Disability and mental health: Addressing discrimination and enhancing participation

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The global understanding of disability has shifted radically over several decades, away from a purely medical understanding of impairment as the direct cause of any disability. Instead, there is a growing recognition that disability arises when persons with 'long-term physical, mental, intellectual or sensory impairments encounter various barriers that hinder their full and effective participation in society on an equal basis with others'.[1]

This chapter critically examines the link between physical, mental, intellectual, or sensory impairments and the development of psychosocial disability, and explores how to enhance the mental health of children with disabilities by addressing the following questions:

- What is the prevalence of disability and mental disorders?
- How do impairment and the associated discrimination and exclusion impact on mental health?
- How does participation enhance mental health?
- What are the opportunities to strengthen policy and programming?

What is the prevalence of disability and mental disorders

The World Report on Disability estimates that about 15% (over a billion) of the world's population has some type of disability.[2] Of these, it is estimated that between 110 and 190 million are children under 15 years old and that the overwhelming majority of these children are located in low- and middle-income countries (LMICs). This prevalence appears to be increasing and is likely related to the increased neonatal survival rates in LMICs.[3]

Underreporting and discrepancies in population-based survey questions mean that there are no reliable prevalence data on childhood disability in South Africa.[4] The 2011 South African census addressed six domains of functioning: seeing, hearing, communication, remembering/concentrating, walking and self-care. An individual was identified as having a disability if they experienced moderate to severe limitations in a specific domain or if there were limitations across different domains.[5] Yet this approach cannot be satisfactorily applied to developmental disabilities or children under the age of five.[6] Considering these limitations, the national prevalence rate for disability was found to be 7.5%, while prevalence rates for children decreased with age, from 11% of 5 – 9-year-olds to 4% of 10 – 14-year-olds, and 3% of 15 – 19-year-olds. The most common impairments are loss of vision, 'cognitive difficulties', and loss of hearing.[5]

In addition, it is estimated that one in five children under 14 years of age worldwide are affected by mental disorders.[7] Without proper treatment and environmental supports, children struggling with mental health problems or mental disorders may go on to develop a temporary or long-term psychosocial disability that impairs their ability to function and participate in society. But this is not inevitable and depends on whether the child's environment is enabling or disabling.[8] For example, children with mental disorders living in the rural areas of the Western Cape may face far greater difficulties in accessing services and support than those living in a well-resourced metropolitan centre such as Cape Town.

At the same time, children and adolescents with physical, sensory or intellectual impairments are at increased risk of developing mental health problems and psychosocial disabilities when exposed to environmental barriers such as stigma and social isolation. Yet, a supportive environment and positive social interactions can prevent an impairment from becoming a disability.[9] For example, children with cerebral palsy (CP) in various LMICs have been found to have poorer mental health and self-esteem than their typically developing peers,[10] and in some studies over one-third of children with CP have reported mental health symptoms.[11] High rates of mental disorders are reported amongst children and youth with intellectual disability, with studies from the United Kingdom suggesting that 36% of this population

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have a mental disorder, compared to 8% of children without disabilities.[12] Similarly, there are indications that children and youth with visual impairment had more emotional problems than sighted children.[13]

How do disability, discrimination and exclusion impact on mental health?

The World Health Organization (WHO) views mental health as 'a state of well-being in which children and adolescents can fulfil their potential, cope with life stressors, be productive in their learning, and contribute to their communities'.[14] Such a state of well-being is only possible when children are supported by a nurturing and responsive environment. Such environments not only meet children's basic physical, emotional and social needs, they also ensure that children enjoy emotionally responsive relationships with primary caregivers within a family-oriented setting which protects them from harm and encourages their efforts to cope with life's challenges and grow their talents within their community.

Yet, common responses to children with disabilities undermine this. Children with disabilities and their families often face ongoing battles for access to health care, education, transport, and other services, as well as stigma, bullying[15] and discrimination, on top of the everyday demands of coping with an impairment.[6] Confronting these challenges daily can readily give rise to feelings of anxiety and depression in both children and parents, and the very real sense of being alone in one's struggle. For many children and families, the experience is one of living in 'survival mode', where inner distress must be managed while continuing to negotiate a world which is often unwelcoming, and even hostile.[16] All of this works against thriving and increases the risk of the emergence of diagnosable mental disorders.

The experience of impairment is shaped in powerful ways by children's environments and living conditions. Therefore, two individuals may have the same impairment (medically speaking), but the level of disability they experience becomes significantly different, depending on environmental factors such as spatial and income inequalities.[9] These differences are also more pronounced in countries with high levels of inequality, such as in South Africa, with its brutal legacy of apartheid and colonialism coupled with inequality that continues to limit children's life chances. Exclusion from social contexts and lack of access to social networks leads to poorer health.[17] While this may be true for the general population,[18] the magnitude of the problem is compounded for persons with disabilities because of the lack of assistive devices and reasonable accommodation for their impairments,[19-21] their frequent marginalisation in society, and increased vulnerability to neglect, abuse, poverty, and violence,[1] as well as disability-related stigma and discrimination.[19, 22] Similarly, the social isolation and disruptions in social networks and support systems caused by the COVID-19 pandemic further intensifies mental distress, stress and anxiety among people with disabilities[17] and additional efforts are needed to make sure that the needs of these children are met.

In addition to widespread inequalities and discrimination on the basis of race, class and gender, children and youth with disabilities may experience discrimination on the basis of disability, including poorer access to quality education[23] and healthcare[24]. It must be borne in mind that with nearly two in three children in South Africa are living below the poverty line,[25] and that poverty is likely to have a disproportionate effect on children with disabilities.[26] It is imperative to recognise that impairment in and of itself does not cause mental disorders. This is not to say that the personal experience of impairment, including functional limitation, pain and fatigue, are not in themselves factors which also threaten mental health.[22, 27] But, as noted above, the impact of these issues is best understood as the product of their interaction with environmental factors, and both these elements need to be considered to understand the origins of psychosocial disability and to design effective interventions.

How does participation enhance mental well-being?

We have already established how discrimination and stigma undermine the right of children with disabilities to 'full and effective participation and inclusion in society' as enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRDP).[1] Participation is considered both a basic human right and a critical health outcome for children with disabilities. Imms and colleagues capture the tensions in defining participation in their family of participation-related constructs framework, which distinguishes between attendance ('being there') and involvement ('the experience of participation while attending').[28] For example, children attending school are simply 'being there', while what the child actually does during a maths lesson is their 'involvement' or 'engagement' in the learning process. Participation, therefore, not only addresses barriers that prevent the attendance of children with disabilities, but it also aims to address the ways in which they are included or involved in life situations.

As noted above, having a disability does not necessarily lead to the development of mental health problems, and it has

Figure 29: Levels of intervention and support from the Nurturing Care Framework

Adapted from: World Health Organization. *Nurturing care for early childhood development: A framework for helping children survive and thrive to transform health and human potential.* 2018.

been argued that participation helps improve the well-being of children and adolescents with developmental disabilities.[29] A cluster of studies report that there is a strong association between exclusion and mental health problems.[30] It may be the case that, were participation possible in all aspects of one's life, the prevalence of mental health problems would be the same between children with and without a disability.

A study led by the Centre for Augmentative and Alternative Communication at the University of Pretoria used the Picture my Participation measure to evaluate the participation patterns of children with intellectual disabilities. The study found that both children with intellectual disabilities and their primary caregivers reported that the child had high levels of attendance in formal learning, family mealtimes, interactions with families and celebrations.[31] Yet, children with intellectual disabilities participated significantly less in social, community, leisure, and self-care activities than their peers.[32, 33]

Similarly, a study with children with intellectual disabilities in South Africa using the Children's Assessment of Participation and Enjoyment (CAPE) scale[34] found that children reported participating most in the informal domain, social activities, and skills-based and self-improvement activities. Children in South Africa were most likely to participate in activities once a week, with other relatives, and at a relative's house, and enjoyed participating in activities 'very much'. Another important consideration in enhancing participation of children with intellectual disabilities is the social support received by caregivers, with increased social support for caregivers resulting in increased intensity of participation for children with intellectual disabilities.[35, 36] This cluster of studies makes an important contribution to the argument for i) including the self-reported perceptions of children with intellectual disabilities (the child's perspective) in clinical practice and future research, and ii) the importance of participation-focussed interventions for children with intellectual and other disabilities to ensure that they have the same opportunities to 'be there' (attendance) and 'engage in activities' (participation).

What are the opportunities to strengthen policy and programming?

Nurturing care

The Nurturing Care Framework (NCF) draws on state-of-the-art evidence to strengthen policies and programmes to help children thrive.[37] The five domains of nurturing care include nutrition, responsive caregiving, security and safety, learning and stimulation, and health. Providing nurturing care to children with impairments may pose additional challenges across each of these domains, so it is important to adopt an inclusive approach and make a deliberate attempt to ensure that all children have equal access to services and support.[6] While efforts to promote mental health and well-being, and prevent mental disorders, apply equally to children and youth with disabilities, targeted and indicated support is also needed as illustrated in Figure 29.

Reasonable accommodation

While all children need universal support regardless of impairments or health conditions, a smaller number require targeted support that addresses areas of potential risk, and indicated support is required for those who have demonstrable additional needs. An important aspect of indicated support is the provision of reasonable accommodation for children with impairments.[38] This includes the provision of assistive devices to enable inclusion and participation. Examples include digital devices for children with visual impairments. quieter spaces at school for children on the autism spectrum, and adjusted work or schoolwork programmes to allow access to ongoing therapeutic support or catch up following an episode of illness where schoolwork was interrupted. (see Figure 30) The absence of such supports not only constructs a barrier to learning and development but also has an impact on mental well-being, as this sends a message that the child's needs are not thought about and prioritised, leading to feelings of low self-esteem, depression and anxiety.[39] Lack of attention and accommodation to the child's school programme can also lead to child and family concerns about progression and career development, further impacting on mental health and well-being.

A twin track approach

In response, one of the recommendations has been to adopt a twin track approach.[40] A twin track approach includes a mainstreaming track to ensure that children with disabilities

Figure 30: Illustration of the twin track approach

Source: CBM and the Twin-Track Approach to Disability and Development. *Twin-Track_Paper_final_version_October2008 2/10*. 2008.

are included in all forms of service provision, and an empowerment track that recognises the need for disability-specific supports and reasonable accommodations with a strong emphasis on participation and respecting the views of children and adolescents with disabilities.

In the following section, we will review the opportunities for intervention through the lens of the NCF under the following categories – child participation, caregiver capabilities, empowered communities, supportive services, and enabling policies. This framework should be linked to a life-course approach to mental health and disability, as risk and protective factors are cumulative rather than unrelated discrete events, and priorities differ during critical transitional periods of the life course.[8] The strong connection between impairments and the development of psychosocial disability should therefore be considered through the different developmental stages.

Child participation

In line with the UNCRPD perspective on self-representation, the voice of children and adolescents with disabilities needs to be heard and play a central role in service provision and community building. The Lancet Commission on the Future of the World's Children argues that meaningful participation leads to 'improved social cohesion, more egalitarian communities, and helps adolescents make a better informed, healthier, and more empowered transition into adulthood'.[41] The United Nations Convention on the Rights of the Child notes that children have the right to be involved in decisions and actions that affect them, and that they should be able to express their views which should be heard and taken seriously by adults.[42]

Children and youth can indicate their preferences for what works for them and help identify and address 'barriers to doing' and 'barriers to being'. For example, children with physical disabilities identified 'barriers to doing', such as physical or material barriers that restricted their participation, as well as 'barriers to being', such as bullying and hostile behaviour.[43] Parents can also be over-protective and have low expectations, which is why children with psychosocial disabilities should be supported to advocate for their own needs.[44]

Family strengthening

Families are best placed to understand the experiences and needs of their children, and these insights are crucial in providing a responsive, attuned and nurturing environment.[45] This is because parents and/or families of children with disabilities have insight into what activities their child will find enjoyable and meaningful, and can help recommend strategies to support their children's participation and emotional well-being.[46] However, support for caregivers and children with disabilities is often lacking in both primary and community levels of health care.

Family strengthening programmes, such as the Caregivers Skills Training programme outlined in Case 30, aim to respond to two distinct but related challenges. The first challenge is to develop caregivers' knowledge and skills so that they are able to provide the interventions needed to promote their children's development,[47] and to do so in a way that affirms – and does not negate – their existing knowledge and skills. The second challenge is to provide psychosocial support, as the economic, physical and emotional stressors of caring for a child with a disability render parents vulnerable to mental disorders such as depression or anxiety disorders. Stress experienced by parents and caregivers should be prioritised because their well-being is pivotal to the provision of nurturing care for children with disabilities.[48]

Empowered communities

Empowering communities to facilitate the inclusion of children with disabilities is a critical element in promoting mental well-being. Services should ideally support community members and organizations to become agents of change to enable children with disabilities to participate in community life and recreation.[50] This goes beyond service provision to a situation where community members are supported to take responsibility and make the changes they want, through consultation and training, and the sharing of physical and educational resources. This would include addressing some of the pressing safety issues, especially for children with developmental disabilities, that prevent them from venturing into their community spaces.[51]

A study across three countries (South Africa, Botswana and Malawi) identified the benefits of community programmes in enabling access, participation and inclusion.[52] The development of parent support groups has also been found to be very effective in advocating for changes in the community. For example, Kambowe found that a parent advocacy support group was effective in enhancing community participation and social inclusion of adolescents with Down Syndrome in Namibia.[53] In addition, parent training programmes have been found to be effective in enhancing the self-efficacy of caregivers so that parents are better able to 'think and act in ways that will optimise the developmental outcomes of their children'.[54]

Case 30: WHO Caregivers Skills Training Programme

Given that most children with developmental disorders do not have equitable access to care, the WHO launched the Caregivers Skills Training (CST) for families of children with developmental delays and disorders.[49] This aims to strengthen access and quality of health services and support to families, and forms part of a broader Mental Health Gap Action Plan to address the treatment gap for priority mental, neurological and substance used conditions.

Taking a family-oriented approach and designed to be delivered by trained non-specialists (such as peer caregivers and community-based workers), CST's primary goal is to promote better understanding and acceptance of developmental delays and disorders and to help caregivers promote child development, communication and functioning. The secondary aims of the programme include strengthening caregivers' coping skills and psychological well-being. CST builds on existing resources and services to maximise sustainability. The WHO CST consists of nine group weekly sessions of 2.5 hours each and three 90-minute individual sessions in caregivers' homes, focused on training the caregiver on how to use every day play and home activities and routines as opportunities for learning and development. The home sessions are geared towards assessing the child's development, engaging the family, determining needs and setting goals. Thereafter, caregivers participate in various modules including getting and keeping children engaged, understanding and promoting communication as well as skills for daily living, preventing and responding to challenging behaviour, and a separate module on caregiver well-being, self-care and problem solving. Specific sessions cover communication, engagement, daily living skills, challenging behaviour and caregiver coping strategies.

A key feature of the CST is that it can be delivered by non-specialists and can be adapted linguistically and culturally to ensure that it is understandable, culturally relevant, acceptable and feasible for use in low resource settings.[48]

Supportive services

Children with disabilities are entitled to access inclusive health and educational services. Additionally, social assistance is available to caregivers of children with disabilities in need of permanent care or support services in the form of the Care Dependency Grant (CDG).

Yet, early identification and early intervention for children with intellectual and psychosocial disabilities can be difficult as current measures do not easily detect the more subtle or 'invisible' neurological or psychosocial disabilities. This leads to the exclusion of these children from early intervention strategies, which are essential for improving outcomes and preventing secondary disabilities. Children with 'invisible disabilities' are also excluded from other important domains, such as the statistics used to inform planning and budgeting for services. For instance, disability prevalence rates in South Africa exclude children under the age of five, as well as children with psychosocial and certain neurological disabilities. It is therefore important to review the medical assessment criteria to enhance the identification of children with intellectual and psychosocial disabilities, to ensure that these children and their caregivers are able to access a basket of support services including the CDG.

Already scarce services for children and adolescents with disabilities, such as rehabilitation services in hospitals, special care centres and schools, faltered during COVID-19, creating difficult times for both families and children with disabilities, and many mothers have been unable to see their children during the pandemic due to isolation measures introduced at residential care facilities.[55] The closure of special schools for children with disabilities, who require daily therapeutic services, similarly left most parents and caregivers with no or limited resources, and little or no training on how to assist their own children adequately at home. Furthermore, in the context of having to share a one-roomed dwelling, many children may have found playing and learning extremely difficult during lockdowns in households.[56] This is where targeted responses are needed. The best practice would have been to ensure continuity of care by extending services to children at home, and supporting carers through online training, mentoring and supervision, yet these efforts were unlikely to reach those most vulnerable given the digital divide in South Africa. The case study on the following page outlines how alternative and augmentative modes of communication have an important place in bridging one of the gaps in service provision.

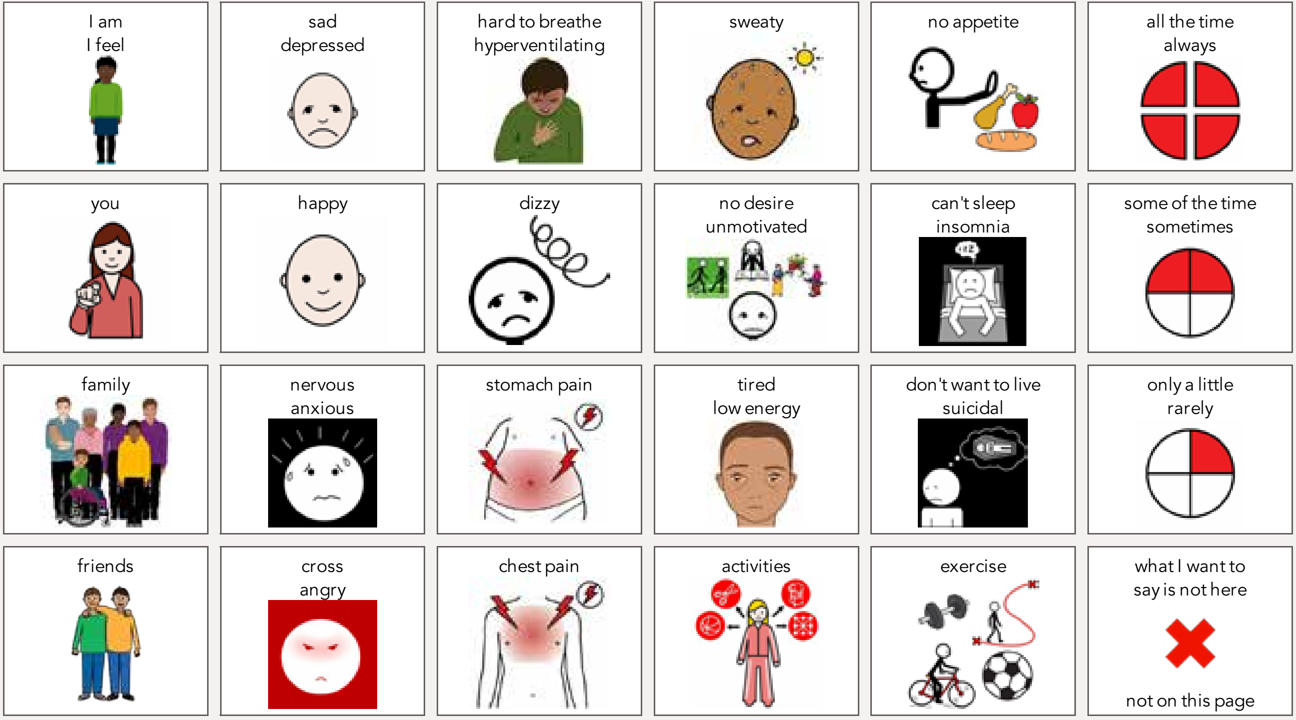
Case 31: Closing the gap through augmentative and alternative communication

While physical access to services that support mental health is a right to be afforded to all people,[57] persons with disabilities – and specifically persons with complex communication needs – are less likely to utilise these services. Persons with complex communication needs are defined as “having limited or no access to functional verbal speech and are unable to use speech to meet their daily communication needs”.[58] This may lead to mainstream mental health services not being fully aware of their needs,[59] yet this group faces various risk factors for mental health problems, including experiences of discrimination and stigma, physical health challenges, and difficulties in establishing and maintaining relationships.[60]

Individuals with complex communication needs would benefit from Augmentative and Alternative Communication (AAC). AAC encompasses any form of communication used to supplement or replace oral speech and plays a critical role in supporting communication and promoting the participation and inclusion of persons with complex communication needs.[61] It is often challenging for persons with complex communication needs to take care of their health, and the COVID-19 pandemic exacerbated the situation. Health information is often couched in confusing and inaccessible language and provided in formats and modalities that do not support comprehension. The Centre for Augmentative and Alternative Communication and Future Africa (at the University of Pretoria) and UNICEF embarked on a project entitled ‘Co-designing health communication and education materials’ during the COVID-19 pandemic. The health education materials were developed in collaboration with youth with disabilities, caregivers of children and youth with communication disabilities, and professionals who work in the health and education sector.[62] A variety of resources, in various South African languages, is available for download, including a series of animated stories specifically focused on maintaining mental health.[i]

In addition, an example of a communication board that can be used to communicate about mental health was specifically prepared to accompany this chapter.

Figure 31: A communication board to discuss aspects of mental health



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[i] https://www.up.ac.za/centre-for-augmentative-alternative-communication/article/2938080/co-designing-health-education-materials-.

Enabling policies

Given the close connection between mental health and participation, enabling policies should support not only access but also meaningful engagement. The White Paper 6 on Inclusive Education[63] aims to create an inclusive and supportive learning environment that would facilitate mental health and well-being in schools, if effectively implemented. Similarly, health policies emphasise equal access and reasonable accommodation for children and adolescents with disabilities and their families and could help to address some of the environmental barriers that influence mental well-being. The Framework and Strategy on Disability and Rehabilitation has also done well in highlighting the need to improve access to services, however, this policy has been critiqued for excluding learning or intellectual disabilities,[64] and does not address psychosocial disabilities. The draft National Disability Background Paper[65] also acknowledges barriers to participation – a call which requires enacting changes in national policies, laws and environments. The recent Strategic Policy Framework on Disability for the Post-School Education and Training System[66] signified one such positive step towards change and includes measures to provide financial support and upgrade infrastructure and services to improve participation of those with disabilities. The policy also advocates for institutions to report on initiatives for all disability types.

The more recent National Strategic Framework on Reasonable Accommodations for Persons with Disabilities is important as it focuses on environmental as well as technological supports to accommodate persons with disabilities.[67] This framework supports the independence of persons with disabilities through advocating for provision of assistive devices, reasonable accommodation measures and support services to enhance the well-being and participation of persons with disabilities as fully as possible in activities such as education and later employment. It specifically notes that service providers and sectors implementing this policy must integrate psychosocial services and interventions within reasonable accommodation measures.

Policies also need to prioritise getting services to both children and their families, to effectively nurture the development of children with disabilities. To ensure that both long-term and short-term needs are addressed, policy solutions must expand home-visiting programmes as these bring services close to home and benefit both the child and caregivers. The programmes should be complemented with investments in telehealth services for those who can access virtual platforms. Policymakers, therefore, need to enhance both these support services by allocating public funding for community-based services and ensuring that families and service providers have the digital access and training needed to make telehealth a possibility. We have recently witnessed how limited funds disrupt services for children with disabilities in South Africa. For example, TimesLive reported in December 2021 that workers who care for 84 persons with profound disabilities at Durban and Coastal Mental Health's Jona Vaughan residential facility did not arrive at work because they had not been paid since September 2021, and amid this funding crisis, children were left without care.

Additional costs incurred to provide for the disability-related needs of their children can be a significant source of stress for both families living in poverty, and low-income earners for whom the cost of assistive devices and other supports add a taxing burden on their limited financial resources. Policy makers can help alleviate the additional costs of caring for a child with a disability by increasing the value of the CDG, while policy implementers can take steps to enable greater access to this support. This targeted support is in line with other calls to increase the value of social grants for children and their caregivers and would respond decisively to persistent inequity in South Africa.

Alongside this, government services should support the multidimensional – and therefore multisectoral – needs of children with disabilities. For example, if the Department of Health enhanced the provision of services and access to assistive technologies and the Department of Basic Education provided fully inclusive quality educational services to children with disabilities, then this would enhance the impact of the CDG, as families would be able to use this limited resource to meet the home care needs of their children, instead of using to cover the costs of other services.

Conclusion

Meaningful participation is central to the mental health of children with disabilities and is an area where children with disabilities are most likely to encounter significant barriers, including stigma and inaccessible environments. To address this problem, mainstream environments and communities need to become more inclusive and welcoming, while at the same time, more specific (and possibly more individualised) supports should be provided to enable the participation of children with disabilities.[6] It is critical that supportive services adopt a family focus and a developmental, life-course perspective in a way that is congruent with African contexts and aspirations. Given that exclusion and isolation undermine the mental health of all children, adolescents and their caregivers, efforts to support the meaningful participation of children with disabilities have the potential to prevent and mitigate the mental health impacts of exclusion and disability – including psychosocial disabilities. This includes putting in place reasonable accommodation and child-friendly measures to support the participation of children, adolescents and their caregivers in the design and implementation of policies and programmes.

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