

# Welcoming all children: The inclusion imperative

Sue Philpott (School of Education, University of KwaZulu-Natal) and Judith McKenzie (Division of Disability Studies, University of Cape Town)

The Sustainable Development Goals (SDGs) are unequivocal about the need to leave no one behind in an inclusive development process. This requires an approach in which every child – in all their diversity – is included and able to participate and thrive. In this chapter we use the example of childhood disability to explore key concepts and the current evidence base on inclusion. Disability, we argue, serves as a limit case and we assume that, if we can transform environments so that children with disabilities are able to survive and thrive, it will enable the inclusion of other vulnerable groups. A disability lens turns our gaze to those requiring the highest levels of support, providing a useful tool to explore the concept of inclusion and move from rhetoric to inclusive practice. Indeed, a focus on children with disabilities in the context of the SDGs is particularly relevant because evidence suggests that there are more children with disabilities as child survival rates improve. The challenge then is the transformation of services and approaches to ensure they are inclusive and enable all children to thrive.

In this chapter, we ask:

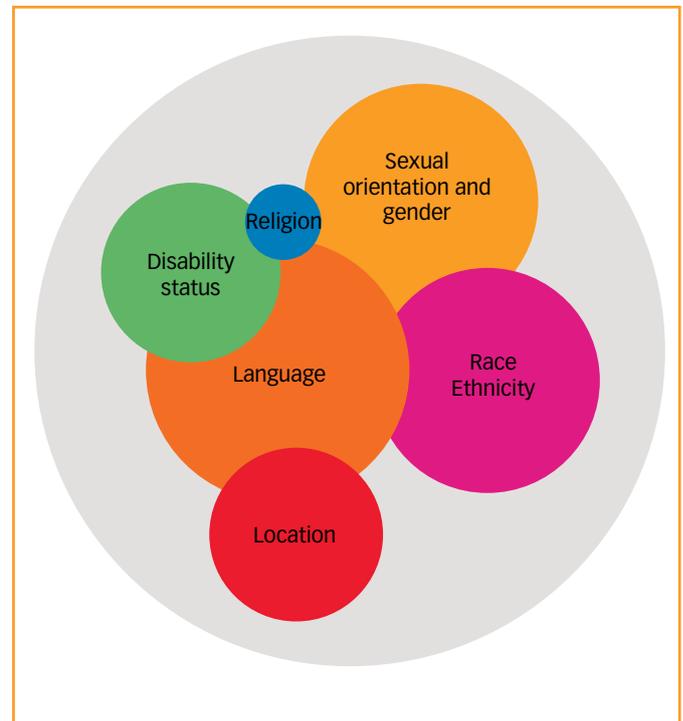
- What does inclusion mean for children with disabilities in South Africa?
- What are the state's obligations to ensure that no child is excluded from its provisions?
- How is exclusion of children with disabilities perpetuated?
- What is needed to create an enabling environment for children with disabilities to thrive?

## What does inclusion mean for children with disabilities in South Africa?

Disability does not necessarily constitute vulnerability. Instead, it is the interaction of the bodily impairment with the context that determines the extent to which people are marginalised or excluded. Disability intersects with other characteristics to render a child extremely vulnerable. For example, children with disabilities who live in extreme poverty, or remote rural areas, or who are HIV positive are at high risk of exclusion from education, health and social services.<sup>1</sup> This is referred to as “compounded marginalisation” and protecting the rights of such groups is one of the pillars of the White Paper on the Rights of Persons with Disabilities.<sup>2</sup>

The concept of inclusion resonates with the core principle of the SDGs “that the dignity of the human person is fundamental, and that we endeavour to reach the furthest behind and the most vulnerable first”.<sup>3</sup> While inclusion efforts specifically target those

Figure 24: Examples of diverse identities that may intersect to create compounded vulnerability

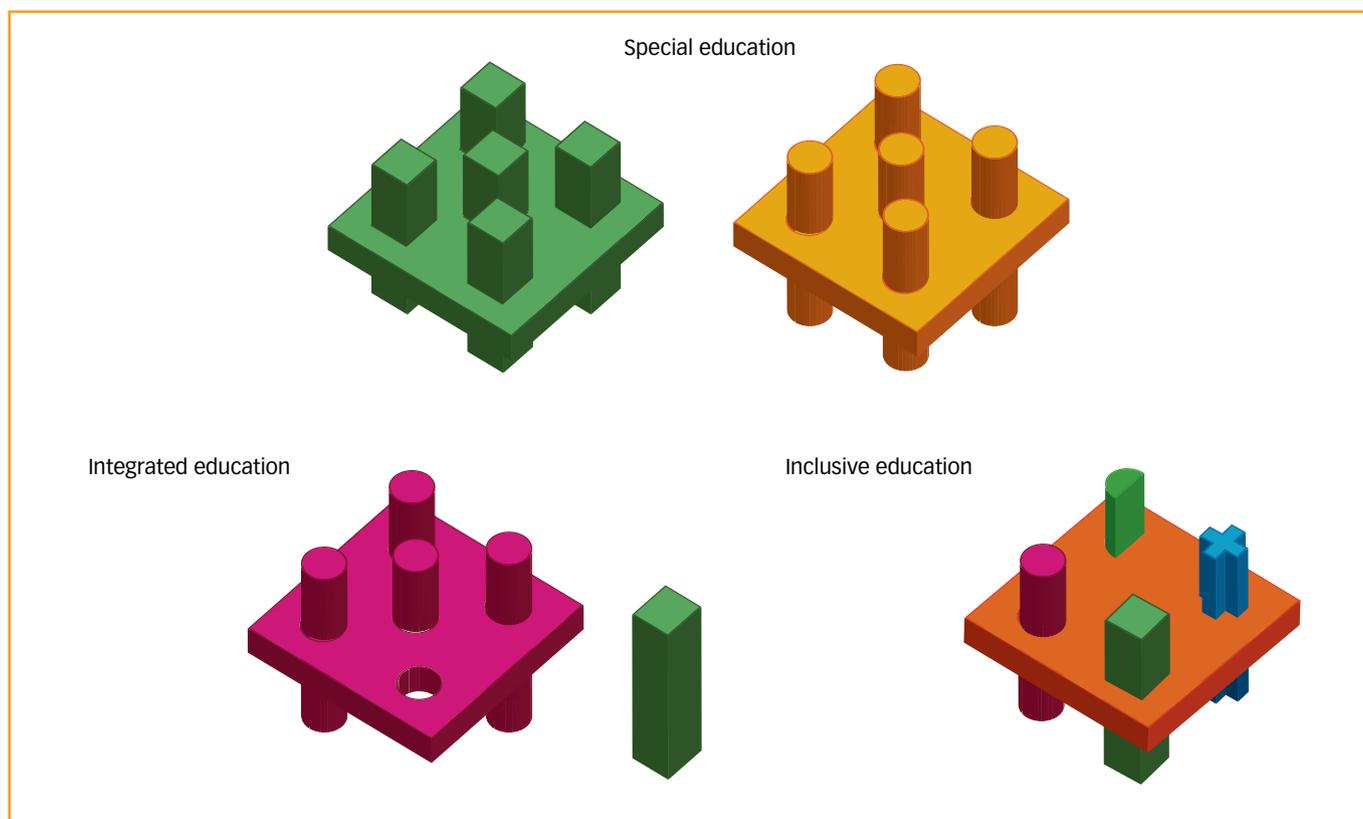


who are most vulnerable, marginalised and subject to highest risk, the premise is that everyone benefits in an inclusive approach, not just those perceived to be vulnerable.

Inclusion is understood as the process by which systems, cultures and processes accommodate a range of diversity. For children with disabilities, inclusion requires “overcoming of significant social, economic and political barriers to achieve meaningful involvement in society ... inclusion ... establishes a basis for overall well-being and is a critical component of becoming a valued and contributing member of the community”.<sup>4</sup>

Policies within the education sector illustrate the notion of inclusion. Education White Paper 6<sup>5</sup> stresses the need to acknowledge and respect diversity among learners; affirms that every child is capable of learning and needs support; and recommends that the structures, systems and learning methodologies of education should be responsive to the needs of all learners. This may require changes in attitudes, behaviour, teaching methods and the teaching environment so that barriers to learning are removed and *all* learners are able to participate in the culture and the curricula of educational institutions.

Figure 25: Inclusion requires accommodation of diversity



Source: Inclusive Education South Africa (no date) *What is Inclusive Education? Factsheet*. Viewed 15 September 2017: [www.included.org.za](http://www.included.org.za). Reproduced with permission from Inclusive Education South Africa.

Inclusive education policy has been further strengthened through the adoption of the Care and Support for Teaching and Learning Framework<sup>6</sup>. This is a multidimensional organising framework bringing together various sectors such as health, psychosocial and welfare services, safety and protection, nutrition, sports, arts and recreation, infrastructure, water and sanitation. The framework makes inclusive education everyone’s business, with the well-being of children seen as a collective effort. It supports the creation of enabling environments for teaching and learning for all children.

Such an understanding of inclusion gives life to the constitutional imperatives of equity, access and redress<sup>7</sup> by recognising the rights of all children and affording them dignity while embracing their diversity. It is also a reminder that inclusion is a systemic issue and must be addressed across various social domains. Figure 25 illustrates a core tenet of inclusion: systems need to accommodate the diversity of children by being responsive and flexible, rather than children having to fit into rigid systems of mainstream provision.

### What are the state’s obligations to ensure that every child is included?

The principle that every child is valued and of equal worth before the law is enshrined in the Constitution. Section 9 (the equality clause) prohibits unfair discrimination on various grounds, including disability. The right to equality is not the same as “treating all

children the same”. Indeed, the provisions for non-discrimination require that positive (or affirmative) action is taken to ensure that everyone is able to enjoy their rights.<sup>8</sup> This may require the state to provide additional support for some children in order for them to enjoy the same rights as others. The Constitution also recognises the inherent worth of every human being and protects the right to dignity, which is seen as inseparable from the physical conditions within which children develop as it “secures the space for self-actualisation”.<sup>9</sup>

In 2007, the South African government signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>i</sup> which specifies what is needed to ensure the inclusion of children with disabilities in a range of sectors. For example, under this Convention the state commits to providing early identification and intervention services;<sup>10</sup> for children with disabilities this includes encouraging stimulation and interaction with their parents soon after birth, and supporting family members to monitor children’s development and understand their children’s capabilities.<sup>11</sup>

In addition, a recent court ruling – in response to the state’s failure to meet the educational needs of children’s with severe to profound intellectual disability<sup>12</sup> – has reaffirmed the state’s obligation to make positive and appropriate provision for all children<sup>13</sup>.

i The UNCRPD has been domesticated through the White Paper on the Rights of Persons with Disabilities, approved by Cabinet in 2015.

Andile<sup>ii</sup> is 10 years old and lives with his mother and brother in Bruntville, a township in the KwaZulu-Natal Midlands. Andile's mother reports that she had a normal delivery, but noticed that Andile did not develop at the same rate as other children as he grew up. For example, he did not try to imitate words and could not walk by the time he was 18 months old. She grew increasingly concerned about his inability to communicate and express himself until, after many visits to different doctors, he was diagnosed at age six with Autism Spectrum Disorder.<sup>iii</sup> At the time, the doctors did not explain to his mother what autism is, and what it would mean in terms of her child's behaviour.

Nompilo,<sup>iv</sup> Andile's mother, collects medicine (Ritalin) every three months from Grey's Hospital in Pietermaritzburg at a cost of R240/trip for herself and her child. However, she feels that the medicine is not working. Andile's levels of hyperactivity are still high and his aggression is a problem. She has had to stop working as a petrol attendant because she could no longer leave her mother to take care of Andile, particularly when crises occur. (For example, Andile went out of the yard, got into

a neighbour's car, and crashed it, causing R25,000 damage. His mother is still paying R1,000/month to settle the R15,000 that she owes). Nompilo experiences high levels of stress and has confessed to considering suicide at times.

Although Andile looks like any other 10-year-old (and is tall for his age), he has severe learning and behaviour challenges. He can eat by himself, but struggles with dressing. He loves singing, but cannot hold a conversation. The local primary school say they are unable to cater for Andile because he cannot sit still in the classroom to listen to the teacher. In 2015, Andile was put on a waiting list for a special school that caters for children with intellectual disabilities but he is still waiting for a space.

Andile's family did not fully understand his condition and spent a lot of money in trying to help him with traditional *muthi* (medicine). His mother has been accused by neighbours of a being a negligent parent because she can't control him. Social workers have told her that she lacks parenting skills but have not given her any advice on how to manage Andile's behaviour.

### How is the exclusion of children with disabilities perpetuated?

Despite the constitutional and policy imperatives underpinning an inclusive approach, many children with disabilities do not receive the services and support that they require and are entitled to.

The 2011 census<sup>14</sup> measured disability prevalence using the six domains of functioning: seeing, hearing, communication, remembering/concentrating, walking and self-care, using questions developed by the Washington Group. Disability was identified where there were moderate to severe limitations in a specific domain or if there were limitations across different domains. A major limitation of the census, however, is that it does not include results for children under the age of five because difficulties in functioning may be attributed to developmental delay rather than impairment. Measuring child disability is also more difficult than measuring adult disability and requires measures that are sensitive to developmental progression. Both the census and national household survey questionnaires have been criticised for lacking the necessary precision for measuring child disability.<sup>15</sup> Internationally, use of the Washington Group disability short set of questions in data collection has been found to be an effective method for disaggregating indicators by disability status, and for monitoring the SDG objective of leaving no one behind. Recently a module to assess child functioning was developed by the Washington Group and UNICEF to specifically monitor the

status of children with disabilities.<sup>16</sup> It is recommended that data disaggregated by disability status begin at the level of services (for example at clinics, early childhood development (ECD) centres or non-governmental organisations (NGOs), using the same tool across sectors so that comparisons can be made and progress measured).

Nevertheless, the national prevalence rate for disability was found to be 7.5%, while prevalence rates for children ranged from 11% for 5 – 9-year-olds to 4% for 10 – 14-year-olds, and 3% for 15 – 19-year-olds.<sup>17</sup> The data indicate significant provincial variations, with the Free State and Northern Cape having the highest prevalence rates. The census gives a profile of different types of disabilities – the most common are loss of sight, cognitive difficulties and loss of hearing. There are 131,040 children with disabilities receiving Care Dependency Grants (CDGs) nationally,<sup>18</sup> but it is not possible to assess take-up rates because prevalence data are not available.

Whilst the census gives some indication of the scale of the problem, case 11 illustrates the many challenges faced by children with disabilities and their caregivers, and their impact across the life course.

### Early childhood

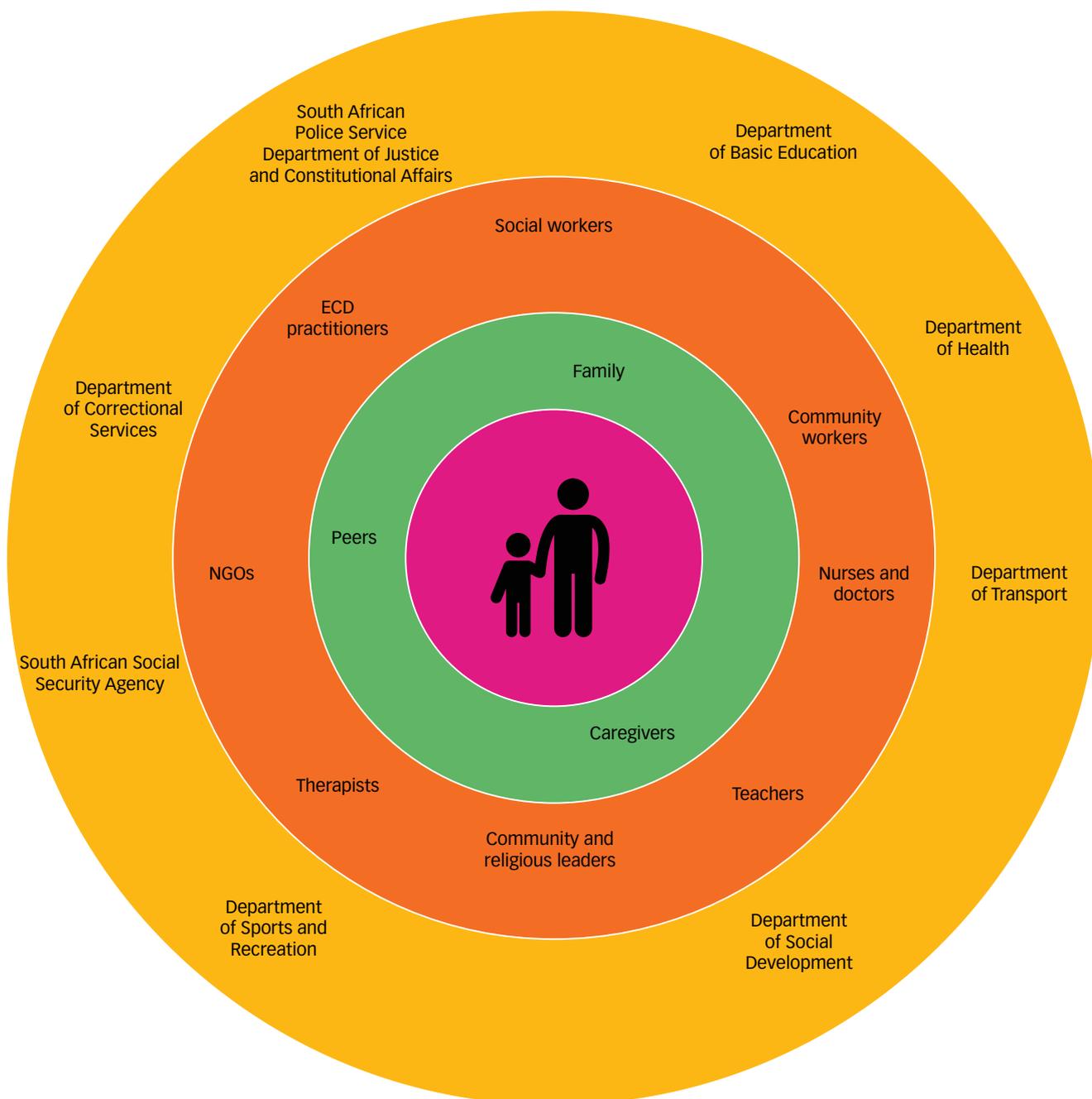
Although the current Road-to-Health Book contains a table of developmental milestones as a tool to monitor children's

ii Not his real name.

iii Autism is a developmental disorder, beginning in early childhood and continuing throughout adulthood. It affects three areas of development: communication, social interaction and behaviour.

iv Not her real name.

Figure 26: Levels of support for children with disabilities – an ecological system



Adapted from: Donald D, Lazarus S & Lolwana P (2002) *Educational Psychology in Social Context*. Second edition. Cape Town: Oxford University Press. P. 55.

development from birth to five years of age, research shows that this table is not systematically used at all clinics.<sup>19</sup> This contributes to children such as Andile not being diagnosed and treated from a young age, and as a result the child's disability and associated challenges are likely to grow in severity. Health providers' lack of understanding of particular disabilities further results in families having unrealistic expectations of their child's development, and being ill-equipped to provide appropriate support.

Even where a diagnosis is made, many young children with disabilities struggle to access basic rehabilitation services such as occupational therapy or assistive devices. Early childhood is a time to learn through playing and interacting with the environment and

where this is not encouraged or facilitated (as in the case of a blind child who is kept indoors) young children with disabilities are not able to develop their capabilities. Such services need to be provided on a regular basis (for example, a child who receives a buggy at age four to assist mobility is likely to require a different one at age five or six); yet there are often lengthy delays in accessing such devices, and the transport costs of reaching rehabilitation services are high. Many services for young children and their parents do not cater appropriately for children with disabilities and their families. For example, caregivers are not properly informed of the diagnosis and its impact, or given information or support to provide a stimulating home environment.

## Childhood and adolescence

While all children in South Africa have the right of access to education, children with disabilities are disproportionately represented among out-of-school learners, and they get poor-quality education (and outcomes) from special schools. This has a knock-on effect of limiting access to further education and employment. A report by DeafSA<sup>20</sup> found that, in 2015, 12 schools for the deaf entered 143 learners for the national senior certificate. Of these, only 29% passed, compared to the national average of 73%. Of those who passed, only four deaf learners (10%) obtained a pass that would enable them to apply for a bachelor's degree. The report highlights the importance of addressing the specific needs of deaf learners in teacher training (including in the use of South African sign language), materials development and appropriate and effective teaching methodologies.

Difficulties in accessing services are worsened by stigma and shame associated with cultural and religious beliefs about disability as a curse or punishment for sin. A tendency to focus on the inabilities and shortcomings of the child (and parent) by both the community and service providers deepens families' sense of inadequacy. A 2012 situation analysis found children with disabilities to be particularly vulnerable to bullying and violence, resulting in trauma, social isolation and loneliness. They also experience high levels of neglect and abuse.<sup>21</sup>

## Systemic weaknesses

A key weakness in respect of services for children with disabilities is the lack of a continuum of support between different sectors. While Andile receives a CDG, he has not yet been placed in appropriate (or any) schooling, nor benefitted from rehabilitative services or psychosocial support. Policies are in place and attempts have been made to develop tools for such coordination (such as the Department of Basic Education's Policy on Screening, Identification, Assessment and Support), but a lack of collaboration and synergy continues to prevent a seamless transition for children with disabilities from one sector to another. Consequently, many children with disabilities fall through the cracks in the system.

The absence of disaggregated data indicating the size of this population and identifying the particular support they require poses a further challenge in terms of allocating resources for children with disabilities. Such data are necessary for planning and monitoring of appropriate services, as well as enabling comparison of outcomes between disabled children and their able-bodied peers.

The impact of these different dimensions of exclusion accumulate over the life course and is often compounded by poverty, heightening children's vulnerability and increasing their risk of failure to thrive. Therefore transformation is needed to raise awareness, remove barriers and provide specific supports.

## What is needed to create an enabling environment for children with disabilities to thrive?

The 2016 State of the World's Children report focused on children's right to a fair chance in life, and the United Nations noted that:

"We have a choice: invest in the most excluded children now or risk a more divided and unfair world."<sup>22</sup> Ensuring that no child is left behind requires recognising the broader social, economic and policy contexts within which children live – what is known as the eco-systemic approach as outlined in figure 26. This foregrounds how actors at each level of the system need to work together to create an enabling environment, and identifies where barriers to inclusion may arise.

The following recommendations provide direction towards evolving practices in which the values of children's rights, equality and social justice have meaning for every child. They recognise the central importance of linkages *between* each level – families and caregivers, community-based and non-governmental organisations, and government service providers – to ensure a continuum of support. This requires transformation of the systems through which services and support for children are provided to ensure children with disabilities are included.

## Awareness and visibility

In order to plan and track services for children with disabilities, it is necessary to obtain accurate prevalence data, and to disaggregate data on the basis of disability. The latter is recognised in the UNCRPD as a necessary step to realising disability rights, and is a critical element of unmasking the invisibility of children with disabilities. It is encouraging to see disability inclusion reflected in the SDGs where it is highlighted in a number of targets, including Goal 17 which underlines the importance of data collection and monitoring of the SDGs, with emphasis on disability-disaggregated data.<sup>23</sup> This requires putting tracking mechanisms in place to monitor increasing or decreasing discrepancies between children with disabilities and their able-bodied peers.<sup>24</sup>

## Reaching out and welcoming children with disabilities and their caregivers

The first level of support is to families and caregivers. In accordance with the disability rights maxim "nothing about us without us", children with disabilities and their immediate support network need to be part of determining and shaping inclusive services.<sup>25</sup> This may require outreach strategies, such as home visits by community-level workers, to identify children who are not easily able to access services.

In addition, there is a need to redesign services and to shift institutional cultures and practices to make them more inclusive, with participation of children with disabilities as a key driver. All services, including immunisation campaigns, parenting programmes and HIV/AIDS education for adolescents should ask: "How can we welcome and accommodate children with disabilities?"

Planning and providing such services require identifying and removing barriers that lead to the exclusion of children with disabilities:

*Changing attitudes and behaviour:* Children with disabilities are often looked upon with pity, evoking responses of charity or are treated as passive recipients of care. They become defined by what is "wrong" with them or what they are unable to do. Viewing

## Case 12: Siyakwazi – Promoting inclusive ECD services in KwaZulu-Natal

Cathy Mather-Pike & Makhosi Shusha (Siyakwazi)

*Siyakwazi* is a community-based organisation working in rural communities of the Ugu district of KwaZulu-Natal. We believe that all children can learn. We focus on giving support to children under the age of seven who experience particular barriers to learning due to disability, learning difficulties or circumstances, such as living with an abusive father. The core focus of *Siyakwazi* is to promote inclusion of children with barriers to learning within ECD centres, schools and communities through our *siyasizas* (meaning “we support”) who are local young people committed to helping children.

We promote inclusive practices and appropriate early learning programmes to reduce developmental delays and ensure early identification of children with disabilities and/or learning difficulties. This is done by the *siyasizas* through regular site or home visits, individual support plans and laddering<sup>v</sup> early learning activities to enhance learning for all. These activities increase early identification, inclusion and active play, and increase involvement of parents, resulting in improved early learning for all children.

In 2016, we worked with 158 children displaying varying degrees of difficulties and/or barriers to learning, of which 99 individual support plans were developed with specific goals to move each child forward in their development and learning. An ECD practitioner shared that this training was informative and “gives us more energy to do our job.”

Meeting the developmental goals of children has benefits for parents too as they gain insight into the potential of their children and realise that their own role is essential in this process. A parent describes how she felt when she found out that her child had a disability: “I felt very bad, confused with a lot of questions in my head - like how am I going to raise such a child?” After having received two years of support from *Siyakwazi* and her child being successfully included in their local ECD centre, she says: “I have noticed big changes because she is out of nappies even at night, the thing I thought would never happen. Her talking is really improving. She is playing confidently with other children. I can tell she is very happy and I am happy too.”

children with disabilities as rights-holders, entitled to dignity and equality with all other children implies a shift in thinking towards a greater recognition of agency. This requires a more appreciative asset-based approach, concentrating on maximising their capabilities, autonomy and participation.

*Access to the built environment:* Everyone should be able to benefit from products and places throughout their lives, with universal design aiming to accommodate diversity rather than the “average” person. South Africa has guidelines<sup>26</sup> to ensure accessibility of the built environment, but enforcement of legislative provisions must be strengthened, particularly in facilities frequented by children of different ages – such as clinics, ECD centres, playgrounds and youth centres.

*Access to information and communication:* Children need to be able to engage with the world around them to learn about it. Information therefore needs to be provided in ways that are meaningful for children including those who struggle to hear, see or understand. For example, the use of pictures or simple explanations may be needed to help those with intellectual disabilities learn about topics such as HIV prevention. Access to information can also be supported through use of appropriate technology or assistive devices.

Information about disability (its causes and consequences) and support services needs to be communicated with parents, community members and service providers.<sup>27</sup> Widespread disability awareness-raising and sensitisation of traditional and religious leaders as well as the general public are also needed.

*An integrated and coordinated approach:* Disability has been found to be both a cause and a consequence of poverty;<sup>28</sup>

supporting vulnerable children with disabilities therefore cannot be separated from addressing the marginalising effects of poverty. This requires allocation of human and financial resources to ensure that children’s disabilities are identified at the earliest possible stage and that they receive the necessary medical, rehabilitation and education services. It also requires that social assistance, in the form of the CDG is provided not as an isolated response but as part of a broader basket of services and support for children and their families.

### Specific interventions and supports

Children with disabilities may require specific services that are not needed by other children such as rehabilitation, assistive devices or sign language interpretation. Parents and caregivers may need specialised knowledge and skills to support their children in becoming as self-reliant and independent as possible. These are necessary to enable children with disabilities to participate on the same basis as other children and to foster a sense of feeling respected, being valued and belonging. For example, a young person with a visual impairment will need textbooks in electronic or Braille formats if he or she is to participate in a history lesson.

### Conclusion

While significant progress has been made in improving child survival rates in South Africa, greater efforts are needed to ensure that every child can thrive and develop to their full potential. The inclusive development process envisaged by the SDGs will only be achieved through the transformation of systems. This includes increasing awareness and visibility of vulnerable children through

v “Laddering” is a way of choosing the right level of learning for an individual child and then gradually moving towards a higher level of achievement and mastery.

the disaggregation of data and equity targets; welcoming all children; removing the barriers that currently perpetuate their exclusion; and providing an enabling environment through a continuum of care and access to specific support that meets the individual needs of every child with a disability.

The principle of inclusion is based on the premise that society needs to change to accommodate diversity and respond to a wide range of differences and needs. Embracing inclusive practices has benefits for all children, not only those who are disabled or considered vulnerable and provides further motivation to the goal that no child is left behind.

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