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Disabled Children's Action Group
(DICAG)

**Submission to the Portfolio Committee
on Social Development on the**

Children's Bill:

Section 75 [B70-2003 (Reintroduced)]

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Contact persons

July Nkutha
Ph: 082 819 4991
Fax: 013 9300750

Sue Philpott
Ph: 033 3864796 Cell: 073 5507123
Fax: 033 3864796
SuePhilpott@hotmail.com

This submission is endorsed by the following organisations:
Autism South Africa, Cape Mental Health Society, Centre for Early Childhood
Development, Childline South Africa, Epilepsy South Africa, Johannesburg Child
Welfare Society, Molo Songololo, Resources Aimed at Prevention of Child Abuse &
Neglect (RAPCAN), South African National Council for Child Welfare, South African
Federal Council on Disability and Sunshine Centre Association.

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¹ Section 75 Bill B70-2003 reintroduced in 2004

Profile of the Disabled Children's Action Group

The Disabled Children's Action Group (DICAG) was established in 1992 as a programme of Disabled People South Africa (DPSA). The first march to Parliament in 1993 was the turning point for parents - they were protesting against the numerous difficulties being experienced by children with disabilities in getting access to social assistance. This made the government aware of some of the inequities that exist within the system, and a long process of lobbying and advocacy began, the outcome of which was amendments to the Social Assistance Act.

DICAG became autonomous in 1997, with close affiliation to 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. 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 disabilities.

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

- empower parents of children with disabilities with knowledge and life skills to be able to respond to their children's rights and needs;
- empower children with disabilities 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 disabilities and the contribution that they can make to creating a "Society for All".

1. Introduction

The Integrated National Disability Strategy (1997) embodies a vision of a "Society for all", in which all people with disabilities are seen as citizens with rights, and not as helpless and tragic victims. Indeed, unfair discrimination against anyone on the basis of disability is prohibited by law². How does the current draft of the Children's Bill protect and promote the rights of children with disabilities and chronic illnesses? To what extent does it ensure that these children are included in all aspects of service delivery and that this is done in a comprehensive and co-ordinated way?

This submission highlights key principles that need to be central to the development of policies, programmes and services for children with disabilities and chronic illnesses. It then focuses on some specific areas of concern with regard to the Children's Bill. The first part focuses on the Bill currently before Parliament [B70 of 2003] while the second part looks at the provisions in the s.76 Bill that has not yet been tabled.

2. The situation of children with disabilities and chronic illnesses

It is estimated that over 14 million children in South Africa currently live in situations of extreme poverty and deprivation³. Given that approximately 4% of children aged 0-9 have disabilities⁴, and the fact that disability is both a cause and consequence of poverty⁵ - the situation of children with disabilities and chronic illnesses⁶ can well be described as "an emergency submerged".

Living in remote rural areas, and informal urban settlements, in situations of poverty, often means that children with disabilities and chronic illnesses have very limited access to services that they require. For example:

- Children with disabilities account for only 1.36% of those enrolled in Early Childhood Development (ECD) provision, including special facilities⁷
- There are approximately 280 000 children and young people with disabilities of school-going age, who are currently not in any formal education system.⁸ They therefore do not benefit from early development of life skills, or programmes such as the Primary School Nutrition Programme.

² RSA 2000 Promotion of Equality and Prevention of Unfair Discrimination Act Government Gazette Vol 416 No 20876. Chapt 2 s.9

³ Streak estimated that they live below a poverty line of R490/month per capita. (Streak, J. 2002 Child Poverty Monitor, IDASA - Budget Information Service)

⁴ Census 2001, Statistics South Africa

⁵ Poor maternal nutritional status, lack of health (antenatal) services and conditions of severe poverty directly contribute to higher morbidity. In addition there are numerous costs - such as medication, visits to health facilities and assistive devices - which mean that disability makes financial demands on the resources of a household.

⁶ A chronic illness is defined as an illness that lasts for a year or longer (Children's Institute 2003 The situation of children in South Africa).

⁷ Submission on the Children's Bill by the Early Learning Resource Unit (ELRU)

⁸ Education White Paper 6 "Towards an inclusive education & training system" Dept of Education 2001.

A consequence of this is that many disabled young people are not able to access development/training programmes or work opportunities, because of very limited formal education. This is compounded by the fact that many poverty alleviation programmes fail to specifically address disabled people as a target group, resulting in total or partial exclusion of people with disabilities.⁹

3. General principles

To a large extent, disability is determined by the attitudes and behaviour of society, which do not take into account people with impairments. This means that children with disabilities are excluded simply because their specific needs and requirements are not considered in policy formulation and service provision. It is critical that definitions of disability take into account the barriers that are created by *environmental factors*, rather than focusing only on those resulting from an impairment.¹⁰ (For example, the assumption may be made that a child with an intellectual impairment "has nothing to say", and cannot contribute to a discussion on issues that affect his/her life. This assumption is based on a discriminatory attitude and prejudice, in which the ability of the child to participate meaningfully is completely underestimated, because the focus is on the *impairment* of the child). Disability is a function of the economic, political, cultural and social barriers encountered by people with impairments. Numerous environmental factors create barriers, contributing to the exclusion and disablement of persons with impairments, thereby violating their human rights.

It is therefore recommended, in accordance with the original draft report of the South African Law Commission (SALC) that there be a chapter in the Children's Bill that specifically refers to "Children in especially difficult circumstances", which includes children with disabilities and chronic illnesses. There also needs to be clarification of terminology used, which includes definitions of disability and chronic illness.

3.1 Adopting an inclusive approach

It is sometimes argued that inclusion means "treating all children the same". The problem with this arises when one recognises that the playing fields are not level, and 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 in an equitable and culturally-sensitive manner and their rights protected in an adapting society. Most importantly, disabled people (both adults and children), should be involved in shaping an inclusive society¹¹

⁹ Disabled People South Africa 2001 Pocket guide on disability equity: an empowerment tool.

¹⁰ This is often described in terms of the "medical model" (with the "defective individual" defined as the problem) vs the "social model" (with the problem defined as the barriers created by a "disabling world").

¹¹ Based on Save the Children UK 2000 Community based rehabilitation. Global review and seminar report. SCF UK.

Inclusion and disability-focused programmes are not mutually exclusive, they can happen together in a twin track approach¹². The two elements of this strategy are:

1. Making disability a cross-cutting issue, and by so doing remove attitudinal, environmental and institutional barriers that discriminate against disabled children, and prevent them from benefiting from a particular service. This needs to be the approach of *every government department* that works with communities, as disabled children are present in all communities. One of the key principles here is that of *universal design and universal access*.¹³ Another principle is training and awareness-raising among staff to ensure that they have the necessary skills and appropriate attitudes in dealing with people with disabilities.

This means that specific mechanisms need to be put in place to ensure that children with disabilities and chronic illnesses have equal access to services as do all other children. Aspects of accessibility include the following:

- physical accessibility (e.g. provision of ramps and lifts)
 - financial accessibility (e.g. ensuring that services and the transport thereto are affordable for children with disabilities and chronic illnesses)
 - attitudinal accessibility (e.g. attitudes of administration staff and service providers towards children with disabilities and chronic illnesses).
 - access to information (This is especially important for children with hearing and visual impairments. In addition it is critical that all caregivers and service providers working with children with disabilities and chronic illnesses have the necessary information about different conditions.)
2. The second element of the strategy is to support disability-specific programmes and advocacy work that has a primary goal of promoting the rights of children with disabilities and chronic illnesses. Examples of such programmes include community-based rehabilitation, support to self-help groups of parents, disabled children and adults and inclusive education programmes.

3.2 Establishing mechanisms for monitoring and evaluation

*"It is vital that national goals for children include targets for reducing disparities, in particular those that arise from discrimination on the basis of race, between boys and girls, rural and urban children, wealthy and poor children and those with and without disabilities."*¹⁴

Given the history of marginalisation and exclusion of disabled children from consideration in service provision, it is essential that there be development of specific

¹² This is an approach advocated by the Department for International Development (DFID) (Disability, poverty and development, February 2000)

¹³ This considers the potential ability of all people, maximises the benefits of products and environments to the largest number of people who wish to participate and emphasises the creation of products and environments that everyone can use, regardless of age, physique and degree of disability (Seirlis 2002).

¹⁴ United Nations 2002 Resolution adopted by 27th Special Session of the General Assembly: "A world fit for children" A/RES/S-27/2

mechanisms to monitor the extent to which inclusion is being implemented. Indicators should be child-rights based, and take into account social and economic aspects of participation and inclusion of children with disabilities and chronic illnesses. Each component of service provision to children (e.g. health, education, social security, courts) needs to be able to account for what has been done to ensure that these are also accessible for children with disabilities and chronic illnesses.

4. Concerns with regard to the s.75 Bill [B70 of 2003]¹⁵

National Policy Framework: inter-sectoral implementation of the Act by all departments and levels of government

Provision for an intersectoral National Policy Framework has been removed from the Children's Bill¹⁶. Such a framework (as proposed by the SALC), would be binding on all government structures with responsibilities for children and critical to ensuring co-ordinated and holistic approaches to the issues faced by children. The removal of the integrated framework is a serious threat to increased provision of services. In addition, responsibilities for local and traditional authorities to monitor and address the needs of children in their areas have been removed.

The move by the Department of Social Development towards developing a needs-based approach to Care Dependency Grant assessments is to be welcomed. However, it is critical that these grants be seen in the context of other social services, as part of a *package of support services*, which includes education, transport, housing, assistive devices etc. It is essential that in developing comprehensive social services for children with disabilities and chronic illnesses, a developmental and human rights-based approach be taken in line with the Integrated National Disability Strategy. This means that:

- Children with disabilities and chronic illnesses are seen first and foremost as children who have rights, who are respected and treated with dignity.
- There is a framework to ensure an integrated and co-ordinated approach to dealing with children with disabilities and chronic illnesses. This includes co-ordination between different programmes within the Department of Social Development (e.g. social security and social services) between different government departments and between the Department of Social Development and organisations of civil society.
- Sufficient provision must be made by government for purchase of services for children, which are provided by NGOs. (For example children with mental health conditions who are in need of psycho-social rehabilitation and intervention are a vulnerable group and are often left out of the realm of service provision.) Most NGOs catering for these young people are not government endorsed or government funded, yet render a vital service which social workers are unable to provide, due to impossible case loads and lack of human resources.
- Information about such services is easily available and accessible to children and their families.
- There are systems in place to monitor the extent to which children with disabilities and chronic illnesses are able to participate in activities and benefit from services. It is essential that data collected on service provision be disaggregated, thus indicating how particular groups (such as children with disabilities and chronic illnesses) benefit

¹⁵ Section 75 Bill B70-2003 reintroduced in 2004

¹⁶ This was contained in the Draft Children's Bill submitted to Minister for Social Development 2002:
Chapt 2

from specific interventions. (For example, it should be obligatory to report on the numbers of children with disabilities and chronic illnesses currently attending ECD centres or benefiting from school nutrition programmes.)

In keeping with an inter-sectoral approach, and under the umbrella of the National Policy Framework, the SALC had recommended (s.161 and 162) that municipalities be required to:

- keep statistics of children in the area (including children with disabilities and chronic illnesses)
- monitor their location and socio-economic conditions
- conduct a needs analysis at least every 3 years
- submit these statistics to provincial and local government and
- use the statistics and needs analysis to budget for services, including access to basic nutrition, shelter, health care and social services.¹⁷

It is a matter of great concern that the provisions for a needs analysis and monitoring of the protection of the rights of children with disabilities and chronic illnesses have been removed from the Children's Bill. It is feared that unless a comprehensive, co-ordinated, rights-based approach is taken to the development of services, and interventions are monitored, children with disabilities and chronic illnesses will continue to be excluded by disabling attitudes and practices.

We therefore recommend that Chapter 2 of the SALC Draft Children's Bill, containing the National Policy Framework should be re-incorporated into the Bill and that the sections obliging local government to monitor and do needs analysis must be re-inserted into the Bill. This is in accordance with the Integrated National Disability Strategy, which calls for all government departments to plan, budget and provide services for persons with disabilities.

Strategies and provisions to address children in especially difficult circumstances

The Children's Bill does not contain provisions designed to address the situation of children in especially difficult circumstances¹⁸. Both the clause identifying children with disabilities and those with chronic illnesses as being those in especially difficult circumstances as well as specific strategies concerning these children, which were to be included in a National Policy Framework, have been omitted from the Bill.

The assumption that programmes developed for the general population of children will automatically benefit children with disabilities is false: disabled children do not have equal access to resources and opportunities, and *specific measures are necessary to*

¹⁷ Draft Children's Bill submitted to Minister for Social Development 2002: Chapt 10 s 162 (2)

¹⁸ These provisions were contained in the draft of the Children's Bill submitted to Minister for Social Development 2002: Chapt 16 s231 (1) (c) (d) and s 232 (1) (a) (iv) and (v)

*ensure their full inclusion and participation*¹⁹. The SALC draft of the Bill contained a chapter on Children in Especially Difficult Circumstances (Chapter 16). This Chapter defined certain categories of children as being especially vulnerable and then contained a list of strategies aimed at providing for these children's needs. The chapter identified vulnerabilities of each group that are specific to South Africa's situation and then specified that strategies would need to be drafted and incorporated under the umbrella of the National Policy Framework to ensure inter-sectoral co-ordination and service delivery.

The Chapter identified children with disabilities and chronic illnesses as one of the categories of children in especially difficult circumstances and then specified that the Minister of Social Development must draft strategies to provide for the needs of this category of children. These include strategies aimed at –

- Assisting children with disabilities or chronic illnesses to have access to educational, rehabilitation and health care services and empowering them to develop their self reliance and potential;
- Empowering parents or care-givers of children with disabilities or chronic illnesses to care for their children in the home environment and educating parents or care-givers of such children on matters affecting their children.

"This should be achieved through the establishment of rehabilitation and health care services within communities, by making schools accessible for children with disabilities, the provision of assistive devices free of charge or at an affordable cost, and developing support programmes for parents with disabilities. Furthermore an integrated approach must be followed in the delivery of rehabilitation services and the role and responsibility of each Department towards rehabilitation of children should be clearly outlined."²⁰

The strategies would have to set out the roles and responsibilities of each government department and each level of government, thereby ensuring co-ordination and holistic service delivery.

However, the Bill no longer contains this chapter and therefore removes the much-needed provisions and strategies that would have helped ensure a more co-ordinated and inter-sectoral approach to delivering services to children with disabilities and chronic illnesses. As a result, these issues continue to be addressed in a piecemeal, fragmented fashion and available resources are not used maximally. (For example, the Dept of Health recognises the value of Community-based Rehabilitation Workers for extension of rehabilitation services to remote rural areas. However, the Dept of Education does not recognise the potential role of these personnel to support inclusive education and encourage young people with disabilities to get access to schooling.)

Children with disabilities and chronic illnesses require a range of support services (including health, ECD, appropriate assistive devices, social assistance, transport, personal assistance²¹) to enable them to participate in different life areas (such as

¹⁹ Harris, A. 2003 *Disability, equality and human rights* Oxfam: UK

²⁰ SALC 2002 Project 110 Review of the Child Care Act: Report 12.3.1

²¹ For example, a classroom assistant for a child with a high level of need, or a Sign Language Interpreter

education and recreation). In addition, service provision needs to take account of a young child's changing needs as they grow and develop in the early years, or (in the case of a child with a degenerative disease) how a child's capacity is diminishing.

It is recommended that the strategies and provisions to address children in especially difficult circumstances be re-inserted into the Bill. Indeed, this is a means of working towards the "enabling environment that will lead to the full participation and equalisation of opportunities for persons with disabilities" as envisaged in the Integrated National Disability Strategy²².

Section 2 - Objects of the Act

The objects section of an Act describes the nature and scope of the Act. The objects section as it is currently formulated, makes no reference to the obligation to promote and protect the rights of vulnerable children such as children with disabilities and chronic illnesses.

We recommend that the objects section should be amended so as to include an express reference to the obligation to provide services, support and protection to children in especially difficult circumstances. The recommended amendment is as follows:

"2. The objects of this Act are –

- (a) to make provision for structures, services and means for promoting and monitoring the sound physical, intellectual, emotional and social development of children;
- (b) to strengthen and develop community structures which can assist in providing care and protection for children;
- (c) to protect children from maltreatment, abuse, neglect, degradation, discrimination, exploitation and any other physical and moral harm or hazards;
- (d) to provide care and protection for children who are in need of care and protection;
- (e) **to provide assistance, support and protection for children in especially difficult circumstances**²³

[(e)](f) to give effect to the Republic's obligations concerning the well-being of children in terms of international instruments binding on the Republic; and

[(f)](g) generally, to promote the protection, development and well-being of children."

Chapter 3 - Children's rights

In the Children's Bill, coverage of children's rights is minimal. Children's rights, as contained in the Bill of Rights of the Constitution, are re-stated with no additional elaboration or the accompanying obligations.

One of the greatest concerns with regard to the Children's Bill is the exclusion of specific reference to the rights of children with disabilities and chronic illnesses. The Integrated

²² Office of the Deputy President 1997:19

²³ Including children with disabilities and chronic illnesses

National Disability Strategy calls for a rights-based approach to the development of services for children with disabilities and chronic illnesses, in line with the recognition that disability is a *human rights issue*. Given the historically medical/welfare approach that has been taken in response to issues of disability, the rights-based approach is one that needs to be reflected in policy formulation, budgeting and service provision.

In line with international instruments designed to promote and protect the rights of children with disabilities and chronic illnesses²⁴, the rights of children with disabilities and chronic illnesses need to be specifically addressed in the Children's Bill. This should

- refer to rights of children with physical, sensory, neurological, intellectual or psychiatric disability, as well as those with chronic illnesses;
- ensure access to basic social services.

In addition, a number of other specific rights need to be highlighted with regard to their application to children with disabilities and chronic illnesses:

- Protection from unfair discrimination due to their disability or chronic illness (including HIV/AIDS)
- Protection from abuse and exploitation
- Prevention of disability through effective promotive and preventive programmes (e.g. Antenatal care, reduction of malnutrition, road safety campaigns)
- Access to quality ECD services
- Access to a quality education
- Social security - the need to fast-track the fulfilment of this right, and to improve efficiency of application and approval processes.
- Right to own property - a parent of a child with a disability may make provision for them on the death of the parent. However, these provisions may not be recognised for children with disabilities and chronic illnesses, as they are considered to be "incompetent". In the absence of a will, the child may have no other source of security and may not be in a position to secure employment even when s/he reaches adulthood.
- Registration - every child with a disability or chronic illness has the right to have a birth certificate and (at the age of 16) an Identity Document. These must be done sensitively and effectively by Home Affairs officials, even if the child has a severe and/or multiple disability.

(Note that most of these rights were highlighted in the original submission made by SALC, but have subsequently been excluded from the Bill.)

We therefore recommend the following insertions and amendments²⁵

Unfair discrimination

(1) No organ of state, and no official, employee or representative of an organ of state, and no other person may unfairly discriminate directly or indirectly against a child on the grounds of –

²⁴ Convention on the Rights of the Children, African Charter on the Rights & Welfare of the Child, UN Standard Rules on the Equalisation of Opportunities for persons with disabilities.

²⁵ Adapted from the submission of the Children's Institute's on the Children's Bill

- (a) the race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language or birth of the child or of any parent, guardian, care-giver or family member of the child; or
- (b) the family status, health status, socio-economic status, HIV-status or nationality of the child or of any parent, guardian, care-giver or family member of the child.

(2) Discrimination on any of the grounds listed in subsection (1) is presumed to be unfair unless it is established by the respondent that the discrimination is fair.

10. Child Participation

- (1) Every child capable of participating meaningfully in any matter concerning that child has the right to participate in those proceedings in an appropriate way and views expressed by the child must be given due consideration.
- (2) Children with disabilities must be supported²⁶ where appropriate to enable participation

Name, nationality and identity

Every child has the right –

- (a) to be registered promptly in terms of the Registration of Births Act, 1992 (Act No. 51 of 1992); and
- (b) to the preservation of his or her identity and nationality, subject to the other provisions of this Act.

Property

Every child who owns property or who is a dependent of a deceased person who owned property, has the right to the administration of that property in the best interest of that child.

Maltreatment, abuse, neglect, degradation, exploitation and other harmful practices

- (1) Every child has the right to be protected, through administrative, social, educational, punitive or other suitable measures and procedures, from all forms of torture, physical violence, mental harassment, injury, maltreatment, abuse, neglect, degradation and exploitation.
- (2) Every child who has been tortured, maltreated, harassed, abused, neglected, degraded or exploited has the right to have access to recourse and social services including counselling and medical treatment at state expense.

Education

(1) Every child has the right to –

- (a) have access to education on the basis of equal opportunities for all

²⁶ The term "supported" is used in place of "assisted" to avoid the connotation of helplessness of the part of children with disabilities. The emphasis is on support for participation in a manner that also addresses their specific needs.

- (b) have access to educational and vocational information and guidance; and
- (c) receive education and information through a medium which makes such education and information accessible to the child, having regard to the child's language, personal circumstances and any disability which the child may experience.
- (2) The education of a child must be directed towards –
 - (a) the development of the child's personality, talents, intellectual and physical abilities to their fullest potential;
 - (b) the development of respect for the democratic values of human dignity, equality and freedom enshrined in our Constitution;
 - (c) the development of respect for the child's parents, cultural identity and values, and language;
 - (d) the preparation of the child for a responsible life in a free society, in the spirit of peace, friendship, humanity, tolerance and national unity; and
 - (e) the development of respect for our natural and cultural heritage.

Health Care

- (1) Every child has the right to health care that promotes the child's health, prevents acute and chronic health conditions and disabilities, and adequately manages acute and chronic health conditions, and provides rehabilitation.
- (2) Every child has the right to have confidential access to contraceptives and health related information on sexuality, reproduction, STDs and HIV, regardless of age.
- (3) Every child has the right to confidentiality regarding his or her health status and the health status of a parent, care-giver or family member.
- (4) Every child has the right to request and receive information on health promotion and the prevention of ill-health and disease.
- (5) Children with disabilities have the right to have access to appropriate assistive devices that are necessary to enable their participation in community life.
- (6) Every child who requires medication for the treatment or control of a chronic illness or health condition has the right of access to such medication.

Social security

- (1) Every child has the right to social security, including access to social assistance if the parent or care-giver cannot or does not provide for the basic needs of the child.
- (2) Every child with a disability has the right to have access to social assistance if such social assistance is needed to enable the child to survive, develop and participate to their full potential.

Water and sanitation

- (1) Every child has the right to have access to clean water within a reasonable distance from his or her home.
- (2) Every child has the right to have access to sanitation services in order to prevent infections and diseases

Environment

- (1) Every child has the right to an environment that is not harmful to his or her safety or health.

Social services

- (1) Every child has the right to basic social services, including services that are aimed at:
 - a. Assisting the child's caregiver or parent to provide for the child's survival, development and participation needs
 - b. Assisting the child and the child's parent or caregiver to address social problems within the family and community that are violating the child's rights
 - c. Assisting parents and caregivers of children in especially difficult circumstances to provide adequately for their children's needs
 - d. Providing adequate alternative care for children whose parents or caregivers are unable or unwilling to care for them, or who have succumbed to HIV/AIDS
 - e. Providing adequate shelter and care for children living on the street or in child headed households

Children with disabilities and chronic illnesses

- (1) Every child with a physical, sensory, neurological, intellectual or psychiatric disability and every child with a chronic illness, has the right –
 - (a) to enjoy life in conditions which ensure dignity, promote self-reliance and facilitate active participation in the community; and
 - (b) to receive support that contributes to and enhances their quality of life; and
 - (c) to receive financial assistance from the state to ensure a standard of living adequate for his or her development and equal enjoyment of his or her constitutional rights.

Chapter 4 - Parental responsibilities and rights

Issues relate both to parents of children with disabilities and chronic illnesses, as well as disabled adolescents who are parents. The following are of particular concern:

- It is not uncommon that if a child is born with a disability, the father of that child denies paternity, accusing the mother of having an affair, or that she is one that caused the problem. There is a sense of blame that often is laid on the mother, with the father taking little or no responsibility towards the child. *Both parents need to be responsible for promoting the growth, well-being and development of the child.* Where necessary, legal assistance may be required to determine paternity.

- Parents of children with disabilities or chronic illnesses need to be made aware of their rights and responsibilities towards their children.
- There is also the issue of young disabled girls who have become parents as a direct cause of rape. Such children often have no recourse available to them and the perpetrators, where identified, often are not obligated to assist in the support of the child. The tendency is to provide to the parents through a structure of “damages” being paid. There need to be some measures within the legal system that can assist in this regard. It is imperative that parents or caregivers of children with disabilities and chronic illnesses to report all incidents of abuse and/or rape of these children.
- There is a tendency for parents of children with disabilities and chronic illnesses to take decisions on behalf of their children. These children are rarely consulted or given opportunities to participate in decisions that affect their lives. Parents tend to feel pity and as a result over-protect their children, not transferring skills or equipping them to lead independent lives. There is a need to meaningfully involve the child in all decisions affecting their lives, taking into account their developmental stage (as opposed to chronological age).
- Chastisement and discipline are also key issues that need to be dealt with effectively by parents of children with disabilities and chronic illnesses.
- Parents of children with disabilities and chronic illnesses need to make provision for their children in their wills.
- Parents of children who are Deaf should learn Sign Language in order to communicate effectively with their child.
- Another issue for consideration is the needs and rights of disabled youth who are parents. These young people require particular support in making decisions that are in the best interests of their own children.

Chapter 5 - Children's Courts

Children with disabilities and chronic illnesses are particularly vulnerable to abuse of all kinds, including sexual abuse. It is essential that the development of child protection services, including children's courts, be done with consideration of children with disabilities and chronic illnesses to ensure their *equal access*. It is critical that the appropriate services are rendered to children with disabilities. (e.g. Children with hearing impairments or intellectual impairments may not benefit from conventional counselling services)²⁷. Particular emphasis should be placed on ensuring physical accessibility as well as access to information.

Programmes need to be developed to ensure the appropriate training of personnel working in this field, so that they are able to deal effectively with disabled children to progress from the status of being victims of abuse to that of being survivors of abuse. Effective communication and intervention should be provided from the beginning of the process (taking statements) to the end of it - including provision of secure placement where necessary. At present many places of safety are not suitably equipped and personnel do not have the skills to care for child with disabilities or chronic illnesses.

²⁷ Sign Language interpreters are required for Deaf children, so that their parents or caregivers are not obliged to interpret for them.

5. Concerns with regard to the s.76 Bill

Chapter 6 and 7 – Partial Care and Early Childhood Development

Despite a policy commitment to broad programming, the main focus of the ECD chapter in the Children's Bill is on centre based services, and not on family programmes. Family programmes (such as those run by parents of children with disabilities or chronic illnesses) have the potential to provide direct support to the primary caregivers of vulnerable young children. However, in order to provide a sustainable and high-quality service, they need subsidies, training for practitioners and nutritional support²⁸.

Opportunities for ECD are critical for young children with disabilities or chronic illnesses who (more than many others) require every opportunity for stimulation, in order to develop basic communication, mobility and life skills. Particular focus needs to be placed on children with visual or hearing impairments, as well as those who have multiple disabilities. Children with intellectual disabilities need intense stimulation during their early stages of development, as this is when brain development is at its greatest.

It is essential that the principles of ECD be consistent with those of the Education White Paper 6²⁹, so that an *inclusive approach* to ECD is advocated and that there is a focus on removal of barriers to learning. It is also recommended that the ECD sector specifically play a role in terms of:

- *Promotion* of children's well-being, including nutritional support and *prevention* of illnesses, secondary disabilities and injuries. Prevention in early childhood is particularly important - as this is a stage at which much potential damage can be averted.
- *Early identification and intervention* for children with disabilities and chronic illnesses.
- Appropriate *referral* of children identified who have health or social needs.

Currently in the Children's Bill³⁰, there is no reference made to appropriate norms and standards for ECD facilities to cater for children with disabilities and chronic illnesses. (For example the physical adaptations that may need to be made, or specialised seating provided). There is also no reference made to the appropriate training of ECD personnel to ensure that they are suitably trained and equipped to cater for children's diverse needs (e.g. First Aid training, feeding children through feeding tubes, comforting a child whose parent has passed away).

Recognition and support need to be given to parents of children with disabilities and chronic illnesses, who run home-based informal stimulation centres. These parents need to be given training and financial support, so that the centres can be registered and further

²⁸ Draft submission for discussion - ECD sub-group submission on the Children's Bill (ELRU August 2003)

²⁹ Dept of Education 2001

³⁰ Children's Bill, Minister for Social Development August 2003

developed in partnership with the Department of Social Development, Health and/or Education. Given that registration fees often restrict access to ECD, fees should not be regarded as the norm in deeply impoverished communities, which are characterised by unemployment and the impact of AIDS.³¹ Funding policies need to include ECD sites that cater for children with a range of impairment types, as well as NGOs that provide critical support (through training and resources) to centres run by parents.

It is recommended that there be a comprehensive national strategy aimed at securing an inclusive ECD system which is properly resourced, co-ordinated and managed, as proposed by the SALC.³²

Chapter 8 – Protection of Children

Part 1 - Child protection system

Provision for an intersectoral mechanism to ensure proper planning, resourcing and co-ordination of the child protection system have been omitted from the Children's Bill.

Children with disabilities and chronic illnesses are particularly vulnerable to abuse of all kinds, including sexual abuse. 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.

It is recommended that

- The development of child protection services, including children's courts, be done with consideration of children with disabilities to ensure their *equal access*.
- Particular emphasis should be placed on ensuring physical accessibility as well as access to information. It is critical that the appropriate services are rendered to children with disabilities (e.g. children with hearing impairments or intellectual impairments who will not benefit from conventional counseling services). Effective support mechanisms for communication and intervention should be provided from the beginning of the process (taking statements) to the end of it - including provision of secure and accessible placement where necessary.
- 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.

Part 3 : Protective measures relating to the health of children

Significantly, the Children's Bill deals only with very specific issues around protective measures relating to the health of children. These are: consent to medical treatment & surgical operations, HIV-testing & access to contraceptives.

³¹ Submission to the Portfolio Committee on Social Development from the South African Congress for Early Childhood Development and Early Learning Resource Unit 19 July 2004

³² Draft Children's Bill submitted to Minister for Social Development 2002: Chapt 7 s106A (1)

The submission by the SALC³³ affirmed the State's responsibility to provide basic health services for all children.³⁴ However, no clarification was given on what this entails for children with disabilities and chronic illnesses.

The definition of Primary Health Care includes the components of promotive, preventive, curative as well as rehabilitative and palliative care. Given that the provision of rehabilitation services and assistive devices to children with disabilities is essential to improve their level of functioning in society, and to enable equal participation, it is essential that these are recognised as areas of service provision that need much further development.

Access to *information* on health care is particularly important for children with disabilities and chronic illnesses, and these children have the right to participate in decisions about their health and treatment as well as health research. This information must be communicated in a language and medium that is developmentally appropriate for the child. Children with disabilities and chronic illnesses also have a right to *confidentiality* of their health status and health records. Information about a child's disability or chronic disease should be disclosed only when it is in the child's best interests, and not used as a basis for labeling or stigmatising the child.

In addition to testing and counseling for HIV/AIDS, consideration needs to be given to children who are being tested or assessed for conditions that may impact on the child's ability to participate meaningfully in life (e.g. genetic testing). These children and their parents or caregivers may require support before the test is taken (pre-test counseling) as well as in dealing with the outcome of the test (post-test counseling and support).

The Children's Bill states that a child may consent to medical treatment, provided s/he is 12 years of age and of sufficient maturity to understand the benefits, risks, social and other implications of the treatment or operation³⁵. However, consideration needs to be given to children of 12 years and older who have intellectual impairments, and the criterion of "sufficient maturity" must be clearly defined.

Particular consideration needs to be given to the health rights of disabled girls in terms of their ongoing experiences of forced hysterectomies to manage menstruation, or the young boys who are forced to receive injections that would control their hormonal development and sexual urges.

Studies have shown that young women with disabilities have limited access to reproductive health care, and as a result they suffer greater vulnerability to reproductive health problems. There is a lack of awareness of the reproductive health needs of young people with disabilities and chronic illnesses, and often it is assumed that they do not form part of the target group because being disabled is associated with being sexless³⁶.

³³ Draft Children's Bill submitted to Minister for Social Development 2002: Chapt 4 s22.

³⁴ Section 28 (1) c) of the SA Constitution 1996

³⁵ Children's Bill, Minister for Social Development August 2003 Chapt 8 part 3: s 129 (2) (a)

³⁶ DFID 2000 Disability, poverty and development Issues series.

Another issue for consideration is the needs and rights of disabled youth, as parents, in providing consent regarding health decisions over their own children. These young people require particular support as parents, and in making decisions that are in the best interests of their own children. In addition, information on sexuality, reproductive health and contraception needs to be available for adolescents with disabilities.

Chapter 9 – Prevention and Early Intervention Services

The Children's Bill contains no reference to prevention of disability or chronic illness of children. Neither is there specific reference to the need for early intervention services for children with disabilities and chronic illnesses.

As many as 50% of disabilities are preventable and directly linked to poverty.³⁷ Preventable causes of disabilities and chronic illnesses include poor nutrition, dangerous living conditions, limited access to vaccination programmes and to health and maternity care, motor vehicle accidents, poor hygiene, bad sanitation 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.

It is recommended that the Children's Bill make specific reference to addressing the causes of disability and chronic illnesses among children. In addition, the use of developmental screening tools that are appropriate to the South African context and cultures needs to be facilitated to ensure early detection of disability and chronic illness. Identification of a child at risk, or who already has a functional limitation should be followed by referral to the necessary services to ensure early intervention.

An important mechanism for prevention and early identification is that of local government. The SALC had recommended that municipalities be required to:

- keep statistics of children in the area (including children with disabilities and chronic illnesses)
- monitor their location and socio-economic conditions
- conduct a needs analysis at least every 3 years
- submit these statistics to provincial and local government and
- use the statistics and needs analysis to budget for services, including access to basic nutrition, shelter, health care and social services.³⁸

It is essential that data collected on service provision and up-take be dis-aggregated, thus indicating how particular groups (such as children with disabilities and chronic illnesses) benefit from specific interventions. (For example, it should be obligatory to report on the numbers of children with disabilities and chronic illnesses who have been immunized over a given period of time, or the number of adolescents with disabilities who have received counselling on HIV/AIDS.)

³⁷ DFID 2000 Disability, poverty and development Issues series.

³⁸ Draft Children's Bill submitted to Minister for Social Development 2002: Chapt 10 s 162 (2)

Chapter 10 – Child in need of care and protection

The definitional provision for a child in need of care and protection in the Children's Bill is much narrower than that proposed by the SALC. In addition, reporting mechanisms and persons are not specified.

In its concluding observations on the initial report submitted by South Africa, the Committee on the Rights of the Child (2002) expressed concern regarding "inadequate legal protection, programmes, facilities and services for children with disabilities, especially mental disabilities".

It is recommended that:

- The definitional provisions as outlined in the SALC proposals be re-inserted, with the addition of the group of children with disabilities and chronic illnesses as those that who require particular care and protection. This would help to ensure that the focus is not only on the *child*, but also recognises the failure of *parents* to fulfil their responsibilities. This recognition would emphasise that prevention and early intervention programmes need to focus on support of parents and caregivers. Parents of children with disabilities and chronic illnesses need particular support to assist them, in turn, to support their children.
- There is a need to specify who can report a child who is in need of care and protection, as is done by the SALC³⁹. In addition, provision needs to be made for a child to report another child to be in need of care and protection.
- Regarding orders when a child is found to be in need of care and protection⁴⁰, 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.

Chapter 14 – Child and youth care centres

The Children's Bill currently provides no reference to the appropriate accommodation of children with disabilities and chronic illnesses at child and youth care centres.

Given the particular vulnerability of children with disability and chronic illnesses, it is essential that child and youth care centres are able to accommodate them appropriately.

Recommendations are that:

- Provisions include accessibility of the environment, as well as provision of access to information (e.g. Sign Language Interpreters) and services. (For example, children with psychiatric disabilities need to be counselled and treated by appropriately trained personnel. Particular sensitivity needs to be shown towards children with intellectual disabilities.)

³⁹ Draft Children's Bill submitted to Minister for Social Development 2002: Chapt 10 s 167(1)

⁴⁰ Children's Bill, Minister for Social Development August 2003 Chapt 10 part 2: s156

- Provisions are made for the health-related needs of children with disabilities and chronic illnesses (such as the need for a child with epilepsy to receive regular medication).

Children in Especially Difficult Circumstances

The chapter on children in especially difficult circumstances needs to be re-inserted into the Bill. Refer to s.75 section above.

6. Conclusion

After 10 years of democracy, South Africans are justifiably proud of the many achievements that have been made. Key to these are the building of a democratic non-discriminatory society, a society that embraces diversity and nurtures a spirit of tolerance. Despite this, progress towards meeting the needs and protecting the rights of the most vulnerable members of our society - among them children with disabilities and chronic illnesses - has been minimal.

The vision of a "Society for All" is clearly articulated in the INDS, with anti-discrimination legislation embodied in the Promotion of Equality and Prevention of Unfair Discrimination Act. But what does this mean for the daily lives of children with disabilities and chronic illnesses, living in rural areas or informal settlements? To date, it has meant very little. There is still no guaranteed access to health care and assistive devices, ECD services, education and social security, despite numerous policies and policy guidelines. Children with disabilities are still disproportionately under-represented as beneficiaries of social services. (Indeed, many government service providers do not even have the necessary dis-aggregated information systems to be able to monitor the extent of reach or budget allocations for children with disabilities and chronic illnesses.)

How do we ensure that meeting the needs and protecting the rights of children with disabilities and chronic illnesses becomes a priority for government, and a reality for children? The Children's Bill presents an opportunity to develop legislation that translates policy into services and opportunities for children with disabilities and chronic illnesses. We cannot dream of a "Society for All Children" or profess to the nation and the international community that we are progressively ensuring and working towards the improvement of quality of life of our children, unless we make specific provisions for all children to be included.