

Opinion Editorial

Gaps in the implementation of legislative provisions and policy pertaining to children with disabilities in South Africa¹

PAN: Children from time to time invites experts in the child rights field to write Opinion Editorials on specific topics to stimulate debate. The opinions expressed in this opinion editorial are those of the author and do not necessarily reflect the views of PAN: Children, HSRC or UNICEF, and neither should it be assumed to do so.

Legal and policy imperatives for the care, protection and education of children with disabilities

The legal provisions for children with disabilities need to be seen against the backdrop of the international conventions that the South African government has ratified. These include the Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child and more recently, the Convention on the Rights of Persons with Disabilities. All of these conventions contain key principles of non-discrimination and equity for children with disabilities, emphasizing that the focus of actions must be on removal of structural, physical and other barriers that prevent inclusion and participation of children with disabilities in society.

What legislation and policies give effect to these principles? There are a range of policies and legislation that have important implications for children with disabilities:

- The Social Assistance Act provides for funds to be allocated to parents who care for children with severe disabilities. The Care Dependency Grant helps to cover costs associated with the disability, such as transport to rehabilitation services.
- Education White Paper 6 describes a 20-year roll-out plan for inclusive education. It envisages a tiered system of support which includes mainstream schools (catering for children requiring low levels of support), full service schools (supporting learners requiring moderate levels of support) and special or resource schools (assisting learners requiring high levels of support). As this policy was released in 2001, we are about half way through its anticipated timeframe.
- The Children's Act applies to *all* children, and provides for prevention and early intervention, early childhood development and protection services. It has numerous references to 'children with disability or chronic illness,' emphasizing that consideration must be given to them in service planning and provision.
- The Free Health Care policy of the Dept of Health provides for children under the age of 6 to receive free health care, which includes rehabilitation and assistive devices.

¹ This Opinion Editorial was written for PAN: Children by Sue Philpott, an expert in disability issues in South Africa.

Disparities on the ground

Despite this comprehensive legislation, children with disabilities remain one of the most marginalized groups in society. Why do they remain outside of early childhood development and education services? Why are they not able to benefit from preventive and rehabilitative health care? The following discussion highlights some of the reasons as to why existing legislation and policies are not effectively addressing the situation of children with disabilities.

➤ **Medical model of disability**

Despite the provisions of the CRPD, and a great deal of advocacy from the disability sector itself, social security allocations are still based on the medical model of disability (i.e. allocation of a grant is based primarily on the medical condition or diagnosis of the child). It does not take into account social and other factors that may contribute to the extent of the disability. This means that children who do not have so-called 'severe' disabilities, but are from low-income families and have major expenses, are not able to access the Care Dependency Grant.

A second challenge in this regard is the lack of a clear 'measurable' definition of disability that would enable identification and inclusion of children with disabilities in information and data systems.

➤ **Attitudes**

Another major challenge is persisting negative attitudes towards children with disabilities on the part of personnel in the education and health sectors. This is compounded by lack of information about disability and available resources, and lack of skills in catering for children's diverse needs.

➤ **Lack of mechanism for targeting**

While the vulnerability of children with disabilities has been acknowledged in many policies and evaluations, government departments lack effective mechanisms for targeting interventions. Some models for doing so are being implemented on a limited scale. For example, the Isibindi initiative of the National Alliance of Child Care Workers supports children with disabilities in its work with orphans and vulnerable children (www.naccw.org.za/isibindi/); while Malamulele Onwards provides a link between therapists and rural children with cerebral palsy (www.cpchildren.org). However, these have not been thoroughly reviewed and analyzed to learn from their successes and failures with a view to rolling them out more comprehensively.

➤ **Lack of co-ordination and integration of services**

Children with disabilities require a range of services, but unfortunately the tendency for government departments is to act in silos, undermining the possibility and potential benefits of co-ordination and collaboration. Lack of communication and joint strategizing with organizations of civil society in the disability sector remains an ongoing challenge.

➤ **Lack of focus on early identification and intervention**

The government has made significant progress in reducing many of the causes of childhood disability through increased access to antenatal care for pregnant women and immunization and nutrition programmes for young children. However, programmes focusing on identification and early intervention for children at risk or with diagnosed disabilities are not well conceptualized and under-developed. One of the reasons for this is the lack of recognition of the importance of rehabilitation within Primary Health Care and the low numbers of professionals being trained and employed within the public sector. While the new Integrated Health Policy is a very positive development, its omission of early identification and intervention for children with disabilities means that the potential to support children with disabilities at an early stage is negated.

Advocacy initiatives to address disparities

What is being done to address these disparities?

Rural Rehab South Africa (RuReSA - www.ruralrehab.co.za)

In September 2011, rural therapists established RuReSA with the intention of raising the profile of rural disability and rehabilitation within Health and other government departments. Now numbering 127 therapists from across the country, RuReSA has developed a support network for rural therapists, encouraging the sharing of both professional and personal support. It is supporting government in developing rehabilitation policy and services in rural areas. It is also actively encouraging research and dissemination of evidence and innovative models of service delivery, in order to develop best practice for rural populations. The network has been consulting with universities to support alignment of curricula with rural and PHC needs, and encouraging students to select rural electives and community service placements.

Campaign on the Right to Education for Children with Disabilities

This Campaign comprises a wide range of civil society organizations advocating for an education system that promotes inclusion of children with disabilities, maximizing their personal development and enabling their participation in society (www.saaled.org.za/R2ECWD). Set up in 2010, the Secretariat of the Campaign is based at the Community Law Centre of the University of the Western Cape. Member organizations participate in a range of advocacy activities through sub-groups which focus on policy development, early childhood development, community awareness and support for training of personnel for inclusion.

Court action by the Western Cape Forum on Intellectual Disability (WCFID)

In 2010 the Western Cape Forum for Intellectual Disability took the Western Cape provincial government and national government to court for failing to provide for the educational needs of children who are profoundly and severely intellectually disabled. The court found in favour of WCFID and the government was compelled to take steps to realize the rights of these children to a basic education, protection from neglect, equality and dignity. These



steps include ensuring that every child in the Western Cape who is severely and profoundly intellectually disabled has affordable access to basic education of an adequate quality. The government has been providing regular updates on progress which can be obtained through WCFID.

This judgment is now part of the 'legal landscape' in South Africa, providing a strong advocacy tool that can be used in engagements with provincial Departments of Social Development, Education and Health. It provides the grounds for a legally justified call for similar provisions in other provinces and should these not be forthcoming, there is a strong foundation for similar court action.

Examples of future initiatives which have the potential to improve the situation of children with disabilities

What initiatives have the potential to improve the situation of children with disabilities?

ECD – early identification and intervention

During 2012, South Africa has seen a renewed awareness of the importance of early childhood development, and a commitment to investing in services and programmes to support young vulnerable children. Given that ECD is a mechanism of promoting equity, this emphasis holds tremendous promise for children with disabilities.

ECD practitioners trained to identify developmental lags and barriers to learning in young children can play an important role in early identification. With the support of personnel from Dept of Health (e.g. therapists), these practitioners can work closely with parents in implementing intervention programmes. This requires that personnel at clinics and hospitals are aware of the important role played by ECD centres in identification and intervention for children with disabilities. The Road to Health Booklet is a means of tracking the progress of the child and providing a link between parent, clinic and ECD centre.

ECD – early inclusion

Given their child-centred orientation, ECD centres are well-placed for inclusion of children with disabilities. However, staff must be equipped with the necessary attitudes and skills for elementary interventions, referral and collaboration with parents and Health and Social Development. Course materials on inclusion as well as practical experience of inclusion are an important part of the training of ECD practitioners.

A sustainable strategy for inclusion requires that Social Development recognizes inclusive centres and provides a raised subsidy for these centres, and/or grants to individual children to cover costs of expenses such as teacher aids and assistive devices. Inclusion needs to be supported through wide-spread dissemination of information on available services to support children with disabilities (e.g. at clinics, SASSA offices and schools).

Re-engineering PHC to include rehabilitation

Another recent development has been the re-engineering of PHC, an important component of which is community based rehabilitation i.e. services made accessible and appropriate to children with disabilities in their homes and communities. Given that habilitation or rehabilitation is the key means by which children can (re)gain their independence, this is a critical key for access to other services. This too holds tremendous promise, but is contingent on priority being given to rehabilitation as well as the training and recruitment of suitable professional and community-level personnel. Health personnel, such as community health workers, also have a critical role to play in identifying and supporting children with disabilities through visits to homes and ECD centres.

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