

Submission from the
Disabled Children's Action Group (DICAG)
to the Portfolio Committee on Social Development
on the
Children's Amendment Bill [B19B-2006]

August 2007

This submission is endorsed by the following organizations:

Disabled People South Africa
National Council for Persons with Physical Disabilities in South Africa
Pietermaritzburg & District Cerebral Palsy Association
Baby Therapy Centre
Pathways-Kloof
Community Rehabilitation and Training for Empowerment (CREATE)
South African Federation on Mental Health
Children's Rights Centre
Carol Bower (Independent Consultant)
Children's HIV and AIDS Network (CHAIN)

For more information please contact
Nonceba Meyiwa - Cell: 073 273 1126
Sue Philpott - Cell: 084 6812016
Sandra Ambrose - Cell: 084 548 2861
Christina Sadiki - Cell: 083 596 0945
July Nkutha - Cell: 082 809 1616

Introduction

The Disabled Children's Action Group (DICAG) has been working closely with other organizations in the child disability sector to ensure the inclusion of children with disability or chronic illness in all provisions of the Children's Amendment Bill. Over 22 submissions on disability were made during the provincial hearings on the Bill during 2006-2007. This submission presents key recommendations for amendments which we believe need to be made to the B19B-2006 Bill. They are based on the discussions held at a national disability workshop in June 2007.

The Principles chapter of the Children's Act makes reference (in Clause 11) to specific areas around which consideration is to be given to children with disability or chronic illness. These include child participation, conditions that ensure dignity and promote self-reliance and provision of support services. This submission builds on Clause 11, and spells out what inclusion of children with disability means in terms of implementation of specific areas of service provision (e.g. partial care, ECD, child and youth care centres).

As DICAG, we recognise that, like all other children, children with disability or chronic illness have a range of needs and require different levels of support. We are therefore recommending that in planning for inclusive services, the Department of Social Development work towards provision of both

- o services that enable equal access for children with disability or chronic illness to general services for children, as well as
- o services that they require in addition to general services because of specific needs.

In June 2007, South Africa ratified the United Nation's Convention on Disability (UNCD)¹, affirming the government's commitment to protect the rights of disabled adults and children. We believe that the Children's Act and the Children's Amendment Bill present an opportunity to legislate these rights for disabled children in South Africa.

¹ United Nations A/RES/61/106

CHAPTER 5: Partial care

Section	Recommended amendment	Motivation
Clause 76 Partial care	(c) Remove "or other medical facility"	A partial care centre which provides therapy for disabled children may be classified as a "medical facility" and would then not qualify for funding.
Clause 77 Strategy concerning partial care	Retain reference to clause 11 here. 77 (1) The Minister, after consultation with the Ministers of <u>Transport</u>	When departmental strategy is formulated, there is no initial plan to include children with disability into partial care. As a result, most are at home or are in informal centres run by their parents. This clause will facilitate the inclusion of children with disability into partial care centres, as it places an obligation on the MEC to establish a range of facilities and services that cater for all children. It is very positive that there is cross-reference to clause 11 of the Act. It is extremely positive that this clause includes Health and Education, as well as "interested persons". Often children with disabilities living in rural areas do not get access to partial care because of transport problems. Where a child is in a buggy, or on crutches and has to cross a river, this is not only dangerous for the child, but also difficult for the parent. On a rainy day, the child may not get to the centre. Also there is the potential for abuse and abduction of children with disabilities where they have to travel long distances on their way to centres. Provision of accessible transport is one of the key mechanisms to ensure the dignity of children with disability ² .
Clause 78 Provision of partial care	78 (1) The MEC for social development of a province <u>must...</u>	The way that the clause is currently phrased, there is no obligation placed on the MEC to fund partial care. This makes provision of services discretionary and as a result, it may exclude certain children from accessing these services. If the MEC is left with the discretion of funding services, then children in dire need of the service may suffer. This has a particular impact on children with disability, as their families face many financial demands as a result of the extra costs associated with the child's condition.

² See UNCD Article 9 (1), and African Charter on the Rights and Welfare of the Child, Article 13 (1)

<p>Clause 79 Norms and standards for partial care</p>	<p>(2) (k) <u>employ persons that are trained in childcare and provide training to persons employed at the facility</u></p> <p>(3) A partial care facility for children <u>requiring high levels of support</u>³ <u>must</u>, in addition to the norms and standards....</p>	<p>The way this clause is currently structured, it differentiates between children with disability and those without disability. We recognise the need for the provision of specialized partial care centres for children with severe and/or multiple disabilities, but this must be on a continuum of services that addresses the different levels of support required. It is important that parents should be given the choice as to where they would like to send their child (i.e. it is not assumed that every disabled child would automatically have to attend a specialized facility). The training of staff working with children with disability is critical and is articulated strongly in the UNCD (Article 4 (1) (i)).</p>
	<p>(3) (iii) <u>basic therapeutic intervention</u></p>	<p>A facility for children with disability has as one of its main aims to maximize the skills of the children so that they can develop their full potential and become active members of society. Therefore not only are the “caring” needs of the children important, but even more critically the therapy-intervention and development needs.</p>
	<p>(3) (d) <u>act a source of advice and support for other partial care centres where required.</u></p>	<p>Specialised centres should act as a resource to train and support partial care centres to cater for a wide range of diversity amongst children⁴.</p>
<p>Clause 82 Consideration of application</p>	<p>2 (c) the applicant <u>has the necessary knowledge or training and support to utilize funds</u></p> <p>(5) ... a provincial head of social development <u>must</u> assist the owner or manager of a partial care centre with the <u>provision of the necessary funds and resources</u>, in order to comply...⁵</p>	<p>Clause 78 (1) and 82 (5) suggest that funds for partial care be made available from the Dept of Social Development. Nevertheless, there must be a trained and accountable manager in order to ensure that the facility and the service are sustainable.</p>

³ This term refers to e.g. children with severe or multiple disabilities, or those in the later stages of terminal illness

⁴ This is the model being used in the Education sector (based on Education White Paper 6), where special schools are being converted into resource centres. Not only do they cater for children requiring high levels of support, they provide an outreach service to schools in the district.

⁵ This is consistent with 78 (3)

<p>Clause 87 Record and inspection of and provision for partial care facility</p>		<p>(2) (b) It is important to define what is meant by “most urgently required”. We need to ensure the provision of services for children with severe disabilities, as the consequences of NOT providing services for them may even lead to their death. (2) (c) It is important to determine what constitutes “suitable premises”. It is needs to be in line with regulations on access – Part S of the SABS Building Regulations.</p>
<p>Clause 89 Death, abuse or serious injury of child in partial care facility</p>	<p>89 (3) If a child is abused or [seriously] injured while in partial care.... the person operating the partial care facility, <u>or a child at the partial care facility or parents of children attending the facility....</u></p>	<p>There may be instances where the person operating the centre is themselves responsible for the abuse or injury of a child. Provision needs to be made for a child or parent/caregiver to “immediately report” such abuse.</p>

CHAPTER 6: ECD

Section	Recommended amendmt	Motivation
<p>Clause 91 Early childhood development</p>	<p>ECD means the process of emotional, cognitive, <u>sensory, communication</u>, spiritual, moral, physical and social development of children from birth to school-going age, <u>taking into consideration the child's developmental stage</u>⁶.</p>	<p>If the aim of ECD is to provide “learning and support appropriate to the child’s developmental age and stage” (CI 91 (3)), then all senses need to develop at an early stage, to enable the child to know about his/her world. This would be crucial for a blind child who has to be taught to feel, hear and smell different things, or a Deaf child learning to express themselves and communicate their basic needs. Due to the many barriers to learning and development experienced by disabled children (including lack of availability of appropriate learning materials and lack of access to facilities) they may not</p>

⁶ ELRU submission contained in Western Cape mandate, and DICAG submission to DSD 20 June 2007

		achieve developmental milestones at the same age as able-bodied children.
Clause 92 Strategy concerning early childhood development	Recommend the retention of this clause	This is a necessary clause to ensure that children with disability or chronic illness are specifically targeted for inclusion into ECD services. Statistics indicate that children with disability are disproportionately represented in ECD facilities ⁷ , and this obliges government to plan for provision of ECD services to all children.
Clause 93 Provision of early childhood development services	93 (1) The MEC for social development of a province [may] <u>must</u> from money... (4) The funding of early childhood development programmes <u>must give priority to children in poor communities and those with disability or chronic illness.</u>	This is necessary to ensure that all children, including those in poor communities and those with disability or chronic illness, benefit from ECD.
Clause 94 Norms and standards for early childhood development	94 (4) We recommend the insertion of a clause relating to staff to children ratios ⁸ .	This is necessary in order to ensure the safety and well-being of all children and to optimize service provision.

⁷ Dept of Education (2001) The nationwide audit of ECD provisioning in South Africa. Pretoria

⁸ See also 209 (4)

CHAPTER 7 - Child protection system

Section	Recommended amendment	Motivation
Clause 104 Strategy concerning child protection	Within Clause 104 (1) we recommend inclusion of a reference to Clause 11 of the Act. ⁹	It is important to foreground children with disability or chronic illness as they are particularly vulnerable to abuse and neglect. Communication differences in particular need to be addressed in order to ensure that children with disability receive the necessary protection from the wide range of service providers involved (e.g. SAPS, clerks, social workers).
Clause 106 Norms and standards concerning child protection	(2) Norms and standards must relate to the following: (b) <u>identification and</u> assessment	There need to be ways of identifying children who are “hidden” by their families as a result of neglect.
Clause 110 Reporting a child in need of care and protection	(1) [...who on reasonable grounds concludes...] ... <u>who on reasonable grounds suspects...</u>	It may not be possible for someone to conclusively state that abuse is happening. However, if they suspect that this is so, they are responsible for reporting it. Only an official investigation can lead to a conclusion.
	(3) (a) must substantiate that <u>suspicion</u> to the provincial department...	(3) (a) The term “must substantiate that conclusion or belief” is problematic.
	(4) A police official to whom a report has been made in terms of subsection (2) must- (c) <u>be appropriately trained to respond to the report</u>	The appropriate training is necessary to enable police officials to effectively communicate with children, including those children with communication and intellectual disabilities, and to ensure that these children are treated with respect and dignity.
		It is critical that (mandatory) reporting of a child being abused or neglected be accompanied by the provision of services which are required in response.

⁹ See CI 77 (1) on partial care

CHAPTER 8: Prevention and early intervention

Section	Recommended amendment	Motivation
Clause 143 Prevention and early intervention programmes	<p>143 (1) Early intervention programmes means programmes (b) provided to families where there are children identified as being vulnerable to or at risk of harm <u>or disability</u>, or removal into alternative care.</p> <p><u>(c) targeted at children from birth who are at risk or whom have established risk based on biological, environmental or social factors, or those who have delayed development.</u></p>	<p>The definition of EI needs to stress the importance of prevention and early intervention at a very early age, and even before birth.</p> <p>Research has shown that while the brain is still growing, there is the potential to have the most impact to lessen the effect of a developmental delay.</p>
Clause 144 Purposes of prevention and early intervention programmes	<p>144 (1) Prevention and EI programmes must focus on (j) <u>integrated strategies for health promotion and prevention of childhood disability</u></p> <p>144 (k) <u>facilitating access to assistive devices and other support</u></p>	<p>Over 50% of disabilities are preventable and are caused by poverty-related factors. (The high rates of Foetal Alcohol Syndrome in the Western Cape are a cause of particular concern¹⁰.) In turn, disability has a very high social and economic impact on children and their families. For this reason, Health and Social Development in particular need to be working closely to ensure improved maternal nutrition, high uptakes of immunization, and other disability prevention programmes.</p> <p>Access to provision of assistive devices is critical, as this is the means by which there can be equalization of opportunities¹¹. Also,</p>

¹⁰ May, P.A., Gossage, J.P., Brooke, L.E., et al.. 2005. Maternal risk factors for foetal alcohol syndrome in the Western Cape Province of South Africa: a population-based study. American Journal of Public Health, 95: 1190-1199.

¹¹ See Article 20 (b) of the UNCD.

	<u>services to promote the development of and/or prevent deterioration of children with disability or chronic illness</u>	there needs to be consideration of the comparative costs of prevention vs. long term care and support.
	144 (1) (e) providing psychological, rehabilitation therapeutic and counselling programmes for children	These interventions need to equip parents and caregivers to contribute to the development of their children at home and in the wider community.
	(l) <u>peer group counselling and support groups</u>	An important mechanism through which support can be provided to parents – particularly young mothers with disabled children – is that of support groups. Often contact with others in a similar situation gives young mothers an opportunity to share their hopes and fears as well as to obtain practical information about services available and strategies to promote the child's development.
	145 (1) The Minister, after consultation with the Ministers of Education, of Finance, of Health and of <u>Transport...</u> ”	The inclusion of the Departments of Health and Education are endorsed. Through the Road to Health charts, Health personnel are able to monitor the growth and development of children, and need to work closely with Social Development when difficulties are encountered. Education has an important role to play especially in addressing barriers to learning as articulated in Education White Paper 6. However, lack of access to transport remains one of the key barriers that prevent children with disabilities and their families from benefiting from services. It is recommended that the Dept of Transport be included.
Clause 145 Strategy for securing prevention and early intervention	Within this clause we recommend inclusion of a reference to Clause 11 of the Act.	
Clause 146 Provision of prevention and early	146 (1) The MEC for social development of a province <u>must</u> , from money appropriated ... provide	We are concerned that 146 (1) implies that the provision of these critical services is discretionary. There should be a cost comparison between prevention and early intervention services and a lifetime of

intervention services	and fund prevention and early intervention programmes for that province.	health care and support services should these services NOT be provided ¹² .
Clause 147 Norms and standards for prevention and early intervention programmes	147 (2) The norms and standards... must relate to the following (b) education, <u>accessible</u> information and <u>health</u> promotion,	147 (1) (b) refers to "education, information and promotion". It is critical to ensure that all information is accessible to children with disabilities and their families/caregivers. Health promotion includes ensuring access of children to adequate nutrition as well as specific services such as immunizations ¹³ . The right of access to information is strongly articulated in the UNCD (Article 9 (1), (2) (f)).
	147 (2) (c) therapeutic <u>and counselling</u> programmes, <u>including access to assistive devices</u>	Counselling services also need to be included, and to be distinct from therapy. Counselling services greatly assist disabled children and their families to develop resilience in order to cope with the challenges that they face. They should also result in linking children and their families to the necessary services.
	Insert the following clause: <u>The MEC of Education in each province must establish and maintain for all schools in the province a mechanism for the identification, referral and support of children</u> ¹⁴ .	This would facilitate the early identification of children experiencing difficulties, both at home and at school. This clause needs to be read in conjunction with Education White Paper 6 (Inclusive Education), which provides for screening, identification, assessment and support for learners. In addition, the White Paper envisages the setting up of District Support Teams, which could be a mechanism to ensure intersectoral collaboration in addressing specific issues e.g. substance abuse.
	Insert the following clauses <u>1) Every local authority must take children's needs into account when developing its Integrated Development Plan</u>	It is essential that the needs of all children are considered in the development of the IDPs. This would ensure that the appropriate resources are allocated and would promote the progressive realization of the goal of inclusion of all children.

¹² See Article 23 (3) of the UNCD.

¹³ There needs to be close co-ordination with the Dept of Health around this, particularly in relation to Integrated Management of Childhood Illnesses (IMCI)

¹⁴ See CASNET submission to the Department of Social Development, August 2007

	<p><u>2) Every local authority must develop, in co-operation with all relevant local role-players, including parents of disabled children, an intersectoral plan for supportive services to children with disability or chronic illness¹⁵</u></p>	
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CHAPTER 12 - Foster care

Section	Recommended amendment	Motivation
<p>Clause 184 Determination of placement of child in foster care</p>	<p>184 (1) <u>(c) the capacity of the person to provide an environment that is conducive to the child's growth and development</u></p>	<p>Often social workers report that it is difficult to find foster care placements for children with disability. This contributes to the assumption that "no one would want a disabled child". Instead social workers and social service professionals should be actively seeking out suitable foster (or adoption) parents for children with disability or chronic illness and giving them the necessary support in order to ensure the provision of an environment that is conducive to the child's growth and development.</p>

¹⁵ See SASPCAN submission to Department of Social Development: proposal on the role of local authorities, August 2007

CHAPTER 13 - Child and youth care centres

Section	Recommended amendment ¹⁶	Motivation
<p>Clause 191 Child and youth care centres</p>	<p>191 (3) A child and youth care centre may in addition to its residential care programmes, offer – (a) the provision of appropriate care and development of children with disabilities or chronic illnesses;</p> <p>New section: <u>191 (3) All child and youth care centres must ensure an enabling environment to promote equal access and opportunities for children with disability or chronic illness.</u></p>	<p>This sub-section creates the impression that children with disabilities require residential care due to having a disability. Children with disabilities end up in the child protection system for the same reasons as other children: they have been abused, neglected, maltreated, orphaned, abandoned etc. They need care and protection in recognition that they are a child first and then additional assistance in recognition that they have a disability which could compound their vulnerability.</p> <p>We therefore recommend that 3(a) be deleted and a clause inserted that places an obligation on all centres to provide an enabling environment to ensure access of children with disabilities to all centres.</p>
<p>Clause 192 Strategy to ensure sufficient provision of child and youth care centres</p>	<p>The current formulation of 192 (1) is extremely positive and needs to be retained.</p> <p>192(2) The MEC must – <u>(c) include in the strategy a plan for ensuring that a sufficient number of centres take the necessary measures to enable access for children with disability or chronic illness.</u></p>	<p>192 (1) cross references to clause 11 of the Act.</p> <p>Currently, many child and youth care centres are not able to cater for children with disability or chronic illness. We therefore recommend that the MEC take steps towards progressively realizing this goal.</p>

¹⁶ See also the submission to the Portfolio Committee on Social Development from the National Association of Child Care Workers (NACCW), August 2007