bodily and psychological integrity, yet permits sterilisation consent to be given on behalf of "a mentally disabled person" deemed incapable of consenting, after an expert panel review.[11]

Policy data from this review reflect a need for improved policies on early detection, identification and intervention in the case of children with, or at risk for intellectual and developmental disabilities (IDD). Interventions suggested include primary prevention to reduce incidence of IDD, and secondary and tertiary prevention as part of comprehensive community development. Implementation of brief, low-cost,

routine screening tools by lay health and other workers has been recommended.[40]

Children who are HIV-exposed in utero but uninfected, have high rates of neurodevelopmental problems. HIV-exposed, uninfected children are particularly vulnerable, due to a lack of adequate early identification and follow-up of IDD. Reformed policies providing support to these children are required to promote SDG 3.[38]

Deinstitutionalisation policy promotes community-based mental health care over institutional care, but funding has not followed to ensure quality care for persons with ID, mental health problems and other high-support needs, rendering families or NPOs the primary care providers.[65] The Esidimeni tragedy resulted from transfer of adults with mental illness or ID from state-funded institutions to inadequate community care, and at least half of those who died in these centres had ID with complex care needs.[20,27]

Legislation and policy support intersectoral coordination, but service implementation is often siloed. Education White Paper 6 on inclusive education recognises ID as a barrier to learning and promotes the education system's role in detection of IDD in school-aged learners.[14] However, educational responses are insufficient to effect the equality envisaged for learners in SDGs 4 and 10.[35] Children with severe and profound ID are still denied formal schooling within the basic education sector despite a court ruling in 2010 obligating inclusion of these children as learners.[45] Similarly, access to assessment for social grants may be a barrier to securing the benefit.[12] The White Paper on the Rights of Persons with Disabilities recommends review of legislation to remove barriers to rights provision.[13]

Services

Poverty (SDG 1) leads to undernutrition among persons with ID and their families (SDG 2), exacerbating IDD.[49,50,61] Care dependency and disability grants are often the only source of household income or are used entirely for residential care costs.[44] Lack of training prevents persons with ID from entering the open labour market,[44] despite supported employment leading to increased social inclusion, skills and income.[44,76] Poorly supported caregivers may leave employment due to caregiving responsibilities,[45] deepening family poverty.

Funding of health services for persons with ID is largely within tertiary mental health services, with community-based health services remaining under-resourced.[69] The higher prevalence of mental health problems among persons with ID[50,51] can result in inadequate general health care due to diagnostic overshadowing.[50] Progress towards integrated, inclusive services for persons with ID in primary and tertiary services[51] is hampered by access barriers, including inequitable service concentration in urban centres.[3,50,51] Few studies reported on therapeutic interventions for persons with ID,[21,61] including evidence-based practice for behaviours that challenge a complex presentation in persons with ID.

Carer barriers to accessing adequate health care include insufficient understanding of early intervention, having to prioritise work, costly transport, fragmented services, cultural and language barriers, and perceived lack of understanding by providers of caregiving challenges.[45,50,61,67]

Sexual and reproductive health education is important given that sexual knowledge is low among persons with ID.[31,34] Family members often exercise authority over the bodies and relationships of persons with ID,[49] and other caregivers may deny access to sexuality education, contraception, safe sexual relationships,[44,49,55,56] and protection from GBV in settings such as schools.[57-59] Inadequate judicial services may also result in non-reporting of violence and abuse or exclusion from testifying.[59]

Family support services are vital given the impact of high burden of care on caregiver health.[45,50] Caregiver stress is associated with lack of respite, inadequate support in managing behaviours that challenge and limited parental involvement in decision-making.[50,65] The value of multidisciplinary teamwork in ID health services was noted in several papers.[51,52,62,63,68,75] The role of alternative healthcare practitioners needs further attention given that many caregivers consult both medically trained and traditional health providers.[50]

Training and capacity development

Caregivers may have low levels of health literacy and practical skills, especially in managing behaviours that challenge.[65] Community-based workers can provide information to families and persons with ID to enhance self-reliance at home and in their community.[44] Undergraduate and postgraduate health practitioners require curricula in ID to ensure capacity for early detection and intervention.[62]

Health workers can experience high levels of stress, even depression, working with patients with high physical and behavioural support needs.[74] Improved knowledge, management skills and mentoring in supporting complex care needs can reduce stress and prevent burnout.[32,65,74] Delivery of sexuality education programmes to promote sexual and reproductive health and safety requires understanding of stereotypes about the impact of sexuality education on sexual activity.[64]

Advocacy

In terms of SDG 10, children with ID who survive early childhood will not have their needs prioritised without vigorous advocacy.[2]

Meeting the needs of persons with ID requires provider partnerships with caregivers and persons with ID to promote empowerment.[50,65] The court case brought by the Western Cape Forum for ID to assert the right to education of children with ID demonstrates the power of advocacy to address inequalities in service provision.[47]

Discussion

Legislation, policies and services

Review is needed of outdated legislation and terminology that act as a barrier to rights-based, coordinated policy and service development and implementation.[18] Dedicated disability legislation could help to improve intersectoral policy directives for service delivery[19] by 'clustering' areas of action identified in this review. This would support access to poverty-alleviation programmes, employment creation and supported employment programmes, rehabilitation and respite services, and education, including sexuality and reproductive health services.

Service development should also prioritise reduction of preventable causes of IDD and early identification and intervention. A family-centred approach across the lifespan should underpin developments, emphasising community-based health-related supports. Interventions to support families caring for relatives with complex high-support needs at home, is a particular concern.

Reviewed articles did not address the National Health insurance (NHI) Bill of 2019, set to change health-service delivery in South Africa,[80] including for persons with disabilities.

Training and capacity development

The review found insufficient integration of practice-based programmes on ID into academic and in-service training programmes for practitioners, limiting confidence in the delivery of health, social and education services. Enhanced practitioner competence should support capacity-building of caregivers to manage the complex needs of their relatives. Limited research on capacity-development needs of persons with ID has focused on education and supported employment.

Advocacy

The review findings indicated a lack of inclusion of persons with ID in policy, treatment and support-service decisions, with advocacy primarily family and service-provider driven. While more work is needed to improve advocacy by families, particularly for persons whose disability precludes personal input on public policy and service-related processes, the lack of self-representation by persons with ID is notable.

Research

Research can inform evidence-based input on dedicated disability legislative review and service gaps. The development of specific health-related indicators for disability must be included in public service information systems. The evidence base to support service development must involve academics, professionals, NPOs, families of persons with ID, and persons with ID themselves.[81]

Conclusion

Issues identified resonate with the disability-related priorities of South Africa's National Development Plan (NDP) 2030,[82] including the need for disability-adjusted, gender-sensitive strategies to address the cyclical impact of poverty and inequality on disability (SDGs 1, 2, 3, 4, 5, 8 and 10). The NDP acknowledges the role of discrimination in exclusion, particularly for girls and women with disabilities (SDG 5). Future directions can be supported by setting a public health-related research agenda for ID that includes participation of persons with ID.

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