Submission from the Disabled Children's Action Group (DICAG) to the Department of Social Development

on the Draft Children's Amendment Bill

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For more information, please contact:
Sue Philpott
Cell: 084 68 12016
PhilpottSue@gmail.com

Petronella Linders
Cell: 082 771 9322 or 083 785 4218
plinders@mweb.co.za

This submission is endorsed by the following organizations:
Sunshine Centre
National Council for Persons with Physical Disabilities South Africa
National Association for Persons with Cerebral Palsy in South Africa
Disabled People South Africa
Autism South Africa
Cheshire Homes South Africa
Down Syndrome South Africa
Epilepsy South Africa

Chapter 5: Partial care

Clause	Proposed amendments	Discussion
Partial care Clause 76	All NPO disability centres offer partial care for children and need to be recognized (funded and regulated) by the Dept of Social Development. These include developmental stimulation programmes and programmes for physical rehabilitation and therapy.	It is essential that services provided to the most vulnerable children – including children with disability or chronic illness – are adequately provided and funded by government. They should also be regulated and empowered to provide services in accordance with set norms and standards.
Strategy to ensure provision of partial care Clauses 77	**Insert new clause** **Strategy concerning partial care** **X (1)The Minister, after consultation with the Minister of Health, must include in the departmental strategy a comprehensive national strategy aimed at securing a properly resourced, co-ordinated and managed partial care system.** **(2) In order to give effect to section 2(h), 6(d), and 11, the Minister must include within the strategy, a plan for ensuring equal access and equal opportunities for children with disability or chronic illness.**	All the other chapters have strategy clauses which oblige the National DSD to plan for the provision of the service concerned. The partial care chapter does not have such a clause. In order to ensure sufficient provision of partial care facilities, we recommend the insertion of a strategy clause and that such strategy clause make specific reference to the need to provide adequately for children with disability.
Notices of enforcement Clause 80	Should a partial care facility close down, the Department must ensure that there is an alternative and appropriate placement available with immediate effect.	Often when partial care facilities are closed down, there are no alternative arrangements made for the children, and they return home to wait indefinitely.
Application for registration and renewal of registration Clause 81	It is essential to ensure that application forms are user-friendly.	Many people running partial care facilities would find it difficult to complete complex application forms. Therefore this process should be as user-friendly as possible.
	81 (c) (i) replace designated social worker with "social service professional"	There is a concern that generally there are too few social workers and that they would not cope with this extra workload. It is recommended that the clause be re-worded to refer to any social service professional who is appropriately trained to evaluate the specific facility. In the case of a disability-specific care centre, the Department could contact a relevant disability NPO for an "expert" person to evaluate the centre.
Consideration of applications	A clear definition is required of what constitutes a person who is not "fit and proper" to operate or work in a partial care facility.	

Clause 82(2) (b), (d) and (3)		
Norms and standards for partial care Clause 83	We recommend that in developing the regulations on norms and standards for partial care, the following provisions would help to ensure an "enabling environment" for children with disability or chronic illness: - norms and standards for developmental and therapeutic *programmes* that are inclusive of children with disability or chronic illness - norms and standards that ensure *physical access* for all children, as well as a safe environment for them - norms and standards on *training* for partial care personnel, which includes diversity training. All service providers should be trained in first aid, as well as universal precautions.	First aid is essential. For example, staff need to know how to deal with a child if they are having an epileptic seizure.
	It is recommended that the following amendment is made: 83 (f) a hygienic area for the preparation and "provision" of food	Sometimes food is prepared in a kitchen, but then served to children on the floor. It is recommended that the clause include not only the conditions within which food is prepared, but how it is actually delivered or served.
Record and inspection of and provision for partial care facilities Clause 87 (2)	Insert new sub-clause (3) **In order to give effect to section 2(h), 6(d), and 11 of this Act, provincial strategies must include measures to ensuring equal access and equal opportunities for children with disability or chronic illness.**	Children with disabilities do not currently have equal access to partial care facilities. In order to promote equality for children with disability we recommen the insertion of an express obligation on the provincial departments to consider and plan for equal access for children with disability.
Assignment of functions to municipalities Clause 88	88 (1) It is recommended that Clause 87 be excluded from the list of delegated functions to municipalities.	Provinces need to keep a record of all facilities and plan the service delivery accordingly.
	Provisions need to be made for the improvement of intersectoral collaboration at this level.	If an integrated and comprehensive approach is to be adopted, it is essential and structures and mechanisms are in place to promote collaboration between sectors, including disability-related NPOs.
	Provision needs to be made for municipalities to be capacitated by provincial government in order to fulfill these functions.	Many municipalities do not currently have the capacity to carry out the functions stipulated here, and therefore require the necessary training and support in order to do so.

Chapter 6 Early Childhood Development

Clause	**Proposed amendments**	**Discussion**
Definition of ECD Clause 91 (1) The current definition of ECD is stated as being "from birth to school-going age". [Defined by Dept of Education as 4 years].	We recommend flexibility on this, which takes into account the child's *developmental stage*, and not only their chronological age. An alternative definition could read "ECD means the process of emotional, mental, spiritual, moral, physical and social development of children from birth to school-going age, taking into consideration the child's developmental stage."	Due to the many barriers to learning and development that experienced by disabled children (including lack of availability of appropriate learning materials, lack of access to facilities) they may not achieve developmental milestones at the same age as able-bodied children. They then remain in formal ECD or informal centres even after reaching school-going age. Yet these children still need opportunities for support and development. Many children with disabilities do not need much more than an extra 1 – 2 years in an ECD facility to enable them to achieve appropriate developmental milestones. This extra time often enables them to cope more effectively with the increased pressures and expectations of a local, mainstream primary school. It also means that they are able to go to school in their own neighbourhoods, rather than having to attend a special school some distance away. It can be a cost effective strategy in that the costs involved for the family are greatly increased when such a child has to become a boarder in a more expensive special school. In addition to the developmental age, the size of the child has to be taken into account. This is because one also has to consider the safety of the other children attending the ECD facility. The behaviour of some children with certain disabilities can compromise/jeopardize the safety of the other children.
Strategies concerning ECD Clause 92 indicates that the Minister of Social Development should work in close collaboration with the Minister for Education to	We endorse the need for this collaboration, and stress that there needs to be synchronicity between Education White Paper 5 (ECD) and provisions in the Children's Amendment Bill. However, we also recommend the inclusion of the Department of Health in this clause.	Why is it important for the Dept of Health to be involved? If there is going to be holistic development of children through ECD, as is envisaged in the definition, then an important part of the input and support relates to their physical health and well-being. Important input by Health includes the following: - health promotion - nutrition needs to be appropriate for children with disability, where the ability to swallow solids has been compromised.

ensure properly resourced, co-ordinated and managed ECD.		- prevention programmes - including immunizations and regular weighing of young children to monitor their growth - early identification and referral - including children with chronic infections such as otitis media, in order to prevent long-term impairment. Currently, a number of Day Care Centres are being run under the auspices of the Dept of Health. Most of these cater for children with severe physical and/or intellectual disabilities. The focus tends to be on "care" with little emphasis on the stimulation of development of the children. If the ECD strategy of the Dept of Social Development is to cater for all children, it needs to work in close collaboration with those facilities and services being provided by the Dept of Health.
	We recommend the insertion of the following clause under the strategies section: **"In order to give effect to Clauses 6 (2) (d) (f), 7 (i) (j) and 11[1] of this Act, the Minister must include in his strategy a plan to ensure equal access for children with disability or chronic illness to ECD programmes."**	Although there are provisions in the first Children's Bill [B70D-2003] for inclusion of children with disability or chronic illneses, express mechanisms need to be provided for in the Children's Amendment Bill, or it is likely that children with disability or chronic illness will continue to be excluded from access to, and benefits of, ECD programmes.
<u>Provision of ECD services</u> Clause 93 indicates that only ECD services provided by an *organ of state or a designated child protection organisation*, will qualify for state funding if they comply with national norms and standards.	It is recommended that this clause be amended to include NGOs as providers of ECD services. 93 (2) It is recommended that reference to the "financial and fiscal commission" be removed. It is recommended that this clause refer to consultation with the Dept of Health.	Currently, many children with disabilities are accommodated in informal centres, run by parents and caregivers. It is essential that recognition, support and training is given to such centres to enable them to provide quality ECD services to these children. Norms and standards should be based on the needs of children, not on the basis of budgets.
<u>Minimum standards for ECD</u>	94. (1) A partial care facility or child and youth care centre providing services for any children up	

[1] Section 75 Children's Bill (December 2005)

Clause 94 refers to minimum standards for ECD.	to school-going age, taking into consideration the child's developmental stage must provide early childhood development services complying with the minimum requirements prescribed by regulation.	
	We recommend that in developing the regulations on norms and standards for ECD, the following provisions would help to ensure an "enabling environment" for children with disability or chronic illness: - norms and standards for *programmes* that are inclusive of children with disability or chronic illness - norms and standards that ensure physical access for all children, as well as a safe environment for them - norms and standards on *training* for ECD practitioners, which includes diversity training.	
<u>Assistance</u> Clause 100 states that a provincial head of social development may "give advice" to facilities or centres providing ECD, particularly with regard to compliance with the minimum requirements	"May" should be changed to "must"	
	Such advice is welcomed, and is seen to include technical expertise, promotion of inclusive ECD programmes and linking with relevant resource persons/organisations.	Such "advice" should include - strategies to address discriminatory attitudes towards diversity among children and their families. - technical expertise where necessary (design of low-cost playgrounds for all children, seating for children with physical disabilities). - information on how to acquire necessary equipment and materials i.e. making contact with relevant service providers (e.g. Toy Library Association or Mental Health Society). Reference should be made to disability-specific NPOs.
	It is also recommended that in addition to advice, much-needed *material assistance and financial support* is given to ECD programmes.	Such financial assistance is required in order to enable ECD practitioners to fulfil the conditions necessary for registration.

Chapter 7: Protection of children

Clause	Proposed amendments	Discussion
Strategies concerning child protection Clause 104	We recommend the insertion of the following clause under the strategies section: **"In order to give effect to Clauses 6 (2) (d) (f), 7 (i) (j) and 11[2] of this Act the Minister must include in his strategy a plan to ensure equal access of children with disability or chronic illness to protection services"**	
Clause 106 (2): Provision of designated child protection services The Minister must determine the national norms and standards after consultation with the MECS for DoSD, the Financial and Fiscal Commission & Minister of Finance	These need to include the following: - norms and standards for *programmes* that are inclusive of children with disability or chronic illness - norms and standards that ensure *physical access* for all children - norms and standards on *training* for child protection personnel which include catering for diversity of children.	Children with disability or chronic illness are particularly vulnerable to abuse of all kinds, including sexual abuse. The options for placement need to be accessible and suitable to provide the necessary support to children with disabilities and chronic illnesses. This includes foster care and temporary safe care facilities. Programmes that are disability-sensitive need to be developed to ensure the appropriate training of personnel working in the child protection system, so that they are able to deal effectively with disabled children who have been abused.
	The Financial and Fiscal Commission should be deleted from the list of people to consult with.	The norms and standards should be based on the best interests of the child, and not driven by budgets.
Clause 106 (4) (b) Designated child protection services include services relating to…	Provision should be made for curative and rehabilitative services for children who are in need of care and protection	Currently the provisions in the Bill relate to the location of the child in terms of arrangements for care. However, there is no provision for services that aim to assist the child in adapting to the environment and/or dealing with the trauma that they have experienced.
Child headed households Section 136 (3)	This clause needs to include the provision of a package of services to support these children, and protection of their rights, particularly property rights.	It must be recognized that disabled children may themselves be head of a household, or a child who is in a child-headed household.

[2] Section 75 Children's Bill (December 2005)

Chapter 8 Prevention and early intervention

Clause	Proposed amendments	Discussion
Purposes of prevention and early intervention services or programmes Section 144 (1) Prevention and early intervention programmes must focus on "	It is recommended that the following clause is added to 144(1): - preventing disabilities and chronic illnesses (e.g. programmes to support pregnant mothers to stop drinking alcohol, thereby preventing Feotal Alcohol Syndrome) - providing psychosocial rehabilitation services	As many as 50% of disabilities are preventable and directly linked to poverty[3]. Preventable causes of disability or chronic illness include poor nutrition, dangerous living conditions, limited access to health care, motor vehicle accidents, poor hygiene, Foetal Alcohol Syndrome and inadequate information about the causes of different conditions. Prevention in early childhood is particularly important as this is the stage at which much potential damage can be averted and during which period the development and growth of the brain is at its greatest. Even if a child is found to have a disability, early intervention is critical and will have long-lasting effects.
	It is recommended that reference be made to other sectors that are involved in prevention and early intervention strategies for children e.g. Health, Housing.	
Provision of prevention and early intervention services Section 145 (1) The Minister must determine the national norms and standards after consultation with the MECS for DoSD, the Financial and Fiscal Commission & Minister of Finance	These need to include the following: - norms and standards for *programmes* that are inclusive of children with disability or chronic illness - norms and standards that ensure physical access for all children - norms and standards on *training* of personnel which includes diversity training.	
Strategies for securing provision of	We recommend the insertion of the following clause under	

[3] DFID 2000 Disability, poverty and development Issues series.

prevention and early intervention services Clause 146	this section: **" In order to give effect to Clauses 6 (2) (d) (f), 7 (i) (j) and 11[4] of this Act, the Minister must include in his strategy a plan to ensure equal access of children with disability or chronic illness to prevention and early intervention services"**	
	There needs to be a strategy in place to ensure the collaboration of different departments around prevention and early intervention. These include Health, Housing, Water Affairs and Forestry, and Environmental Affairs and Tourism.	

[4] Section 75 Children's Bill (December 2005)

Chapter 13 Child and youth care centres

Clause	Proposed amendments	Discussion
Child and youth care centre Clause 191 (2)	Insert a sub-category into (2) to include programmes designed for providing support and material assistance to children leaving residential care: "assisting children to make the transition when leaving child and youth care centres after reaching age 18"	When children reach 18 years of age, some of them need assistance to make the transition between the centre and the outside world. Programmes designed to provide such assistance should be listed as one of the types of programmes that could qualify for funding.
Clause 191 (3) (a)	This clause should be replaced with the following: 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.	The way the definition is currently structured, implies that children with disabilities need residential care because of their disabilities. The definition needs to reflect that children with disabilities need care because they are found to be "children in need to care and protection" *not because they are disabled*. We therefore recommend that 3(a) should be deleted and a clause inserted that places an obligation on all centres to provide an enabling environment for children with disability or chronic illness.
Strategies to ensure sufficient provision of child and youth care centres Clause 192 (2)	We recommend that addition of the following clause in this section: 191 (2) The MEC must - (c) include in the strategy mentioned in sub-section 2(b), a plan to ensure that child and youth centres take the necessary measures to enable access and equal opportunities for children with disability or chronic illness	
Establishment of child and youth care centres Clause 193	These need to include the following: - norms and standards for *programmes* that are inclusive of children with disability or chronic illness - norms and standards that ensure physical access for all children - norms and standards on *training* of personnel of child and youth care centres as well as for management board members, which includes diversity training.	At present many places of safety are not suitably equipped and personnel do not have the skills to care for a child with a disability or chronic illness.

Management boards Clause 207 (3)	We support the inclusion of this provision. However we recommend the inclusion of a phrase in this clause which reflects the need for the diversity of children in child and youth care centres to be reflected also on the management board. So where there are disabled children in the centre, disabled persons or parents of disabled children should be on the management board. 207 (3) In appointing members of the management board, **the MEC or registration holder must ensure** equitable representation of all stakeholders, including the community in which the child and youth care centre is located, and including people representing the diversity in terms of race, culture, gender, disability and chronic illness, of the children within the centre. ~~must be ensured~~.	The way the clause is currently drafted, it merely focuses on geographical location. However, this would not ensure that the particular interests of children with disability or children with HIV are sufficiently represented on the Board. Just as you wouldn't want a centre for girls only run by a management board of men only, so you wouldn't want a centre with children with disabilities run by a management board with people with no experience or understanding of disability.
Managers and staff of child and youth care centres Clause 208 (1)	(1) (b) there should be an addition of the word "qualified"	