Presentation to the North West Portfolio Committee on Social Development on the

Children's Amendment Bill

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Sana Modikoe

Disabled Children's Action Group (DICAG)
Cell: 072 496 4196

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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. 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 - 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. In each section of the Children's Amendment Bill, it calls for:

- each chapter to include a plan for *ensuring equal access and equal opportunities* for children with disability or chronic illness
- the fostering of *enabling environments* for children with disability through:
    - *programmes* that are inclusive of children with disability
    - ensuring *physical access* for all children, as well as a safe environment for them
    - *training* for personnel working with children, which includes diversity training.

Children with disability 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 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. 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 contains 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.

In the Children's Act, there are several key clauses 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 undertakes 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.

Often people think that inclusion means 'treating all children the same.' The problem with this is that it does not recognize that disabled children have an unequal start in life, and therefore equality cannot be achieved without certain provisions being made to ensure that they 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."*[i][1]

What does it mean to create an inclusive and enabling environment for children with disability in the Children's Amendment Bill? Within DICAG, we believe that it means recognizing the current barriers that exist which exclude children with disability from getting access to effective services, and working towards the removal of these.

2. Recommendations for every chapter

DICAG believes that each chapter describing a particular service should include a plan for *ensuring equal access and equal opportunities* for children with disability. We also recommend that the inclusion of children with disability takes into account the following aspects:

- *programmes* that are inclusive of children with disability
- *accessibility* for all children – both to the environment (buildings, playgrounds etc) and to information
- *training* for personnel, which includes diversity training.

Parents of children with disability and disabled young people themselves need to be involved as partners in developing inclusive services.

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

3. Recommendations for specific chapters

Chapter 5: Partial care

The types of Partial Care that are available in our area for children with disabilities are Day Care Centres. These centres are run by poor and illiterate parents of children with disabilities. These are the centres that are expected to offer developmental stimulation as well as physical rehabilitation to children with disabilities.

Our recommendations:
It is essential that services provided to the most vulnerable children are adequately provided and funded by government. These should be regulated and monitored as well as supported, to ensure that services are provided in accordance with set norms and standards. This should not however open an opportunity for Social Workers to "take over" and run centres for us.

User-friendly application process (clause 78)
It is essential to ensure that the application forms are user-friendly. Many people running Partial Care centres find if difficult to complete complex application forms. Therefore, this process should be as simple as possible.

Arrangements for closing down of facility (clause 80)
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, they Department must ensure that there is alternative and appropriate placement with immediate effect.

Chapter 6: Early Childhood Development (ECD)

Currently, our children with disabilities experience many barriers to learning and development. They do not easily access facilities which offer ECD in their neighbourhoods or communities. Difficulties include the following:

- teachers argue that they are not trained to deal with disabled children
- centres are not physically accessible to our children

As a result, children with disabilities stay at home. Some are in informal day care centres run by parents of disabled children. They remain in these informal centres for indefinite periods. They do not go on to other things, like progressing to Garde R or Grade 1. They do not socialize with other children.

The current definition of ECD is stated as "from birth to school-going age". This would be the age of 6-7. Our disabled children remain in the informal centres long after school-going age. Where will they go if there is a cut-off point based only on age?

Our recommendation
Flexibility in terms of age (clause 91)
We would like to see a lot more flexibility on this, taking into account the child's developmental stage and not just their age.

Intersectoral collaboration (clause 92)
The physical health and the well being of disabled children is important. As an example, the day care and ECD centres as one of the prevention programmes could offer immunization and nutritional food. Children need programmes which prepare them for transition into formal education. This calls for various departments to work together.

Our recommendation for clause 92
We endorse the need for collaboration with the Minister of Education as is currently reflected in the Bill. We would further recommend the inclusion of the Department of Health as a partner as well. This would promote the holistic development of the child through ECD as is envisaged in the definition. The relevant departments will need to work together.

Chapter 8: Prevention and early intervention

As many as 50% of disabilities are preventable and are directly linked to poverty. In our area, it is usual to find pregnant women not attending the maternity clinics for a routine check-up. Families cannot sufficiently feed their children, as they often do not have food for them. Access to health care and maternity care is limited. In the rural areas, clinics are very far for some people, and transport to the clinics is scarce and very expensive. Mobile clinics do come into our area. In most instances, they arrive without the medicines that might be needed for the children. Mother are used to going back home without the medicines for the mobile clinic.

Our recommendations
Unchecked pregnancies may result in undetected pregnancy problems, which may lead to disabilities. The Bill as it stands does not give a specific focus to the prevention of disability as one of its purposes. The Bill should promote programmes which will capacitate parents to support the well-being of their children by attending clinics. It is essential that departments work together to promote prevention and early intervention for all children, particularly the Department of Health.
