Presentation to the Gauteng Dept of Social Development on the

Children's Amendment Bill

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Profile of the Disabled Children's Action Group

The Disabled Children's Action Group (DICAG) was established in 1992 and is closely affiliated to Disabled People South Africa (DPSA). The organisation has mobilised over 12 000 parents of disabled children, of whom 3 800 are registered members. There are 86 affiliated local parent branches, with representation from all of the nine provinces, with its head office in Cape Town. The focus of DICAG at local level is advocacy, monitoring the implementation of government policy, capacity building and parent empowerment.

DICAG is the largest national parent organisation in Africa. The work that it has done in terms of addressing issues of children with disabilities has been recognised nationally and internationally. DICAG is currently a member of Disabled People International, as well as Inclusion International and is involved in a number of initiatives including prevention of violence against children, and improving the quality of life of children with disability.

DICAG has two key programmes - *development* and *advocacy*. The development programme seeks to

- empower parents of children with disability with knowledge and life skills to be able to respond to their children's rights and needs;
- empower children with disability to be self-advocates on their own issues, and
- provide support for individuals and centres to develop their capacity and organisational skills.

The advocacy programme aims to

- ensure that government and human rights bodies formulate and implement policies that will facilitate the full inclusion and participation of children with disabilities by addressing barriers;
- promote and protect the rights of children with disabilities and
- affirm the abilities of children with disability and the contribution that they can make to creating a "Society for All".

Executive summary

The Children's Act, which was signed in to law by the President in June 2006, makes specific provisions for children with disability or chronic illness. It reflects government's commitment to removing discriminatory practices which have excluded these children from many aspects of appropriate service provision. The Act also undertakes to provide an enabling environment for children with disability or chronic illness i.e. one which responds inclusively and appropriately.

What does this mean in terms of specific areas of service provision? This submission identifies key areas for consideration in the Children's Amendment Bill in terms of inclusion of children with disability or chronic illness. In each section of the Children's Amendment Bill, it calls for:

- the strategy clauses contained in each chapter, to include a plan for *ensuring equal access and equal opportunities* for children with disability or chronic illness
- the provisioning clauses in each chapter to foster an *enabling environment* for children with disability or chronic illness through the inclusion of norms and standards:
  - for *programmes* that are inclusive of children with disability or chronic illness
  - ensure *physical access* for all children, as well as a safe environment for them
  - on *training* for personnel, which includes diversity training. All service providers should be trained in first aid, as well as universal precautions.

Children with disability or chronic illness require a great deal of support, particularly in their early years. It is critical that they have access to ECD services. Government needs to take responsibility for the many disabled children currently in informal and partial care centres, so that the necessary support and monitoring can be instituted. These recommendations are made concurrently with the recognition that the Children's Amendment Bill needs to take a comprehensive and intersectoral approach to ensure prevention and early intervention for children with disability or chronic illness. Finally, child and youth care centres, in addition to responding to the diversity of children, and reflecting this diversity in its management structures, need to equip young people with making the transition to the outside world.

1. Introduction

The Integrated National Disability Strategy was published in 1997 and is based on the Constitution of South Africa. It embodies a vision of a "Society for All", in which differences are celebrated, and persons with disability are seen as citizens with rights, and not as helpless and tragic victims who are dependent on the welfare of others.

Several key amendments were made concerning children with disability or chronic illness in the Children's Act, which reflect government's commitment to this vision for children:

- In Chapter 2 (General Principles), the Act protects children against unfair discrimination on the basis of disability. It also goes further, calling for the recognition of a child's disability and places an obligation on the Department of Social Development to create an *enabling environment* to respond to the special needs that the child has.
- Clause 11 details key areas around which consideration must be given to children with disability or chronic illness.

It is often assumed that inclusion means 'treating all children the same.' The problem with this assumption becomes evident when one realises that disabled children have an unequal start in life, and therefore equality cannot be achieved without certain provisions being made to ensure that all children can participate equally.

> *"Inclusion does not mean that disabled children should just slot into an unchanging society. This denies both disability and difference. It is about disabled children having their needs met and their rights protected in an adapting society. Most importantly, disabled people (both adults and children), should be involved in shaping an inclusive society."*[1]

What does it mean to create an inclusive and enabling environment for children with disability or chronic illness around the key service areas contained in the Children's Amendment Bill? Within DICAG, we believe that it means recognizing the current barriers that exist which exclude children with disability or chronic illness from getting access to effective services, and working towards the removal of these. Such barriers may take different forms – they may be physical, attitudinal or institutional – but the onus is on government to remove them in order to foster an environment in which all children can grow and develop.

Recommendations are made here in two sections:

1. those that affect all service provision areas of the Amendment Bill
2. those that are specific to different chapters of the Amendment Bill

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[1] Save the Children UK 2000. Community based rehabilitation. Global review and seminar report. SCF UK.

2. Cross-cutting recommendations

a) Strategies clauses

Within each of the strategy clauses contained in different chapters of the Children's Amendment Bill, the Minister must include a plan for *ensuring equal access and equal opportunities* for children with disability or chronic illness.

b) Provisioning clauses

There are particular issues around norms and standards that relate to children with disability or chronic illness in all aspects of service provision. We recommend that in developing the regulations, 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 personnel, which includes diversity training. All service providers should be trained in first aid, as well as universal precautions.

Parents of children with disability need to be involved in development of norms and standards.

3. Recommendations for specific chapters

Chapter 5: Partial care

<u>Recognition and support that is empowering</u>

All centres that offer partial care for children with disability or chronic illness need to be recognized by the Dept of Social Development. It is essential that services provided to the most vulnerable children are adequately provided and funded by government. These are facilities that offer developmental stimulation, as well physical rehabilitation and therapy. Currently, many of these centres are run by parents of disabled children. These should also be regulated and monitored, as well as supported to provide services in accordance with set norms and standards. It is critical that this support is empowering, and that the Department does not “take over”, and control the centre, just because they are funding it.

<u>User-friendly application processes</u>

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.

Arrangements for closing down of facility

Often when partial care facilities are closed down, there are no alternative arrangements made for the children, and they return home to wait indefinitely. Should a partial care facility close down, the Department must ensure that there is alternative and appropriate placement available with immediate effect.

Intersectoral collaboration

If an integrated and comprehensive approach is to be adopted, it is essential that structures and mechanisms are in place to promote collaboration between sectors, including disability-related NPOs. Provisions need to be made for the improvement of intersectoral collaboration, particularly at municipal level.

Chapter 6: Early Childhood Development (ECD)

Flexibility in terms of age

We recommend flexibility on the ages of children in ECD facilities, such that account is taken of the child's *developmental stage*, and not only their chronological age. 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 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.

Intersectoral collaboration

We endorse the need for collaboration with the Minister of Education, as is currently reflected in the Bill. We 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 as a collaborative partner for ECD. 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. 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.
- 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. 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.

Advice and support required

The Bill indicates that the head of Social Development may “give advice” to ECD centres. Such advice is welcomed and should include

- strategies to address discriminatory attitudes towards diversity among children and their families.
- technical expertise where necessary (e.g. 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).

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

Curative and rehabilitative services

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. Provision must be made for curative and psycho-social rehabilitative services for children who are in need of care and protection.

Support for disabled children in child-headed households

In terms of child-headed households, it must be recognized that disabled children may themselves be head of a household, or a child who is in a child-headed household. This clause needs to include the provision of a package of services to support these children, and ensure protection of their rights, particularly property rights.

Chapter 8: Prevention and early intervention

Prevention of disability and chronic illness

As many as 50% of disabilities are preventable and directly linked to poverty[2]. 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.

Support to parents and caregivers of children with disability or chronic illness

A very important part of prevention (in terms of children with disability) is the support provided to the mother prior to and at the time of the birth of the baby. Often medical staff know when there is an at-risk pregnancy. Counselling, information and psycho-social support for the mother are critical to moulding her attitudes and behaviour towards her disabled child. It is important to preserving the family structures and support.

It is recommended that the following be added to the list of foci of prevention and early intervention programmes:

- preventing disabilities and chronic illnesses (e.g. programmes to support pregnant mothers to stop drinking alcohol, thereby preventing Foetal Alcohol Syndrome)
- providing psychosocial rehabilitation services
- provision of psychosocial support to parents of children with disability or chronic illness

Intersectoral collaboration

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.

Chapter 13: Child and youth care centres

Psychosocial rehabilitation

As stated earlier in this paper, it is important that child and youth care centres provide programmes that are appropriate for all children who have been placed there. The kind of environment should be one that not only protects all children, but one that contributes to their psychosocial rehabilitation.

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

Representivity of management boards

With regard to management boards, we support the inclusion of this provision. However, the way the clause is currently drafted, it merely focuses on geographical location. 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, 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.

We recommend the inclusion of a phrase which reflects the need for the diversity of children in child and youth care centres to be reflected also on the management board. Where there are disabled children in the centre, disabled persons or parents of disabled children should be on the management board.

Preparation for leaving a centre

When children reach 18 years of age, many of them need assistance to make the transition between the centre and the outside world. This is particularly the case for children with disability or chronic illness, who have to deal with the additional stress of societal discrimination against them. Programmes designed equip young people for leaving the child and youth care centre, should be listed as one of the types of programmes that could qualify for funding.
