

### **PREFACE**

Children with disabilities are among the most vulnerable people in South Africa. Recent reports point to the harsh realities of their daily lives. For example, the Department of Basic Education's report *General Household Survey Focus on Schooling 2015* (2017) records that more than a quarter of the 110 000 out-of-school children between the ages of 7 and 15 years are children with disabilities. The recent report, *Out of Harms Way: Tracking child abuse cases through the child protection system at five selected sites in South Africa* (2017), confirms that children with disabilities are twice as likely to be victims of sexual abuse as their non-disabled peers.

The extent of the risks and vulnerabilities faced by children with disabilities points to the need for civil society organisations to step up their advocacy, research and litigation efforts and work strategically to break down the barriers experienced by children with disabilities.

Using the law is one way in which this can be achieved. For almost 20 years, the Centre for Child Law has successfully used the law to establish, protect and affirm children's rights. The Centre therefore wants to encourage and empower the sector to use the law for the benefit of children with disabilities.

The content of this advocacy brief is based on information shared by organisations active in the children's and disability rights sectors at consultative workshops organised by the Centre in 2015 and 2016. The workshops identified common difficulties and barriers that can be addressed through legal intervention. This publication is offered as a resource to colleagues in the children's rights and disability rights sectors to advocate for the shared recommendations.

## **ACKNOWLEDGEMENTS**

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## Introduction to the Centre for Child Law

The Centre is an advocacy organisation which engages in research, information-sharing and dissemination, stakeholder engagement, and legal support and litigation to develop child law and realise children's rights in South Africa.

### **Programme: Children with disabilities**

The Centre has a programme focusing on children with disabilities, given their vulnerability and the current weak laws and systems to protect and realise their rights.

**THE AIM** of this programme is to strengthen the legal framework to ensure that the rights of children with disabilities are fully realised.

**THE OBJECTIVE** of the programme is to promote the development of effective, legally compliant policies, laws and programmes which are properly resourced, implemented and monitored in order to realise the rights of children with disabilities.

#### THE PROBLEM

Children with disabilities are particularly vulnerable and are routinely denied their rights to:

- 1. quality education, including early childhood education;
- 2. social assistance, including the Care Dependency Grant (CDG);
- health-care services, including prevention, early identification and therapeutic treatment (including assistive devices); and
- 4. care and protection against abuse, neglect and exploitation.

South Africa has developed a wide range of policies and strategies supporting the rights of children with disabilities. However, they are poorly implemented for two related reasons:

- 1. There is poor planning, resourcing, implementation, and monitoring of appropriate programmes and services by government for children with disabilities.
- 2. Many of the policies lack adequate legal standing or are not adequately drafted, as measured against the international, regional and constitutional responsibilities the government has to children with disabilities. As a result, it is difficult to hold the government to account using the available legal frameworks.

### THE SOLUTION

The enabling legal framework for children with disabilities must be strengthened through the development of stronger, clearer and more comprehensive, actionable laws and associated plans, budgets and programmes.

Civil society, including NGOs, must then make use of the laws to hold the government to account for fulfilment of its responsibilities to:

- take measures to promote the development of all children to their full potential, and prevent disabilities and developmental delays among children; and
- where it is not possible, ensure that children with disabilities or developmental delays enjoy full and equal enjoyment of their rights to, inter alia, education, health care, social security and protection from abuse and neglect.



### RIGHTS AND RESPONSIBILITIES:

## The legal framework protecting children with disabilities

The government must promote the development of all children, where possible prevent disabilities, and realise the rights of children with disabilities. Its duties are set out in a number legal instruments which the Government of South Africa has committed to upholding.

### INSTRUMENTS INCLUDE

The Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child and the Convention on the Rights of Persons with Disabilities: These conventions guarantee the right of children at risk of, or with disabilities, to:

- 1. survive and develop to their full potential;
- 2. be protected from the risk factors that cause developmental delays and disabilities; and
- 3. equal access to appropriate protection, social assistance, health, and education services.

The Constitution of the Republic of South Africa: Guarantees the rights of all people with disabilities, including children, to freedom from discrimination and equal access to services.

The Promotion of Equality and Prevention of Unfair Discrimination Act No. 4 of 2000: Obligates the

adoption of special measures to overcome barriers and ensure that all people with disabilities, including children, have meaningful access to all their rights.

The National Development Plan (2012): Recognises that the prevention of disabilities and ensuring of equal enjoyment of rights by children with disabilities is key to achieving sustainable development and to eliminating poverty and inequality. It therefore requires that disability be integrated into all facets of government planning so that all policies, programmes and budgets ensure that services address the risk of disability or developmental delays, and guarantee access to services for children with disabilities.

The White Paper on the Rights of Persons with Disabilities (2015): Obligates the adoption of laws, policies and programmes within a social model of disability to make services available to all children to secure their survival and development to their full potential, and to eradicate barriers preventing their access to services.

The White Paper on the Rights of Persons with Disabilities Implementation Matrix 2015 – 2030: Commits the government to take concrete measures, including the adoption of policies, programmes and budgets to fulfil the responsibilities spelt out in the White Paper.

The National Integrated Early Childhood

Development Policy (2015): Obligates the government to take a host of measures in the earliest years of a

child's life, starting from before birth until the child enters formal schooling, to prevent disabilities and developmental delays and secure the rights of children with disabilities.

The Children's Act No. 38 of 2005: Obligates the establishment and funding of a comprehensive child protection system which gives priority to prevention and early intervention services for children with disabilities.

Education White Paper 6: Special Needs Education Building and Inclusive Education and Training System (2001): Recognises the constitutionally protected right of all children to quality education. It provides direction on the steps needed to build an inclusive education system that protects the rights of children with disabilities to quality education.

Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015 – 2020: Recognises that all people, including children, have a right to develop to their full potential and to equal enjoyment of all their rights. It commits the government to provide – through the public health system – a comprehensive set of disability and rehabilitation services to address the multiple, and often intersecting, risks of that cause and aggravate developmental delays and disabilities.



### WHAT ARE THE GAPS IN THE LEGAL FRAMEWORK AND

### **HOW DID WE IDENTIFY THEM?**

The Centre conducted desktop research and hosted a series of workshops with the disability sector in three provinces in 2015 and 2016. The objective of the workshops was to consult with the disability sector on core issues across the four core areas – protection, education, health care and social protection for children with disabilities – and identify critical gaps, understand how these are impacting on the rights of children on the ground, and together agree on focus areas for law reform. The outcomes of the desktop research and consultation processes are described in the remainder of this brief.

### STRUCTURE OF THE ADVOCACY BRIEF

This advocacy brief provides an overview of the gaps and challenges within the legal framework, the underlying causes of problems, the government's unfulfilled responsibilities, and suggested law reforms to improve realisation of the rights of children with disabilities.

The advocacy brief is divided into four sections which cover the following rights:

- 1. protection against violence, abuse and neglect;
- 2. social protection;
- 3. health care; and
- 4. education.

### THE PURPOSE OF THE ADVOCACY BRIEF

The Centre has conducted research and consulted the disability sector on the current situation. It has looked into the adequacy of the current enabling legal framework to protect the rights of children with disabilities and found it to be lacking in crucial respects. The Centre wants to collaborate with the disability and child development sectors to strengthen the enabling legal framework.

This advocacy brief provides a platform for mobilising the sectors and sub-sectors around critical issues that must be addressed and for which the government must be held accountable to ensure the protection of the rights of all children with disabilities.

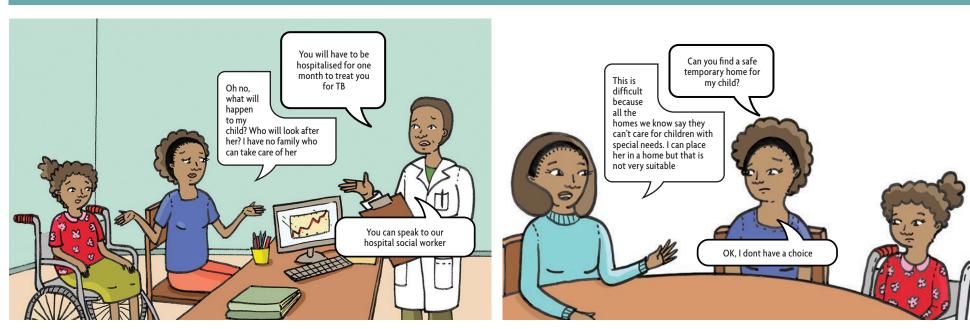
The Centre has published this advocacy brief to inform all stakeholders, including government departments, civil society organisations, parliament, and development partners, about the rights and responsibilities relevant to children with disabilities, and to increase awareness about the current gaps in the child protection system for children with disabilities.

The objective of the advocacy brief is to mobilise all stakeholders to action to advocate and plan for a stronger legal framework that recognises, respects and promotes the rights of all children with disabilities.





## SECTION 1: The right to protection against violence, abuse and neglect











Key national policies and laws	Rights and responsibilities	Rights infringed
Constitution of the Republic of South Africa	REQUIRES:  The adoption of laws, administrative, budgetary, and other measures to ensure that children with disabilities are protected from violence, abuse and neglect through equal access to quality child protection services.	<ul> <li>Children with disabilities are three to four times more likely to be victims of violence and abuse, and are often repeat victims.</li> <li>Ten percent of children with disabilities, compared to six percent of other children, experience physical</li> </ul>
The Children's Act No. 38 of 2005	<ul> <li>REQUIRES:</li> <li>The prioritisation of protection services for children with disabilities.</li> <li>The provision of prevention and early intervention services, which includes family and parenting support services to prevent violence against children.</li> <li>Parental, family or special and alternative care as and when appropriate.</li> <li>Mandatory reporting of cases of abuse.</li> <li>Alternative care where families are unable to care for their children.</li> <li>Minimum norms and standards for partial-care facilities providing care for children with disabilities.</li> </ul>	<ul> <li>abuse, and 23 percent compared to thirteen percent are neglected.¹</li> <li>Children with disabilities experiencing abuse in the home are rarely removed to safe alternative care and where they are moved, appropriate services are not available.²</li> <li>Children with disabilities are at great risk of abuse violence and neglect in their homes. There are few, if any, parenting support programmes educating parents on caring for children with disabilities, the importance of positive parenting, and the risk of physical punishment to their survival and development.³</li> </ul>
The National Integrated ECD Policy	REQUIRES: The development, by 2017, of a national multi-sectoral early childhood development guideline to secure universal availability and equitable access to quality inclusive ECD services for all children.	





### Risks



## Government's responsibilities not yet fulfilled



## Reform required to bring about changes

- Lower status of children with disabilities among families and communities.<sup>4</sup>
- Social isolation and invisibility of children with disabilities.<sup>5</sup>
- Lack of knowledge of rights and what constitutes abusive behaviour among children.<sup>6</sup>
- Lack of opportunities and mechanisms to report violence and abuse.<sup>7</sup>
- Inadequate spread and availability of suitable alternative care for children with disabilities.<sup>8</sup>
- Inadequate spread and availability of alternative and/or partial-care facilities providing care for children with disabilities.<sup>9</sup>
- Very few alternative care facilities/partial-care facilities offer appropriate therapeutic programmes.<sup>10</sup>
- Foster placements of children with disabilities are poorly supported, implemented and monitored.<sup>11</sup>
- Parents of children with disabilities do not receive enough material, social and psycho-social support.
   Often this leads to an inability to care for children and raises the risk of their removal from their homes.

- A comprehensive prevention and early intervention strategy which addresses the special risks and needs of children with disabilities has not been finalised, resourced or implemented.
- NGOs provide most of the services to children with disabilities, but they are not adequately resourced to provide quality services at scale.
- The National Department of Social Development (DSD) has not published a strategy and plan for securing an adequate spread of alternative care facilities, or plans for capacitating existing alternative care facilities to provide care for children with disabilities.
- Provincial DSDs have not developed provincial strategies to secure an adequate spread of partialcare facilities for children with disabilities, as required by the Children's Act.
- There is a lack of training, materials and support on how to develop therapeutic programmes suited to children with disabilities.
- All foster parents of children with disabilities should get specialised training, but they do not.
- There are few, if any, comprehensive parenting support programmes for parents of children with disabilities.

- The DSD must finalise and publish the National Strategy on Prevention and Early Intervention.
- The DSD must develop funding norms and standards for funding NGOs to enable them to provide quality prevention and early intervention services to children with disabilities.
- The Children's Act must be amended to clearly and unequivocally obligate the development of provincial strategies for securing an equitable and adequate spread of partial-care facilities for children with disabilities.
- The provincial DSDs must develop a resourced and targeted population-based strategy and plan for the establishment of sufficient foster homes for children with disabilities.
- The strategy could be informed by innovative pilots, such as specialised cluster foster care arrangements supported by local specialist NGOs.
- The DSD must, in collaboration with the Departments of Health (DOH) and Basic Education (DBE), develop guidelines and training for therapeutic programmes for children with disabilities.
- The government must develop the prescribed multi-sectoral ECD disability guideline as obligated by the ECD policy.
- The government must develop, resource and implement a parenting programme at scale for parents of children at risk of, or with, developmental delays or disabilities.

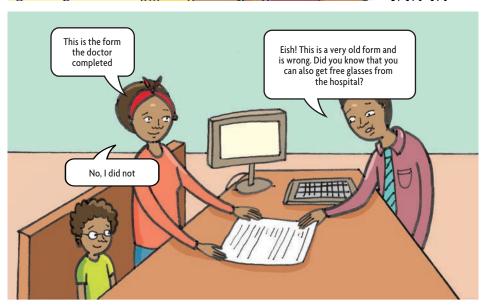


## **SECTION 2: The right to social protection**











Key national policies and laws
Constitution of the Republic of South Africa
The Social Assistance Act No. 13 of 2004
The National Integrated Early Childhood



### **Rights and responsibilities**

### **Rights infringed**

# **REQUIRES:**

- The government to take measures to realise the right to social security, including appropriate social assistance.
- The right of all children, including children with disabilities, to social services to be realised.
- Measures to be adopted to immediately realise the right of all children,

### **REQUIRES:**

That all eligible children get the Child Support Grant (CSG) (a monthly grant paid to (CDG) (a monthly grant paid to the caregivers of children with a disability).

- Few children access the CSG before they reach the age of one year. 13 Early access to the CSG before the child is one year old promotes the health and development of young children.<sup>14</sup>
- Despite the extra material needs of children with disabilities, not all children with a disability qualify for the CDG. The Social Assistance Act is applied in a manner that limits the CDG to children who require permanent care or support services due to their physical or mental disability.
- Even though the Act was strengthened in 2008 to remove the limitation of the grant to only children with severe disabilities who require home care, many children who would qualify under the expanded Act do not access the CDG.15

## Early Childhood **Development Policy**

### **REOUIRES:**

- The provision of the CSG or CDG through service delivery mechanisms that address barriers to early grant registration; and
- pre-registration of pregnant women for the CSG during pregnancy to ensure access from birth.

White Paper on the Rights of Persons with Disabilities & White Paper Implementation Matrix 2015 - 2030

#### **REOUIRES:**

- disabilities through Road to Health Screening programmes and their referral to services, including social assistance.
- That all social assistance programmes address the cost of disability, and that the CDG be reviewed and adjusted to cover the actual cost of disability.
- That social assistance programmes be strengthened to reduce poverty amongst persons with disabilities by addressing all access barriers.





### **Risks**



## Government's responsibilities not yet fulfilled



## Reform required to bring about changes

### Young children do not access the CSG because:16

- parents have poor knowledge of children's rights and of the developmental importance of early access;
- CSG education is not integrated into antenatal and parent support programmes; and
- application processes are time-consuming.

## Children with disabilities do not access the CDG because:<sup>17</sup>

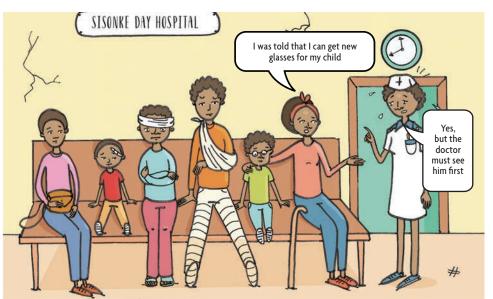
- their parents often can't take them to SASSA's offices:
- the examining doctor often incorrectly recommends that the child should not get it;
- doctors have too much discretionary power to decide if a child gets the CDG;
- doctors often have an incorrect understanding of the law;
- doctors often use outdated assessment forms; and
- inconsistencies between the Social Assistance Act (the enabling legislation) and the regulations (the subordinate legislation) create confusion. The Act makes it very clear that all children with disabilities who require either permanent care or support services are eligible to receive the grant. The regulations, on the other hand, provide that only care-dependent children can receive the grant.

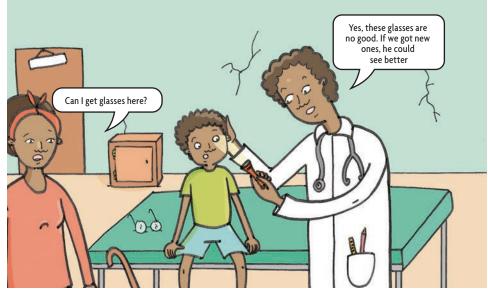
- The pre-registration of pregnant women for the CSG has not been implemented yet.
- The Road to Health Booklet is being revised for better delivery of ECD services through the health system. It does not, in its current format, provide information on the CSG or CDG.
- The CDG has not been reviewed and revised in compliance with the White Paper and Implementation Matrix to include all children with disabilities and meet the real cost of their disability
- Similarly, no measures have been adopted to expand the physical reach of social assistance through, for example, transport policies.
- The SASSA policy on home visits for vulnerable children to enable easier application by their caregivers is not universally applied.<sup>19</sup>
- The DSD has recognised the need to develop a new CDG assessment form for medical practitioners to use. However, a new assessment form is yet to be promulgated.<sup>20</sup>

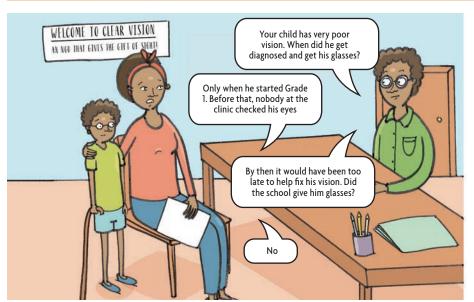
- Develop a policy and processes for preregistration of all pregnant women for the CSG as required by the ECD policy.
- Revise and implement the Road to Health Booklet to educate pregnant women and new moms about the CSG and CDG.
- The CDG policy and Social Assistance Act must be reviewed and revised so as to align with the social model of disability, to reach all children with disabilities, and to address the actual cost of disability.
- The Act and its regulations must be reviewed and revised to remedy inaccuracies and contradictions between the laws, regulations and procedures.
- The new CDG assessment form must be revised and implemented.
- Rights-based guidelines on the revised CDG policy, Act, regulations and assessment forms must be developed for doctors.



## **SECTION 3: The right to health care**

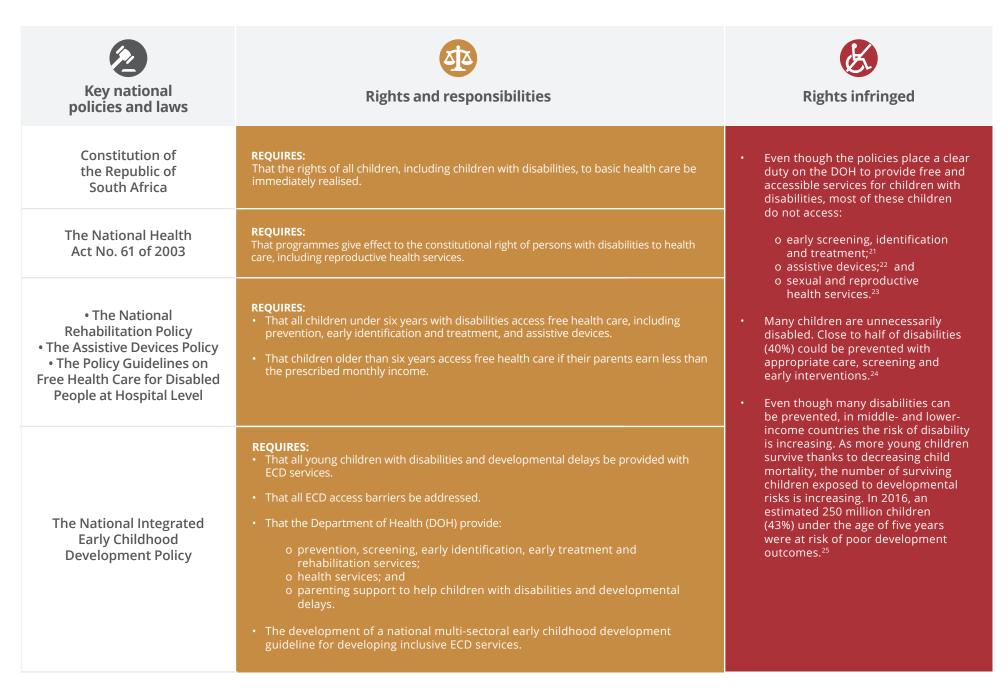














The Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015 – 2020

#### REOUIRES:

- Programming and budgeting to address barriers to access health care, including rehabilitation services, and to ensure that services are available as close as possible to where children live.
- The provision of comprehensive services at all levels of the health system across the life cycle of the child.

 The failure to prevent, identify and treat developmental delays and disabilities early enough infringes children's rights to health care, to develop to their full potential, and to education.

The White Paper on the Rights of Persons with Disabilities Implementation Matrix 2015 – 2030

#### **REQUIRES:**

- That access to health-care services be improved to reach all persons with disabilities.
- Improved transport to access health services
- Affordable assistive devices and support.



### Risks

- Poor implementation of prevention, early screening and identification services.
- The Road to Health Booklet is not used properly for routine development screening and referrals.<sup>26</sup>
- Health-care staff are not adequately trained.<sup>27</sup>
- Assistive devices are not routinely available.<sup>28</sup>
- Inadequate numbers and spread of therapeutic staff.<sup>29</sup>
- Long distances and lack of access to transport prevent access to health services.<sup>30</sup>
- Ignorance and attitudes of parents.<sup>31</sup>



## Government's responsibilities not yet fulfilled

- Child development health systems have not been strengthened to support universal access to quality services to prevent, identify and treat disabilities.
- Provincial health departments do not allocate adequate budgets for services for children with disabilities.
- The Integrated School Health Policy is not comprehensive enough in terms of the development support it provides, and it is no adequately resourced.
- There is no well-resourced community-based model of care which provides services to children close to their homes.



## Reform required to bring about changes

- The revised Road to Health Booklet must be supported by stronger health systems, such as training and monitoring, to ensure implementation of developmental services.
- A clear referral protocol must be developed that clarifies departmental roles and responsibilities, and which establishes referral processes.
- The inclusive ECD guideline required by the ECD policy must be developed to guide the development and revision of department's policies, programmes and budgets.
- The Integrated School Health Policy must be revised and better-resourced to ensure universal coverage of developmental services.



- Health-care staff do not understand how to deal with children with disabilities.<sup>32</sup>
- Lack of community-based services for children.<sup>33</sup>
- Uncertainty about which department must provide assistive devices to school children.<sup>34</sup>
- Sexual and reproductive health is not integrated into the curriculum for special-needs learners.<sup>35</sup>
- The use of traditional medical practices can set back the development of children.<sup>37</sup>

- No parenting support programme for families of children with disabilities has been developed, resourced and rolled out at scale.
- Home- and community-based health care workers are not trained to provide support to children
- The national guideline required by the ECD Policy to secure inclusive ECD services, including health services, has not been developed.
- Provincial health departments must develop and publish plans and budgets to ensure the provision of development services and assistive devices for children.
- The curriculum for special-needs schools should be revised to include sexual and reproductive health education.
- A costed transport policy for ensuring access to all services, including health, must be developed.
- A costed parenting programme that includes support for parents of children with disabilities must be developed.



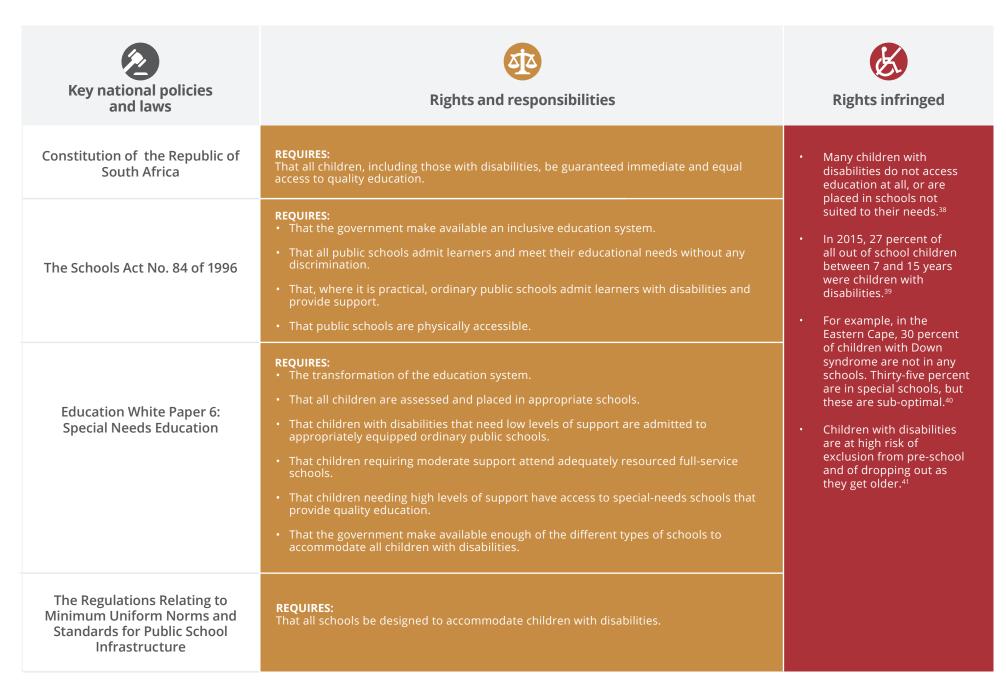


## **SECTION 3: The right to education**











The National Scholar Transport Policy
The National Integrated ECD Policy

The White Paper on

the Rights of Persons

with Disabilities &

**Implementation** 

Matrix 2015 - 2030

#### **REQUIRES:**

Universal access to school transport, including for children with disabilities.

### **REQUIRES:**

- The provision of comprehensive early childhood development services to all young childre with disabilities, including early childhood education from birth.
- The development of a national guideline to support departments to plan for inclusive ECD services, including early education.

# .

#### **REQUIRES:**

- That all children are enrolled in appropriate ECD and compulsory education programmes.
- That all children with disabilities of compulsory schoolgoing age are enrolled in school.
- That all children with disabilities must have access to inclusive learning opportunities in barrier-free settings.
- That all children with disabilities can access appropriate education facilities that provide support and reasonable accommodation.
- The provision of qualified teachers teaching and learning support aids for childrer with disabilities

- Children with disabilities often start school late with the added disadvantage of not having been to an ECD centre.<sup>42</sup>
- The quality of education for children with disabilities is generally poorer than for other children, especially in special schools.<sup>43</sup>



### **Risks**

- Many parents are not aware of the value of education and the rights of children. Other major
- Children are not properly screened, evaluated and placed in appropriate schools.<sup>45</sup>

access barriers are poverty, lack of money for

transport, and stigma in communities.44



## Government's responsibilities not yet fulfilled

- The Minister of Basic Education has not promulgated a minimum age for compulsory basic education for children with disabilities.
- White Paper 6 does not apply to pre-school or post-school education. There is no comparable policy for these age groups.



## Reform required to bring about changes

- The Minister must pass a law setting the minimum age for compulsory basic education for children with disabilities.
- White Paper 6 must be reduced to a time-bound implementation plan with a supporting resource strategy.



- High-risk children are not assessed and are falling through the cracks. They then proceed through the mainstream system as "ordinary" learners and tend to fail.<sup>46</sup>
- Generally, only schoolchildren are routinely assessed and supported, and not pre-schoolers and post-school youth.<sup>47</sup>
- Many ordinary public schools do not have the resources to do proper screening and to accommodate learners with mild disabilities.<sup>48</sup>
- There are not enough full-service or special schools to accommodate all learners, especially in rural areas.<sup>49</sup>
- Incorrect placement of children with mild disabilities in full-service and special schools leaves little space for children with severe disabilities.<sup>50</sup>
- Children identified as needing support are not accessing services and assistive devices because they are not referred to the appropriate service providers.<sup>51</sup>
- White Paper 6 lacks clarity, is ambiguous and lacks specific detail, making it difficult to implement and to hold the government to account for its responsibilities.<sup>52</sup>
- The cost of education for children with disabilities excludes many and compromises quality.<sup>53</sup>

- White Paper 6 is implemented over an extended period. This conflicts with the legal recognition of education as an immediately realisable right.
- White Paper 6 is not being implemented because of poor planning, inadequate resourcing and monitoring.
- White Paper 6 and its supporting programmes are not adequately funded to ensure universal availability and access to quality education for all children with disabilities. 54
- The nine provinces vary in their allocation of resources for implementation of White Paper 6.
   This deepens inequalities in the realisation of the right to education.
- There is no clear and shared national implementation plan with clear time-frames, targets, and funding norms to guide and standardise provincial plans.
- There are no special schools that are designated as "no-fee paying" schools.
- There is no extra per-learner allocation to accommodate the additional needs of learners with disabilities in mainstream schools.
- Referral networks and protocols across the departments are weak.
- The national inclusive ECD guideline required by the ECD Policy has not been developed.

- An implementation matrix should be developed to accompany White Paper 6 and provide time-frames and a shared monitoring and evaluation framework.
- White Paper 6 should be reviewed against the current legal and development obligations on the government.
- An ECD strategy for children with disabilities (akin to White Paper 6, which regulates inclusive education but does not apply to pre-school) must be developed.
- Funding norms and standards must be developed for the allocation of funds to support the implementation of White Paper 6 in all provinces.
- The funding framework for ordinary and special schools should be reviewed to ensure that education is free for children with disabilities.
- Mechanisms must be in place to ensure reporting against disability budgets and achievement of White Paper 6 targets.
- A national communications campaign must be developed to improve knowledge of, and demand for education for children with disabilities, including early education.
- A strong referral protocol must be developed to link the departments of Health and Education.



## **Endnotes**

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