NUMBER 4 • UNIVERSITY OF CAPE TOWN

From Sidelines to Centre Stage: The inclusion of children with disabilities in the Children's Act







From Sidelines to Centre Stage: The inclusion of children with disabilities in the Children's Act

Lucy Jamieson and Paula Proudlock

Children's Institute Case Study Number 4

University of Cape Town

October 2009

We are serious [about seeing] children with disabilities being part of society, being part of every document, being part of every decision being taken; we want our children on board because too long children with disabilities have been sidelined and forgotten about.

Sandra Ambrose, disability campaigner and parent of a child with a disability





Acknowledgements

The authors wish to thank Sue Philpott (DART) and Nonceba Meyiwa (DICAG) for their contribution to this paper, Robin Benjamin (PMG) for conducting the interviews, and

Petronella Linders (Department of Communications) and Marlese Von Broembsen (Law

Faculty, University of Cape Town) for their helpful commentary.

We thank the Centre for Civil Society at the University of KwaZulu-Natal and the ELMA

Foundation for providing the financial support which enabled us to research and produce

this paper.

The opinions expressed and conclusions reached are those of the authors and are not

necessarily attributable to any of the contributors, commentators or donors.

Editing by André Weisner and Charmaine Smith. Production managed by Charmaine Smith

and distribution co-ordinated by Anthea Arendse and Glenda Vena, Children's Institute,

University of Cape Town.

Suggested citation:

Jamieson L, Proudlock P (2009) From Sidelines to Centre Stage: The inclusion of children with disabilities in the Children's Act. Children's Institute Case Study

Number 4, University of Cape Town.

ISBN: 978-0-9814320-3-8

© 2009 Children's Institute, University of Cape Town

Contact details:

Children's Institute, University of Cape Town

46 Sawkins Road, Rondebosch, 7700

Tel: +27 21 689 5404

Fax: +27 21 689 8330

E-mail: info@ci.org.za

Web: www.ci.org.za

Table of Contents

Introduction	. 1
1. Background	.4
1.1 The legal framework in relation to children with disabilities	.4
International law	.4
The South African Constitution	.5
The Integrated National Disability Strategy	.6
Promotion of Equality and Prevention of Unfair Discrimination Act	7
1.2 Challenges faced by children with disabilities and chronic illnesses	.7
1.3 The potential of the Children's Bill to address these challenges	.8
1.4 Key stakeholders in the disability sector	.9
2. Description of the Children's Bill Working Group and the Disability Task Team	10
2.1 The Children's Bill campaign and WG	10
Establishment and structure of the WG	10
Objectives of the campaign and basic methodology	12
Working Group methodology	13
2.2 The Disability Task Team	14
Mandate	14
Composition	15
Linkages with the disability sector	15
Linkages with the Children's Institute	15
3. Preparation and consultation	16
3.1 Joining the broader campaign and understanding the Children's Bill	16
3.2 Consultation within DICAG	16
Making legislation accessible and identifying the challenges	16
Gathering evidence, research and case study materials	16
3.3 Encouraging the participation of a wide range of disability sector stakeholders	17
E-mail networks and key individuals	17
Workshops and conferences	17
3.4 Winning support from other sectors	18

3.5. DICAG's final recommendations for amendments	18	
The DICAG submission	18	
Nonceba Meyiwa's case study submission (2004)	19	
4. Participating in Parliament	20	
4.1 Overview of the National Assembly process	20	
4.2 The public hearings	20	
DTT report on the public hearings	21	
4.3 Mobilising the sector for continued parliamentary advocacy	21	
4.4 The portfolio committee deliberations		
Tracking the debate	21	
The summary of submissions	22	
The working group re-strategises	23	
Lobbying the inter-departmental steering committee	23	
Meetings with MPs on the portfolio committee	23	
Secondary lobbying of MPs not on the committee but in the disability caucus	25	
The policy workshop	25	
Constituency visits	27	
Mini-indaba with the drafter	27	
Attending committee meetings	28	
4.5 Involvement in the costing process	28	
4.6 Media dialogue		
4.7 Summary	29	
5. The story behind clause 42(8)(d): Disabled access to children's courts	30	
5.1 History of the clause	30	
5.2 The eleventh hour briefing and the stand-off between the National Assembly and the Executive		
Hendrietta's story		
5.3 Planning for the NCOP process – identifying the need to defend		
clause 42(8)(d)		
5.5 The Department of Justice strikes back – and the NCOP removes clause 42		
5.6 The last stand in the National Assembly		
Mobilising the sector		
1410011131115 tile 300tol	رد	

	Lobbying phone calls to MPs	35
	Using the media, articles, letters, and investigations	35
	How the clause was won	36
5.7 Sun	nmary	36
6. Evalu	uation of impact	37
6.1 Eval	luation framework	37
6.2 Sec	ondary objectives	37
	Promoting the participation of the children's sector in the writing of the Children's Bill	37
	Characterising the major challenges facing children	38
	Promoting the use of evidence in the decision-making process	39
	Using a co-ordinated approach	39
6.3 Prin	nary objectives	39
	Promoting the incorporation and expansion of constitutional rights in the Bill	39
	Proposing legislative provisions that could be incorporated into the Bill to help address the major challenges facing children	40
	Recommendations not included in the Children's Act	44
6.4 Sec	ondary benefits	45
7. Esser	ntial ingredients – what is in the mix?	46
7.1 A cc	o-ordinated campaign with a central hub	46
	Expert support from the Children's Institute	46
	Being part of a larger campaign	48
	Common messages emphasise points	49
	The importance of a unified stance	49
7.2 Esse	ential ingredients in the sub-group campaign	49
8. Conc	lusion	55
Append	lix A: Analysis of recommendations adopted by other organisations	57
Appendix B: Analysis of Children's rights in the Children's Act		
Append	lix C: List of the Children's Bill Working Group Members	61
Referer	nces	62

Abbreviations and acronyms

ACESS Alliance for Children's Entitlement to Social Security
African Charter African Charter on the Rights and Welfare of the Child

ANC African National Congress
CBO Community-Based Organisation

CI Children's Institute

CRC United Nations Convention on the Rights of the Child

CSO Civil Society Organisation

DART Disability Action Research Team
DICAG Disabled Children's Action Group
DPO Disabled People's Organisation
DPSA Disabled People South Africa

DTT Disability Task Team

ECD Early Childhood Development ELRU Early Learning Resources Unit

GCA Gun Control Alliance

INDS Integrated National Disability Strategy
JCWS Johannesburg Child Welfare Society

MP Member of Parliament
NA National Assembly

NACCW National Association of Child Care Workers

NCOP National Council of Provinces

NCPPD National Council of Persons with Physical Disabilities

NGO Non-Governmental Organisation
NPF National Policy Framework
NYC National Youth Commission

OSDP Office on the Status of Disabled Persons

PMG Parliamentary Monitoring Group

RAPCAN Resources Aimed at the Prevention for Child Abuse and

Neglect

SAFCD South African Federal Council on Disability
SAHRC South African Human Rights Commission
SALRC South African Law Reform Commission

SAPS South African Police Services

SASPCAN South African Society for Prevention of Abuse and Neglect

WG (Children's Bill) Working Group

Introduction

Civil society in South Africa has organised itself into various structures to campaign for changes to laws. These structures range from small groups of policy experts to large and empowered social movements. In 2003, the draft Children's Bill was presented to Cabinet, split into two Bills due to parliamentary procedural requirements, and thereafter tabled in Parliament. The two Bills would eventually repeal the Child Care Act of 1983 and introduce a new child care and protection system for South Africa, namely the Children's Act No. 38 of 2005, as amended by the Children's Amendment Act No. 41 of 2007. Civil society organisations (CSOs) in the children's sector recognised the Bill as a potential vehicle for addressing the complex challenges facing children in South Africa and therefore wanted to exercise their constitutional right to participate in, and ultimately influence, the law-making process.

Leaders in the children's sector realised that a co-ordinated campaign was essential due to the size of the Bill, the breadth of topics that it covered, and the extent of the reforms it proposed. In 2002, the Children's Institute (CI) secured funds to establish such a campaign. Along with Resources Aimed at the Prevention of Child Abuse and Neglect (RAPCAN), it convened a workshop in 2003 to plan the undertaking and, at a subsequent workshop, the Children's Bill Working Group (WG) came into being — a loose coalition of children's sector networks and CSOs wishing to ensure that the Children's Bill would be passed in the best possible form.

The vision was that the Bill would provide the legislative framework necessary for realising children's rights in terms of South Africa's international and constitutional obligations and would offer solutions to the challenges facing children in a society marked by high levels of poverty, HIV/AIDS and violence.

To realise this vision, the project proposal made it the WG's objectives to:

- promote the incorporation and expansion of children's constitutional rights in the new law;
- characterise the major challenges facing children and propose legislative provisions that could be incorporated into the new law to help address these challenges;
- promote the participation of the children's sector in the law-making process; and
- promote the use of evidence in the decision-making process.

To achieve these objectives, the project proposal described a methodology based on research, consultation, and dialogue between CSOs and government decision-makers. As the Bill addressed so many topics, with several of them requiring specialised knowledge, the WG was divided into sub-groups each responsible for a mini-campaign to effect law reform in its area of specialisation.

Some of the sub-groups stood out as success stories in terms of their participation and impact on the final law. One such success story, in the campaign on the first Children's Bill,

¹ At the time of writing the Act had not been put into force in its entirety. Commencement is expected in early 2010.

was the Disability sub-group known as the "Disability Task Team" (DTT). Issues affecting children with disabilities are often marginalised or given inadequate consideration by law-makers. The DTT aimed to change this situation and, according to Dorothy-Ann Howitson, NCPPD, have "disability taken seriously" in the Children's Bill process.

With the support of the CI and the WG, the backing of the major disability sector networks, and the efforts of MPs active in the disability caucus in Parliament, the DTT managed to secure new clauses in the Children's Act that will make a genuine difference to the lives of children with disabilities, a success going far beyond what the disability sector originally expected.

The purpose of this paper is to document the DTT's advocacy initiatives around the first Children's Bill and to analyse the factors contributing to its success; the analysis allows us to describe a methodology that can be replicated in future civil society law-reform campaigns. Throughout the Working Group's collective Children's Bill campaign, the CI recorded and evaluated the model of law-reform advocacy it was developing. Researchers held interviews and gathered other forms of evidence to support both strategic as well as retrospective evaluations of the campaign's methodology. This case study is one of the research outputs.

The first evaluation was conducted at the end of 2004 following initial public hearings on the Children's Bill in the National Assembly. Working Group members were interviewed about the first phase of the campaign, the public hearings, and what they had learned through their involvement in the WG. In this instance, seven interviews were held. In May 2005, at the end of National Assembly deliberations on the first Children's Bill, a more extensive evaluation took place, and it included a purposive sample of 30 structured interviews with role-players who ranged from WG members and executive officials to Members of Parliament (MPs) and parliamentary staff.

One of the early findings was that the model of sub-group organisation had worked well in certain aspects of the campaign. The CI decided to explore the finding in depth, and, in view of the Disability Task Team's notable successes, proceeded to examine this sub-campaign to identify the ingredients of its winning recipe.

In 2006, a field worker conducted 10 semi-structured interviews with members of the DTT, MPs and civil society stakeholders in the disability sector; earlier interviews with the DTT member July Nkutha were also incorporated into the evaluation. To record the DTT's methodology, the first author reviewed a variety of documents produced by both the WG and DTT. In addition, each DTT member wrote a report of his or her experience of particular facets of the campaign.

To evaluate the impact of the advocacy, amendments in the Bill were compared with reforms which the DTT had recommended. But demonstrating that changes to the Bill correspond to the DTT's own recommendations does not necessarily prove causality. To assess the linkages between actions that had been taken and the impact these might have had on the Bill, researchers asked government officials to identify what had influenced particular decisions of theirs. Moreover, all of the WG respondents were invited to specify

the "ingredients" of successful advocacy. By examining campaign records, the authors were able to see if changes to the Bill were made at the time when these specified activities were taking place.

This procedure enabled us to refine the recipe for successful advocacy into a list of "essential ingredients". In turn, the lessons learned were applied by other sub-groups in the latter half of the campaign, in particular the sub-campaign run by the street-children sector in 2006 and 2007 on the second Children's Bill.

Section one outlines the key rights of children with disabilities, the related obligations on the State under international law and the Constitution, and the major laws and policies aimed at giving effect to these rights. The section concludes by delineating pivotal stakeholders in the disability sector and by analysing the sector's capacity to campaign for change as it was when the Children's Bill process began in 2004.

Section two describes the WG, its structure, objectives, advocacy methodology, and the sub-group model. In particular, the section describes the DTT's mode of operation.

Section three elaborates on the preparatory work that the DTT did. The initial consultations between the WG and members of the Disabled Children's Action Group (DICAG) sought to identify key challenges confronting children with disabilities, a dialogue that was broadened to address the disability sector at large. The section describes the methods the WG and DTT used to facilitate these consultations, and ends by summarising the recommendations for law reform which emerged from the process.

Section four outlines the DTT's advocacy activities during the parliamentary deliberations on the Bill. The activities started in July 2004, with preparations for the National Assembly public hearings, and continued until December 2005, when the Bill, including amendments in response to most of the DDT's recommendations, was passed by Parliament.

Section five concentrates on one of the clauses that evoked controversy. The DTT had persuaded the parliamentary portfolio committee to insert a sub-clause in the Bill that would allow children with disabilities to have access to children's court inquiries. This section tells the story of how Parliament – strengthened by a vigilant civil society campaign – stood its ground against the Deputy Minister of Justice who wanted to have the clause removed.

Section six examines the impact of the DTT's campaign. It demonstrates their success by a comparative analysis of the Bill as it was tabled in Parliament, the DTT's recommendations, and the amended Bill enacted into law. Interviews with roleplayers show the causal linkages between the DTT's actions and the final shape of the Bill.

Section seven brings into relief a list of "essential ingredients" that contributed to the success of the DTT as well as that of several other sub-groups.

Section eight presents several general conclusions about law-reform advocacy.

1. Background

Government is bound by international and constitutional law to give effect to children's rights, including the rights of children with disabilities. To fulfil these obligations, the State needs to adopt a range of policies, laws and programmes. Prior to the Children's Bill, the key legislative and policy measures that sought to do this were the Integrated National Disability Strategy and the Promotion of Equality and Prevention of Unfair Discrimination Act. The former envisages "a society for all" that recognises diversity and emphasises the development of human potential; the latter gives individual people with disabilities legal remedy against discrimination, but it does not absolve the State of its own obligations to pursue substantive equality. At the level of service delivery, children with disabilities continued to face multiple violations of their human rights. The Children's Bill held the potential to address many of these gaps, and the disability sector mobilised to seize the potential. A strong disability caucus inside Parliament offered increased opportunity for reform; however, the collapse of the disability sector's national body made the challenge of mobilising the sector more difficult.

1.1 The legal framework in relation to children with disabilities

International law²

South Africa has ratified the United Nations Convention on the Rights of the Child (CRC)³ and the African Charter on the Rights and Welfare of the Child (African Charter)⁴. Ratification demonstrates its political and legal commitment to give effect to the rights and obligations contained in these instruments.

Article 23 of the CRC addresses the specific rights of children with disabilities.

- Sub-article 1 reads: "State Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community."
- Sub-article 2 recognises the right of children with disabilities to special care and appropriate assistance.
- Sub-article 3 provides for free assistance, where possible, to ensure that children with disabilities can access general services including education, training, and health care, "in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development". A similar provision is contained in the African Charter under article 13, which also compels governments to ensure the physical accessibility of buildings and highways, subject to available resources.

² This section looks at the legal framework when Parliament was considering the Children's Bill. The UN Convention on the Rights of Persons with Disabilities was not ratified by Parliament until 2007.

⁴ Organisation for African Unity (1990) African Charter on the Rights and Welfare of the Child. OAU Doc. CAB/LEG/24.9/49.

³ Office of the High Commissioner of Human Rights (1989) Convention on the Rights of the Child, UN Assembly Resolution 44/25.

Rights for all children, but of relevance to children with disabilities, include the rights:

- to protection from discrimination;⁵
- to freedom of expression and the right to participate in decisions that affect them, with specific reference to judicial proceedings;⁶ and,
- to protection against harmful social and cultural practices.⁷

A general principle in international law is that the child's best interests should be the primary consideration in all matters affecting the child.

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the United Nations General Assembly, emphasise that States should ensure that disability aspects are included in all relevant policy-making and national planning. States have financial responsibility for adopting national programmes and measures to create equal opportunities for persons with disabilities. States also have the responsibility to create the legal basis aimed at achieving the objectives of full participation and equality of persons with disabilities. Disability matters should be included within mainstream legislation dealing with particular topics, such as children. 11

The United Nations Committee on Economic, Social and Cultural Rights issued a General Comment on Disability, underlining the importance of addressing disability explicitly and stating that the rights of persons with disabilities must be protected and promoted through general as well as specifically designed laws, policies and programmes.¹² In addition, the UN Committee adopted a resolution on Children with Disabilities which recognises that special attention should be directed towards children with disabilities and their families.¹³

South Africa has an obligation to incorporate the international law provisions into domestic legislation, including legislation that deals with the care and protection of children, such as the Children's Bill.

The South African Constitution

The Constitution embodies the government's commitment to promote, protect and fulfil the rights of all people in South Africa. The Preamble of the Constitution indicates that its intention is to: "... [h]eal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights; ... [and i]mprove the quality of life of all citizens and free the potential of each person; ..."¹⁴

⁵ Article 2 (CRC), and article 3 (African Charter).

⁶ Article 12 (CRC) and article 4 (2) (African Charter).

⁷ Article 23(1) (CRC).

 $^{^{\}rm 8}$ A/RES/ 48/ 96/, 85th Plenary Meeting, 20 December 1993.

⁹ Rule 14.

¹⁰ Rule 16.

¹¹ Rule 15(3)(b).

¹² UN Committee on Economic Social and Cultural Rights, General Comment 5, HRI/GEN/1/Rev.2: 66.

 $^{^{13}}$ Resolution 1997/ 20 adopted at the 36th plenary meeting on 21 July 1997.

¹⁴ Constitution of the Republic of South Africa Act No. 108 of 1996.

The Bill of Rights enshrines an array of fundamental rights and freedoms to ensure that this vision is fulfilled. Some are especially pertinent to children with disabilities. The first is the right to equality, which is continually denied to most disabled people. Section 9 states that "(1) Everyone is equal before the law and has the right to equal protection and benefit of the law" and "(3) [t]he state may not unfairly discriminate … against anyone on one or more grounds, including … disability …"

The Constitution also states that everyone has the right to dignity¹⁵ and to basic education¹⁶.

Section 28 gives all children special protection by applying the best interests principle¹⁷ and gives children additional rights:

- to family care or parental care, or appropriate alternative care; 18
- to basic nutrition, shelter, basic health care services and social services; ¹⁹ and
- to be protected from maltreatment, neglect, abuse or degradation.²⁰

Government is obliged by section 7(2) to give effect to all the rights in the Bill of Rights, including children's rights and the right of children with disabilities to equality. To fulfil these rights, government has to adopt disability-specific policies and programmes; but, more importantly, it needs to mainstream the needs of children with disabilities into all policies and laws affecting services for children.

The Integrated National Disability Strategy

When the government adopted the White Paper on an Integrated National Disability Strategy (INDS) in 1997, it signalled a new approach to dealing with disability. The INDS is based on the Constitution and the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities. It is premised on the social model of disability, one which sees many of the difficulties of disabled people as the result less of their impairments than of the barriers excluding them from society.

The vision of the INDS is "a society for all", a concept which recognises human diversity and emphasises the development of all human potential. This can be achieved only through the integration of disability issues in all government strategies, planning and programmes, and it requires a co-ordinated management system operational at all levels of government. The Office on the Status of Disabled Persons (OSDP) was established to co-ordinate and monitor the implementation of the INDS. The intention was that it would work in conjunction with state bodies and departments as well as maintain links with the non-governmental organisation (NGO) sector.

¹⁶ Section 29.

¹⁵ Section 10.

¹⁷ Section 28(2).

¹⁸ Section 28(1)(b).

¹⁹ Section 28(1)(c).

²⁰ Section 28(1)(d).

Promotion of Equality and Prevention of Unfair Discrimination Act

Section 9(4) of the Constitution obliges the State to enact national legislation to "prevent or prohibit unfair discrimination". In 2000, the State enacted the Promotion of Equality and Prevention of Unfair Discrimination Act²¹ which promotes equality in respect of race, gender and disability, and prohibits unfair discrimination on the grounds of disability.

Where such discrimination occurs, the Act provides a mechanism for people with disabilities to challenge it through the courts. It does not, however, absolve the State of its obligations to ensure that its policies, legislation and actions take adequate account of the needs of people with disabilities and promote the attainment of substantive equality.

1.2 Challenges faced by children with disabilities and chronic illnesses

"Disability" results from the interaction between persons with impairments and the attitudinal and environmental barriers hindering their full and equal participation in society. By adapting physical spaces, providing assistive devices or training people that work with children, these barriers can be removed and enabling environments created for children with disabilities to achieve participation.

Children with disabilities or chronic illness need considerable support, particularly in their early years. Not only do they require specialist services related to disability or illness, but also general services such as health promotion and early childhood development (ECD). Little has been done to provide such support, and children with disabilities have faced years of systematic exclusion. They have a constitutional right to social welfare services, but these services are currently not inclusive, in the sense of their being oriented towards "disabled children having their needs met and their rights protected in an adapting society" (Save the Children UK, 2000).

Many disabilities can be prevented by good care in the early years if social services take greater cognisance of the need to prevent disabilities. Moreover, children with disabilities are extremely vulnerable to abuse, neglect and maltreatment, often because parents lack support and do not know how to address their children's special needs. No funding or training is currently available for organisations that provide support to families or for community-based services to ensure that children with disabilities receive appropriate rehabilitation in the home context. Most support comes through centre-based ECD, but few centres have the willingness and capacity to cater for children with disabilities.

Children with physical disabilities are 3-4 times more likely to be abused than able-bodied children (Lamprecht, 2003). A comparative analysis (Dhai, 2003) showed that intellectual disabilities are 3-8 times more common in abused than in non-abused children. Despite this evidence of need, there is an acute lack of protection services for children with disabilities.

²¹ Promotion of Equality and Prevention of Unfair Discrimination Act No. 4 of 2000.

When a child has been abused or for any other reason cannot remain safely in the family, a children's court must decide if the child is in need of care and protection. However, many courts are physically inaccessible for children with mobility impairments.²² Courtroom layout is not always child-friendly and court personnel not all trained to be sensitive to children's needs. Vulnerable children consequently feel threatened, which in turn undermines their ability to participate in the proceedings. In addition, should the court find that the child is in need of care and protection, there are few children's homes or places of safety with physical environments that are accessible or with staff who are properly trained to cater for the needs of a child with disabilities.

Children with disabilities face exclusion from mainstream services if their specific needs and requirements are not considered in policy and law reform. Such institutional discrimination leads to multiple infringements of their human rights at the level of service delivery. These gaps in the social welfare system mean that many children with disabilities get no protection, sub-standard protection, or, worse still, find themselves subject to secondary abuse.

1.3 The potential of the Children's Bill to address these challenges

In 1997, the Minister of Social Development requested that the South African Law Reform Commission (SALRC) investigate the Child Care Act No. 74 of 1983, the apartheid-era legislation that governed social services for children. The SALRC was asked to recommend reforms that accorded with the new Constitution and the international instruments that the country had signed. In 2003, it finalised its report and proposed a draft Children's Bill, which in several respects held the potential to address the challenges of children with disabilities.

First, the objectives stressed the need to protect children from discrimination, and the Bill included "significant new proposals to address lacunas in the present situation including specific provision for the participation of children in matters affecting them". These objectives provided an opportunity to guarantee access to universal services; the participation element not only fulfilled a right, but ensured that children could articulate their own needs when decisions affecting them were made.

Second, the draft Bill was based on a developmental model of social services. It contained a range of primary preventive measures to promote the care of children in their own families and communities; early intervention mechanisms and services to offer support to children and families at risk; and a system to protect abused children from further harm and provide for their healing to break the cycle of abuse. This rebalancing of the system away from a residual model would be in the best interests of children with disabilities and their families.

Third, the draft Bill defined children with disabilities as "children in especially difficult circumstances" and required the State to devise strategies for giving special assistance to

²² The exact number of physically accessible courts has not been documented.

⁻

²³ South African Law Reform Commission (2003) *Memorandum on the Objects of the Children's Bill*: 3.

children with disabilities and their families.²⁴ In effect, these measures would serve to create an enabling environment for such children.

The Children's Bill had potential; but if it were to be translated into real change, it was vital for the disability sector to respond to the draft legislation and ensure that the Bill's provisions fulfilled its objectives.

1.4 Key stakeholders in the disability sector

This section draws on an extract from a report by Sue Philpott (2006a), the DTT coordinator. The extract delineates the stakeholders in the disability sector and analyses the sector's capacity to campaign for change as it was at the start of the Children's Bill process in 2004.

Disabled People South Africa (DPSA) was aligned with the liberation struggle. When the African National Congress (ANC) came into power in 1994, DPSA members were appointed to key government positions and placed on the ANC lists for Parliament. Along with members of opposition parties, they form the disability caucus in Parliament; and played a pivotal role in deliberations concerning the Children's Bill.

The South African Federal Council on Disability (SAFCD) was the umbrella body for key national organisations in the sector, but with the closure of its national office in mid-2004, it was little more than a networking list during the campaign. Lack of capacity at this level made it extremely difficult for the sector to plan and implement joint action.

The Disabled Children's Action Group (DICAG), a SAFCD member with close links to DPSA, is a disability rights organisation run and managed by parents of children with disabilities. It also has links with impairment-specific groups working with children. In broad terms, DICAG's membership tends to be black, with many parents coming from poor rural communities or townships. By contrast, the impairment-specific organisations tend to focus on middle-class communities.

The sector's key issues were that activists "stolen" for government positions had left a gap in leadership and at times created conflicts of interest. Moreover, during preparations for the public hearings and parliamentary deliberations, there was a need for a co-ordinating body to consult with the sector, find consensus on key issues and facilitate action. This was precisely the time when the national civil society umbrella structure was collapsing and resources were running out, leaving a disparate sector without a co-ordinating body.

In this environment, there was clearly a need for members of the disability sector concerned with children's rights to get together to co-ordinate their advocacy on the Children's Bill.

children."

²⁴ Section 232(1) of the SALRC Bill made provision for strategies aimed at: "(iv) 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; (v) empowering parents or caregivers 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

2. Description of the Children's Bill Working Group and the Disability Task Team (DTT)

Since the DTT's campaign was a sub-campaign of the Children's Bill Working Group (WG), it is necessary to describe the broader structure of which it was a part before providing an account of how the sub-campaign itself was structured.

2.1 The Children's Bill campaign and WG

Establishment and structure of the WG

In 2002, a group of children's sector representatives identified the need for a campaign on the Children's Bill, which was about to begin its journey through Cabinet and Parliament. The SALRC draft bill was generally welcomed, but representatives were concerned that cost implications would see it diluted, and that it did not respond adequately to the particular needs of marginalised children such as those affected by HIV/AIDS, foreign children, and children with disabilities.

The draft had 26 chapters²⁵ and covered a range of critically important issues. These included parental rights and responsibilities, primary prevention of abuse and neglect, protection from abuse and neglect, children's courts, ECD, child and youth care centres, foster care, adoption, trafficking, social security and street-child shelters. The Bill spanned numerous "sub-sectors" in the children's sector; no single organisation could spearhead such a campaign. Not only were the topics large and disparate, but most CSOs did not individually possess the resources for a successful law-reform advocacy campaign, a situation compounded in the case of CSOs representing especially marginalised groups of children. Public participation in law-making processes is more than a constitutional imperative. Children's sector CSOs also happen to be the "workforce" that would be responsible for implementing many of the services regulated by the final Act. Their knowledge and expertise was essential to ensure that the final law was effective.

Leaders from keys CSOs decided that the best results would be achieved by way of combined effort co-ordinated by a central body. The Children's Institute (CI) sought and received funding for this purpose, and in January 2003, the CI and RAPCAN hosted a workshop to plan the campaign. At follow-up workshop, attended by 100 sectoral representatives, the Children's Bill Working Group was established. About 35 major children's sector networks and organisations signed up; more joined as the campaign developed (see Appendix C). The WG convened approximately twice a year to discuss policy positions, draft responses to current debates, and to strategise on engaging with decision-makers.

The majority of members were from national umbrella organisations representing subsectors within the children's sector, with each being expected to cascade information and advocacy tasks to their members to maximise participation across the country and ensure

_

²⁵ The Children's Act No. 38 of 2005 contains 22 chapters; three were excised by Cabinet, one by Parliament.

that the WG's impact extended far and wide. The WG adopted features of the advocacy model used by the Gun Control Alliance (GCA) during the passage of the Firearms Control Act in 2002, notably the practice of supporting people to speak for themselves in dealing with officials and MPs rather than to rely solely on lawyers and parliamentary lobbyists.

The requirements of establishing an organisation to serve as the co-ordinating hub can divert attention from its mission. A conscious decision was made not to form a new organisation but to harness resources within umbrella organisations, social movements and academic institutions towards a short-term, common goal – the passage of the Children's Bill. The approach necessitated that one organisation – the CI – served as the temporary "lead organisation" for the campaign.

The CI's responsibilities included managing fundraising and expenditure, providing administrative support for workshops and consultation opportunities, and acting as an information hub. Due to the specialist political and legal skills and experience of the staff involved, the CI was also able to provide monitoring of and reporting on parliamentary and executive processes, legal advice, political strategic direction, and advocacy guidance.

At the centre of the WG was a secretariat providing children's sector leadership and strategic guidance. It consisted of CI staff skilled in child rights and law-reform campaigns as well as senior representatives from CSOs well-versed in child care and protection services.²⁶

Due to the range of topics covered by the Bill, the WG was divided into sub-groups to enable specialisation according to topic (see Figure 1 on the next page). WG members formed the core of each sub-group but were also joined by other sectoral representatives. The diagram below shows the sub-groups selected by the WG as priority issues for advocacy activity during 2004 and 2005. The sub-groups were again restructured in March 2006 to reflect the new priorities in the second Bill.

Each sub-group was responsible for running a mini-campaign to ensure appropriate law reform in their area of specialisation. Sometimes, but not always, the sub-group was led by the umbrella body that already existed to champion that topic. Some of the sub-groups ensured maximum participation of a broad range of CSOs (e.g. street children, disability, HIV/AIDS, corporal punishment) while others functioned more as expert groupings (e.g. parental rights and responsibilities). Both models achieved successes.

-

²⁶ The secretariat consisted of Jackie Loffell (2002 – 2008) and Carol Bower (2002 – 2008) from the South African Society for the Prevention of Child Abuse and Neglect (SASPCAN), Joan van Niekerk (2002 – 2008) from Childline SA, Zeni Thumbadoo (2006 – 2008) from the National Association of Child and Youth Care Workers (NACCW), and Paula Proudlock (2002 – 2008) and Lucy Jamieson (2005 – 2008) from the CI, UCT.

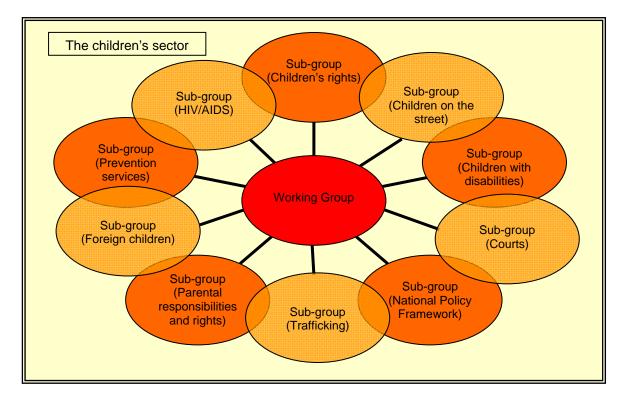


Figure 1: The structure of the Children's Bill Working Group (2003 to 2005)

Objectives of the campaign and basic methodology

The WG's objectives can be split into primary and secondary categories.

Primary objectives:

- to promote the incorporation and expansion of children's constitutional rights in the Bill; and
- to propose provisions that could be incorporated into the Bill to help address the major challenges facing children.

Secondary objectives:

- to characterise the challenges facing children;
- to promote the children's sector's participation in writing the Bill;
- to promote the use of evidence in the decision-making process; and
- to use a co-ordinated approach. 27

The underlying aim of the primary objectives was to influence the Bill's content. In the case of the secondary objectives, it was to enrich the law-reform process and enhance the success of the advocacy. Maximising participation was both a principled objective and a means to an end. It would fulfil a basic democratic right, in keeping with the value the

²⁷ "Use a co-ordinated approach" was not expressly listed as an objective in the funding proposal, but it is referred to continuously throughout the WG documentation as a central pillar of the methodology; therefore we have included it as a secondary objective.

Constitution places on civic participation in law-making and public administration,²⁸ and the best interests of the child would be served if people working directly with children were able to advise decision-makers about challenges facing children and ways to resolve them.

Working Group methodology

The methodology put forward to achieve these aims was based on the experience of previous law-reform campaigns, the Gun control Alliance (GCA) in particular, and evidence drawn from evaluations of them: "We did not propose to set up a large alliance or a new structure, but rather to facilitate a co-ordinated response from the children's sector through providing opportunities for discussions between organizations, for formulating common messages, discussing areas of difference, and co-ordinating submissions and advocacy initiatives." (Proudlock, 2005: 6)

The existing communications and advocacy networks of each member umbrella organisation were utilised, and each organisation was encouraged to invest resources in the campaign. The joint effort also meant that it was possible to provide a central co-ordinating structure to raise and administer funds, facilitate debate by bringing people together in common spaces, act as an information hub, and offer experienced leadership. Central funding was key to bringing people together to debate issues and to paying for them to get to parliamentary hearings. It also meant that expert time could be bought to assist organisations in the way of legal and technical support, political guidance, and a continuous presence at Parliament that monitored and analysed the debate.

The WG's core activities were:

- Making decision-makers aware of children's rights, and the State's related obligations
 Research was conducted on the State's obligation in relation to children's constitutional
 right to social services.²⁹ It was used to support arguments that the Bill's founding
 provisions had to make express reference to this and related rights. In addition, the
 research was constantly taken as a benchmark for assessing the Bill's substantive
 provisions.
- Charactering the challenges facing children
 It was important to understand children's needs and the relevant service delivery challenges before determining how the Bill should be amended. Characterising the challenges for the benefit of MPs and officials promoted informed decision-making.
- Proposing legislative solutions
 Solutions were proposed, explained, and followed by suggested legal text amendments that could be inserted into the Bill unambiguously.

²⁹ The research started in 2004 and was used throughout the process. It was published as a working paper in mid-2006. See: Dutschke M, 2006.

²⁸ Sections 59(1) and 72(1) oblige Parliament to facilitate public participation in its legislative processes; section 195(1)(e) provides that "[p]eople's needs must be responded to, and the public must be encouraged to participate in policy-making".

• Gathering evidence through consultation

WG members were encouraged to shape and test arguments against research and evidence. Each sub-group was asked for a technical submission as a well as a practical case study. The WG was thus able to present leading academic evidence alongside the experiential evidence of children, parents and practitioners. This helped decision-makers grasp the recommended reforms and relate them to their own constituencies.

• Demonstrating broad-based support for proposed recommendations

Gaining broad-based support for a proposal meant extensive consultation within and between sub-sectors. Sub-groups each produced initial discussion papers describing challenges and proposing solutions. The papers were circulated, and organisations were encouraged to use them in workshops on the Bill. After a first round of discussion, draft submissions were prepared and again circulated for comment before being finalised. Broad-based support was demonstrated through endorsements to the sub-groups' submissions, by ensuring that many presenters from different organisations addressed parliamentary committees, and by members repeating each other's messages in submissions.

Developing a co-ordinated strategy

Workshops enabled the WG to identify common messages and address points of contention before engaging with decision-makers. They made for a united front, and having common messages repeated by WG members gave them a better chance of being considered.

Tracking the debate

Having a children's sector representative in the parliamentary committee room who knows what to listen for and how to analyse the debate meant that each sub-group was sent relevant information and guidance — often instantaneously, which allowed remote-location members to contribute immediately to the debate by way of sms or calls to MPs. More detailed summaries (Progress Updates) with legal analysis and political strategy suggestions were sent regularly to the WG mailing list, and were cascaded by the networks to their constituencies.

2.2 The Disability Task Team

Mandate

After identifying the need for a disability sub-group of the WG, the CI approached Sue Philpott from the Disability Action Research Team (DART) to co-ordinate the sub-group. Sue sought a mandate from the leading children's sector disability network, DICAG. The DICAG executive consulted and mandated Sue and Sandra Ambrose (a DICAG staff member) to represent DICAG on the Children's Bill WG. Through DICAG, the DTT was in turn linked to the South African Federal Council on Disability (SAFCD).

Composition

The team combined a range of skills, expertise and experience. Sue Philpott was a disability policy analyst from KwaZulu-Natal. Sandra Ambrose was DICAG's provincial co-ordinator in the Western Cape. Other members were July Nkutha, a DICAG member and community worker in Mpumalanga, and Nonceba Meyiwa, a Gauteng activist and DICAG member. The latter three are parents of children with disabilities: their personal experiences were a constant source of motivation.

Children's Institute staff were *ex-officio* members of all sub-groups. Paula Proudlock was the link person for the DTT during the preparation and early parliamentary advocacy phase in 2004, and Lucy Jamieson took the lead role from 2005 onwards. Petronella Linders, National Youth Commissioner, provided additional content input as well as invaluable guidance.

Linkages with the disability sector

As discussed earlier, SAFCD did not have capacity to co-ordinate the advocacy campaign. In order to maximise input from the disability sector, a three-fold strategy was employed (Philpott, 2006a). First, the SAFCD chairperson was kept informed of progress and asked to forward correspondence to her network. Second, a discussion paper was circulated to the WG and disability sector and their comments used as the basis of the draft and final submissions. Third, specific disability organisations were approached for input on submissions.

Linkages with the Children's Institute

The CI gave administrative and politico-legal support that included:

- organising and facilitating content workshops;
- attending parliamentary committee meetings to brief and advise the DTT;
- helping with advocacy strategies;
- compiling profiles and contact details of MPs to enable the DTT to engage with them;
- identifying specific MPs to target on all parliamentary committees that had a stake in the Bill:
- providing tips on how to lobby MPs as well as encouragement and support;
- writing action briefs;
- reviewing submissions and recommending changes; and
- drafting press releases and letters to MPs.

A critical function of the Children's Institute was to facilitate debate through workshops, and to ensure rigorous preparation for the parliamentary submissions.

They would get us together and they would run workshops, ... follow up, go through the things again over and over; go and do this, come back again, tell me what it is that you understand, tell me what it is that you want; they were very supportive.

Interview 16, Sandra Ambrose, DICAG, 2006

3. Preparation and consultation

3.1 Joining the broader campaign and understanding the Children's Bill

The WG meetings were not only platforms for organisations to discuss the Bill. Given that some members had been on the SALRC committee that drafted the Children's Bill and had important insights to share, the meetings allowed the DTT to form a thorough understanding of the legislative text and its potential impact. They also furnished networking opportunities for the DTT to influence other sub-groups into taking disability issues aboard their own input on ECD, child and youth care centres, and so on.

3.2 Consultation within DICAG

Making legislation accessible and identifying the challenges

Legislation is written in complex terminology and it needs to be translated if people without a legal background were to understand it. The DTT co-ordinator compiled a discussion document and a series of fact sheets explaining the Bill, identifying gaps, and suggesting amendments. In developing these documents, the DTT maintained regular communication with members, circulating drafts by e-mail and discussing them in teleconferences. Moreover, people in the disability sector were encouraged to reflect openly on their own experiences and relate them to the Bill. The DTT used the DICAG structures to educate the sector about the Bill. DICAG works in all nine provinces and each province has branches running parental support groups:

As a sub-group we began with fact sheets, and invited parents and organisations to send real stories or real issues, and gained real experience from the areas. These were consolidated into our submission, and we talked to parents about their direct experiences, and that was how we were able to identify the challenges.

Interview 15, July Nkutha, DICAG, 2005

Gathering evidence, research and case study materials

Having identified challenges, the next step was to write a draft submission. Sue Philpott had researched disability issues for a long time and could draw on her wealth of material and contacts. This empirical research was tested by being compared to the lived experience of practitioners and parents. For the draft submission, DICAG members were consulted by running workshops for provincial co-ordinators and appointing provincial representatives to co-ordinate consultation within each province. The provincial coordinators also worked at grassroots level to identify case studies that supported the arguments in the submission:

What we've done is... we've gone to our different day-care centres. We had one-to-one interviews with parents and they would tell us their stories.

Interview 16, Sandra Ambrose, DICAG, 2006

Since one of the campaign objectives was to ensure that children took part in the debate, DICAG ran child-participation workshops in the Western Cape, Gauteng and Mpumalanga,

using a child-friendly version of the Bill developed by the CI (Proudlock, Nicholson & Dyason, 2004).

3.3 Encouraging the participation of a wide range of disability sector stakeholders

Effective consultation is not about speaking to as many people as possible, but rather about canvassing opinions from a range of people: experts, professionals and affected persons. The support of the sector was important for showing that the proposed amendments were valid, and demonstrating broad-based support for them underlined their credibility:

DPSA, Down Syndrome, Epilepsy, all those organisations had to give in their input; in fact it was necessary to give credibility to the whole issue, it's not about DICAG only; it's for the whole of the country, for South Africa as a whole.

Interview 17, Nonceba Meyiwa, DICAG, 2006

E-mail networks and key individuals

The fact sheets and draft submission were also circulated to the SAFCD network. It was not possible to convene representatives regularly from all corners of the country, and telephone calls and e-mails were targeted at key roleplayers who were able to facilitate discussions and spread the word. It was important to make someone accountable for a response.

Using existing networks enabled extensive distribution, but information had to be adapted to make it pertinent to users. This saw the DTT co-ordinator editing general information for relevance before e-mailing the sector. The SAFCD chairperson would disseminate the information, asking the network to feed back directly to the DTT; occasionally the DTT liaised directly with individual organisations. Stakeholders reported that they were updated by way of e-mails and calls from the DTT and CI, as well as by news reports from a media monitoring project.³⁰

Workshops and conferences

The DTT used every opportunity for advocacy and education. Team teleconferences would identify openings for presentations at workshops and conferences, and sometimes members took impromptu advantage of situations:

I was attending [the] provincial plan of action for children, and the lady there attempted to address the gathering on the current events on the Children's Bill and she was distorting the information there. So I had to come in and correct the information she was telling them.

Interview 17, Nonceba Meyiwa, DICAG, 2006

-

³⁰ The late Ilse Langenhoven of the University of Pretoria monitored the media for stories about people with disabilities.

3.4 Winning support from other sectors

All materials were distributed to the disability sector for comment. Whenever the DTT attended a workshop, they added the participants (and their contacts) to their distribution list. Submissions were sent to both the WG network and this extended list. In the case of the final submission, it was sent to WG members and disability sector organisations and endorsed by SAFCD, Cape Mental Health, the Johannesburg Child Welfare Society, Molo Songololo, Autism South Africa, and Epilepsy South Africa.

Part of the WG's strategy involved repeating the same messages in submissions by different organisations. WG meetings gave the DTT opportunities to do secondary lobbying by asking other sub-groups to incorporate DTT recommendations into their own submissions:

We had what we called a twin-track approach ... we stood in every other sector [i.e. sub-groups] like ECD, child protection, and we wanted those sectors to also understand that they have to address issues of disability. It wasn't just our subgroup's responsibility. So we're working at both levels as a specific issue and also integrating the issue into every other sub-group.

Interview 18, Sue Philpott, DART, 2006

This advocacy strategy worked well. Other sub-groups were sensitised about disability issues, and 16 organisations included disability-related recommendations in their submissions (see Appendix A for a complete list and analysis). In particular, the Community Law Centre and the Johannesburg Child Welfare Society incorporated disability in their communication outputs, including presentations at a policy workshop. They also joined the DTT in their call to reject an amendment to clause 42 of the Bill by the National Council of Provinces (see Section 5).

3.5. DICAG's final recommendations for amendments

The DTT redrafted the submission and distributed it for comment. Seeing that there was little reply to its e-mail prompts, the DTT called key individuals by telephone, a change of tack which improved the level of response. Comments were incorporated and the submission checked by the CI for their consistency with international instruments. Advocate Ann Skelton of the Centre for Child Law, University of Pretoria, was commissioned to assist in formulating certain amendments. The DTT prepared the submission from DICAG and a plain language case study – both were presented at the National Assembly public hearings in August 2004.

The DICAG submission

The disability sector agreed that the new law should meet three requirements. First, it had to create specific mechanisms to ensure that children with disabilities and chronic illnesses have equal access to social services. Staff delivering these services must be trained to have skills and attitudes appropriate to dealing with children with disabilities. Second, the Bill had to make provision for the specialist services such children need, and, third, it should provide for monitoring and evaluation mechanisms.

To meet these requirements, the DICAG submission (2004b) made numerous recommendations:³¹

- Amend the Objects of the Act by adding a sub-clause ensuring assistance for children in especially difficult circumstance (this group includes, but is not limited to, children with disabilities).
- Re-instate a chapter excised by Cabinet that required government to devise strategies for assisting children with disabilities.
- Re-instate provisions describing the National Policy Framework. The NPF would oblige government departments to share responsibility for implementation.
- Re-instate the full list of rights in the SALRC draft Bill. These included: protection from unfair discrimination; access to appropriate assistive devices necessary to enable the participation of children with disabilities in community life; the stipulation that children with disabilities be supported³² where appropriate to enable participation.
- In conjunction with the protection of the right to participation, the submission stressed the need for parents to "involve the child in all decisions affecting their lives, taking into account their developmental stage (as opposed to chronological age)", and to change the definition of parental responsibilities and rights to include learning sign language to communicate with a deaf child.
- Equal access to children's courts, including physical access and sign language interpreters for the deaf.
- Statutory protection services, e.g. children's homes, should be accessible to children with disabilities.³³
- Children with disabilities and chronic illnesses should be added to the list of children who require statutory care from, and protection by, the State.³⁴

Nonceba Meyiwa's case study submission (2004)

DTT member and community activist Nonceba Mewiya drafted a case study that highlighted the difficulties children with disabilities face in accessing services, psychiatric services and community-based rehabilitation in particular. The case study made specific recommendations for the Bill. These included:

- legislative provision of inter-sectoral co-ordination, through the NPF; and
- protection of property rights.

³¹ This summary focuses on areas of contention. Statements supporting the Bill's provisions have been omitted.

³² The term "supported" is used instead of "assisted" to avoid connoting children with disabilities as helpless. The emphasis is on support for participation in a manner that also addresses their specific needs.

³³ The Protection Chapter was originally tagged as part of the second Bill; parts 2 and 3 were retagged on 9 February 2005.

³⁴ Children with disabilities were included in the original SALRC draft.

4. Participating in Parliament

The National Assembly (NA) began deliberating in earnest in July 2004 and passed its amendments in June 2005, after which the Bill was referred to the National Council of Provinces (NCOP) for consideration. The latter started its deliberations in August 2005, passing its amendments in November. The NA then deliberated which of the NCOP's amendments it would accept and finally passed the Bill in December 2005. This section recounts only the first NA process between July 2004 and June 2005, while Section 5 gives some insight into the NCOP process and the second NA process through a detailed exploration of one of the amendments.

4.1 Overview of the National Assembly process

The Portfolio Committee on Social Development took a multi-phased approach before passing the first Children's Bill. It was briefed by the Department of Social Development, whereafter it called for written submissions and held three days of public hearings at Parliament. Thereafter, MPs visited NGOs and provincial departments of social development in four provinces. Returning to Parliament, they reviewed submissions and debated general matters arising from the Bill. To complete their information-gathering, they compiled questions for government departments.

Once it had responses to these questions, the committee scrutinised the Bill and identified "grey areas" where more information was required. At the WG's suggestion, experts were invited to address the committee at a closed policy workshop. It again examined the Bill clause by clause and asked the departmental official to redraft where amendments were needed. When this had been done to the committee's satisfaction, it voted and passed the Bill with amendments. The entire process took just under a year.

4.2 The public hearings

The hearings were held in the National Assembly in August 2004. The CI alerted WG members to the dates and organised and paid for transport and accommodation for WG members from outside Cape Town to attend. Pre-hearing workshops were convened to support WG members and to check the submissions and make final preparations. The CI asked the Committee Clerk to permit people to present in sub-group panels, which would allow submissions to be grouped together by topic and have common messages reinforced. It was arranged that WG members with parliamentary experience spoke first, giving novices the chance to familiarise themselves with the proceedings before taking the floor. Presenting at parliamentary hearings is costly, time-consuming and nerve-wracking, but it is worth the effort:

[Oral hearings are] very important because there you have an interaction with the parliamentarians, and they also have an opportunity of clarifying certain issues that are not clear ... for parliamentarians it was very important because they got to cross examine us and we got to know their way of thinking.

Interview 17, Nonceba Meyiwa, DICAG, 2006

DTT report on the public hearings

In August of 2004, I presented a case study of a boy who had a psychiatric problem to parliamentarians in Cape Town. Prior to the presentations, the Children's Institute orientated all the members of the Working Group on the parliamentary procedures, including how one speaks into the microphone. ... We were even shown where we would be seated, facing the members of Parliament. Nothing was left to chance. The actual presentation was scary. The concern was the nature of the questions that would be asked and whether one would respond correctly. I had been to Parliament before and the reception was unpleasant. The DTT was meeting Mike Masutha [ANC whip for social development and a member of the disability caucus], who snubbed us. ³⁵ On that day, I felt intimidated. The mere thought of possibly meeting him again, made me want to withdraw from the whole process.

It was fortunate that my turn came after a few had already presented. This gave me an opportunity to observe the proceedings. I had been allocated a letter 'P'; I found myself telling them that the letter 'P' was not a co-incidence. Parliament knew that a parent was to speak. I am a parent of a child with a disability. When I said that I was from Duduza, Mr Solo [ANC MP] and the others interjected with remarks like 'Viva Ekurhuleni. How is Beirut?' This was referring to a neck-lacing of a girl in our area during the 'Struggle.' This eased my tension and I could feel that they were engaging with me. I was then able to confidently read through my submission.

Report by Nonceba Meyiwa, 2006a: 1

Directly after the hearings, the DTT co-ordinator sent thanks to participants, including MPs on the committee – attention to detail which is invaluable for building relationships.

4.3 Mobilising the sector for continued parliamentary advocacy

In October 2004, two workshops were arranged for the disability sector, one with DICAG provincial co-ordinators, the other with the DICAG council. These workshops firmly established the members of the DTT as the sector's champions and the team was given a mandate to continue, with DICAG providing additional funds to support their future advocacy activities.

4.4 The portfolio committee deliberations

Tracking the debate

_

The CI attended parliamentary committee meetings and briefed the DTT on the content of the debates. In the latter stages, when decisions were being made on the Bill, issues sometimes demanded immediate response.

³⁵ The DTT had a difficult first meeting with MP Mike Masutha in early 2004, which resulted in Nonceba being fearful of the second encounter. See below how their relationship improved with the use of alternative dialogue mechanisms.

DTT members were alerted by sms:

... [o]r phone calls saying, 'Phone me. This is happening with Hendrietta [ANC MP]; she's arguing against you. Phone Hendrietta.' I mean literally, and 'Phone her now, she's on lunch break'.

Interview 18, Sue Philpott, DART, 2006

The summary of submissions

When MPs returned to Parliament after their study tour, the departmental drafter took them through the recommendations submitted at the hearings. Like many of the MPs, the drafter had been absent from the hearings, and none of the MPs interviewed for this paper had read all of the submissions. Instead, they together relied mainly on the summary of submissions prepared by the committee researcher (Portfolio Committee on Social Development, 2005). Referring to the original submissions was considered impractical, and the summary was seen as having the added advantage of being easier to understand:

You can't go back to a stack of submissions but, certainly as a committee, if you wanted to ascertain anything, you would go back to the summary.

Interview 1, ANC MP, 2005

I mean a summary is more clearer than a big pile books, or whatever.

Interview 2, ANC MP, 2005

Numerous DTT recommendations were recorded in the summary, but not all. Among those recorded were ones relating to children's rights, the National Policy Framework, children in especially difficult circumstances, and disabled access to courts. Recommendations that went unrecorded included General Principles, parental responsibilities and rights, and the definition of children in need of care and protection. The latter was erroneously included in a section dealing with the second Bill, whereas the summary reflected only matters relevant to the first Bill. The other recommendations were overlooked by the committee researcher, including all of those made in Nonceba Meyiwa's case study. One MP reflected:

Very often I was aware that there were areas that weren't coming up, and I had gone back and said, 'But wasn't there this concern here or that concern there?' There were loopholes.

Interview 3, Opposition MP, 2005

Given the omissions in the summary, the MPs' preference for relying on the summary, and many MPs and the main drafter's absence from the oral hearings, it became clear that further lobbying was needed to keep all the DTT issues on the agenda. Meanwhile, the portfolio committee completed its examination of the summary of submissions and instructed government departments to respond to certain of the issues that were raised. The drafter prepared a matrix of such issues, which was presented to the committee before

being forwarded to the inter-departmental steering committee.³⁶ It became clear that the recommendation concerning the NPF in particular would be controversial.

The working group re-strategises

The WG met in November 2004 to review progress and agree on priority advocacy issues for the year ahead. Working on a standardised template, the sub-groups each wrote an advocacy strategy specifying their objectives, targets of the advocacy work, the arguments against their positions and rebuttals of them, and actions they would take (Children's Institute, 2004a). The DTT decided to target members of the inter-departmental steering committee and MPs in Parliament's disability caucus.

Lobbying the inter-departmental steering committee

The DTT co-ordinator phoned all members of the inter-departmental steering committee to lobby for the reinstatement of the NPF in the Bill. The NPF was considered particularly important because inter-departmental co-ordination is essential for integrated services for children with disabilities. Follow-up letters went to the Departments of Education, Justice, and Health, as well as to the South African Police Services. After the inter-departmental steering committee met to discuss the questions raised by the portfolio committee, the latter heard the various departmental responses, and they were generally disappointing. For instance, the functions of the Office on the Rights of the Child are to "facilitate integrated policy implementation"; yet the reply to the NPF's proposed reintroduction was that the Office "has no formal legal standing" and it was thus uncertain if it could exercise responsibilities to do with the NPF (Office on the Rights of the Child, 2005).

Meetings with MPs on the portfolio committee

The DTT arranged its first parliamentary meeting with Mike Masutha,³⁷ an MP on the disability caucus and ANC whip for social development. According to Nonceba Meyiwa:

The DTT's first meeting was planned to be in Mike Masutha's office in Parliament. For some of us it was going to be the first time in Parliament. The aim was to present to him key issues around the Section 75 Bill [the first Bill]. We had targeted him because he had proved in the past to be an influential spokesperson for the ANC and because he is a disabled Member of Parliament, who is also a DPSA member.

He did not give the DTT an opportunity to speak to him, nor did he look prepared to honour his appointment with us. To him, we were just a 'group'. He told us he was very busy to see us and he left us with Maxwell,³⁸ who was very friendly but who was not our target. He later came back and he wanted us to briefly tell him what we were about. We had planned how we would present our story. That all fell off. He was directing the show. I remember clearly that I could not even open my mouth. I

³⁷ The meeting took place in early 2004 before the portfolio committee began its deliberations.

³⁶ The inter-departmental steering committee composed senior officials from government departments that would be responsible for implementing different parts of the Act.

³⁸ An ANC MP and disability caucus member, but not a member of the Portfolio Committee for Social Development.

was shivering ... Paula [Proudlock, CI] rescued me and the others. We immediately met at the coffee shop to swallow down our disappointment over a cup of tea and to re-strategise for the next meeting.

Another meeting was with Lewis Nzimande³⁹; this was a lunch-time meeting in Parliament after the hearings. ... In these meetings we were unexpectedly joined by Mike Masutha. He was a totally different Mike in the dining hall as compared to a Mike we had met in the office during working hours. This meeting gave us an opportunity to affirm our credibility as representatives of the children's disability sector. They both requested to be sent copies of the DICAG submission. This was the beginning of an amicable relationship between the DTT and the disabled members of Parliament. This relationship was cemented subsequently in another meeting with Mike when he was deliberately asked to come to Nigel to see our court, which is highly inaccessible to people with disabilities. We got to know him better in this meetings; he was a very friendly person and a family man, too.

Report by Nonceba Meyiwa, 2006b: 4

What emerged from the second meeting with MP Mike Masutha was of great importance to the WG as a whole. The minutes of this meeting revealed the MP's objections to the NPF:

Mike's response to the concern raised by the sub-committee [DTT] was that the NGOs' call for a National Policy Framework was 'a non-starter'. He went into some detail about this, stating that 'the principle is not the issue, it is the mechanism'. It is about creating legislation which ensures collaboration between different departments. He pointed out that policy cannot be sanctioned in law. A law is defined as policy that has the force of the law. Policy speaks in general terms, and is less specific. Mike pointed out that there is still a need for a policy framework or strategy, but this needs to be developed outside of the legislative process.

Disability Task Team Minutes, 2005f: 1

MPs and the WG wanted the same outcomes, but were talking different languages. Mike Masutha saw emphasis falling on the word "policy" whereas the WG placed emphasis on "framework" and "co-ordinated planning and service delivery". This insight led to a change of tactics and a call for an inter-sectoral co-ordinating mechanism in place of the NPF.

Lewis Nzimande also gave advice on which areas to focus on:

Chapters 2 and 3 of the Bill have been collapsed together. There is an opportunity to put in something in the 'Principles' section, which relates to disabled children. Section 42 could also be amended to ensure that children with disabilities get access to courts.

Disability Task Team Minutes, 2005f: 2

³⁹ An ANC MP on the Portfolio Committee on Social Development, and on the disability caucus.

Secondary lobbying of MPs not on the committee but in the disability caucus

Other MPs in the disability caucus were targeted. The ANC's Wilma Newhoudt-Druchen was targeted as the Chair of the Joint Monitoring Committee on the Improvement of Quality of Life and Status of Children, Youth and Disabled Persons (JMC). She was invited to attend the Children's Bill deliberations, and made numerous stands on providing support services to children with disabilities. Vincent Gore, an Independent Democrat MP and disability caucus member on the JMC, met DTT members and children from a local DICAG group, and played a vital role in monitoring the debate and talking to members of the portfolio committee.

The policy workshop

The committee got stuck on certain key issues, and the ANC whip asked the drafter and WG lobbyist for a list of experts to be invited to a policy workshop. Not all nominees could be accommodated, as there was competition for space at the workshop.

The CI sent letters listing experts, including DICAG representatives (Proudlock, 2006a; 2006b). When the workshop programme was announced, however, it did not include anyone from the DTT. The matter was only remedied after DTT member July Nkutha lobbied MP Lewis Nzimande and succeeded in having a slot allocated to DICAG. Sue Philpott explained:

Significantly, all the suggested [commentators] on the Bill were highly qualified and in positions of authority ... [W]e felt strongly that there needed to be a parent there who could give input [on disability issues] from his/her perspective. The 'expertise' was not derived from academic achievement or prominent position, but from experience gained from involvement in the disability sector (as a parent).

Report by Sue Philpott, 2006b: 1

The sector was consulted in preparation for the policy workshop. Major issues were discussed at a planning meeting, and a draft submission (DICAG, 2005a) and fact sheet (DICAG, 2005b) were circulated to the DTT, WG, and disability networks. During the discussions, it was suggested that the submission include a definition of disability, and a DTT discussion paper (Philpott, 2005b) on the subject was circulated for comment. Several organisations in the sector were vehemently opposed to the insertion of any such definition, but the DTT took the opposition to its proposal as a positive sign that the process was fully participatory:

We did not see their criticism as a reflection that the task team 'had got it wrong', but an indication that we had successfully engaged the sector and through their response to our suggestion (rejection of it) had made their position clear.

Report by Sue Philpott, 2006a: 5

As further preparation for the workshop, Sue Philpott reviewed the Parliamentary Monitoring Group (PMG) minutes to ensure that the DTT had responded to all the concerns of the MPs. CI legal experts helped to draft legal text, and July Nkutha identified case studies to illustrate various points – the DTT knew that while drafters and committee staff

worked with the text of the recommendations, MPs would benefit from having stories that made the recommendations come alive. Moreover, the recommendations in the submission were simplified and clearly linked to clauses in the Bill:

Clause 1 – Interpretation: Change the definition of parental responsibilities and rights to include learning sign language to communicate with a deaf child.

Clause 6 – General Principles: Add a section requiring that due consideration must be given to the special needs of children with disabilities and children with chronic illnesses in any matter concerning the child.

Clause 11 – Rights of children with disability or chronic illness: Add a requirement for children and their care-givers to be provided with the necessary support services.

Clause 12 – Harmful, social, cultural and religious practices: Add a sub-section to prevent children with disabilities being subjected to harmful cultural practices.

Clause 13 – Information on health care: All health information should be in a format accessible to children with disabilities, and secondly, a child should have right of access to information about his or her disability or chronic illness.

Clause 14 – Access to court: Children with disabilities should have access to children's court proceedings.

Clause 42 – Children's court and presiding officers: Children with disabilities should have access to children's court proceedings.

Clause 114 – Contents of part A of the Register: Data on the National Child Protection Register should be disaggregated by age, gender and disability status.

July Nkutha presented at the policy workshop:

We had made further progress by having two [other] presentations, which made reference to children with disabilities before our presentation. That has built an enticing environment for our submission ...

I had a chat with Mike and Lewis the day before as it was agreed in the strategic meeting we held with them in Parliament to keep the contact. But I could not meet with Hendrietta Bogopane [ANC MP], who seemed to be avoiding me, and busy.

The presentation went very well but striking questions were raised by Hendrietta Bogopane [ANC MP], on the issue of the definition of disability and its link to chronic illness. The question was checking whether DICAG was attempting to define disability or what? She also raised another one with regard to parental rights and responsibility. ... But otherwise the atmosphere in the committee meeting was very progressive, showing keenness to finalise this Bill quickly because children are still being subjected to the Child Care Act ... a need to have an immediate intervention was being felt by all the members.

Quoted in report by Sue Philpott, 2006b: 2

Constituency visits

The CI advised the DTT of techniques that could keep debates alive or deepen understanding of particular issues. Visits to communities and facilities were the best way of stimulating detailed discussion and confronting MPs with evidence of the challenges facing children with disabilities. Nonceba Mewiya described how she took MP Mike Masutha on a tour of the magistrate's court in Nigel:

My intention was to get Mike ... [in] a more relaxed, friendly way to come down to my court here, which is highly inaccessible in nature. ... [W]hilst it assisted DICAG, it also assisted the process of the Bill, in that Mike could go back to Parliament and he's the one in fact who brought it up; he went there and found out [about the] court, so the justice department has to do something about it, and he spoke very eloquently about it.

Interview 17, Nonceba Meyiwa, DICAG, 2006

The visit had immediate impact. At the next round of deliberations, Mike Masutha raised the issue of courts being inaccessible to children with disabilities (Parliamentary Monitoring Group, 2005a):

Mr Masutha remarked that he ... had recently been approached by an organisation for children with disabilities to inspect the magistrate's court in Nigel. He had discovered that the lift had not worked for the last eight months, and that the lift itself was outside the public area behind a high security access door. ... This showed that facilities were there but sometimes either not working or inaccessible.

Mini-indaba with the drafter

The committee was under pressure to finish the Bill before the second term of Parliament ended. They moved through it quickly, again flagging difficult issues. To speed up matters, MP Hendrietta Bogopane-Zulu was mandated to meet the drafter and finalise clauses relating to children with disabilities. The CI advised Sue Philpott to ask Hendrietta for an invitation:

What struck me was that we had nothing to lose by requesting to be present at this meeting. Sometimes we do not believe in the potential that we do have to influence things!

Report by Sue Philpott, 2006c: 1

She described what happened:

Because of the previous contact following the PC [portfolio committee] workshop, she [Hendrietta Bogopane-Zulu] was open to my request to join her and [the departmental drafter] in finalising the clauses. It was important that the credibility of the DTT, DICAG and myself had been verified before this. Both Hendrietta and [the drafter] were amazingly flexible in response to this request ...

The discussions took place in the lobby/coffee shop of the Townhouse Hotel. They were very cordial. Hendrietta had ensured that the clause relating to the prohibition of discrimination on the basis of disability had been included. But when I suggested

that we go further, to include the creation of an enabling environment, she was very positive, and motivated for its inclusion, even when it was questioned [by the drafter] about the need for this. We then both argued for the need to go beyond **not doing something negative** [for children with disability or chronic illness] **to doing something positive**.

Report by Sue Philpott, 2006c: 1,2

Although not all of the recommendations were incorporated, there was a spirit of engagement towards finding positive solutions. For example, the submission called for a clause to ensure that hearing parents of deaf children should be obliged to learn sign language; the proposal was originally made by the NGO DeafSA. But the drafter said one can't actually legislate for parents to learn sign language. She proposed an alternative, changing the definition of care to include a parent's communication with the child:

So although she didn't take exactly what we had said, we could understand her position.

Interview 18, Sue Philpott, DART, 2006

Attending committee meetings

The DTT attended the portfolio committee meeting where MPs put the finishing touches to the Bill and debated remaining key issues. A recurring point of contention was the issue of replacing the terms "custody" and "access" with "care" and "contact" in the parenting rights chapter. The WG fought hard for use of new terminology and ANC whip Mike Masutha was championing the change, but other MPs were hesitant in the face of strong opposition by the departmental drafter. Sue Philpott described a significant moment in this regard:

The level of trust that had been built up between us as the task team and individual MPs was evidenced during one of the portfolio committee meetings where the 'care and contact arguments' were being debated. At the time, it seemed that there would be difficulty in reaching finality on this. At the direction of Lucy [Jamieson, CI], I passed a note to Hendrietta which read: 'DICAG supports care'. On receiving this, she took a very convincing position in support of the care argument.

Report by Sue Philpott, 2006c: 2

Hendrietta's support was enough to sway the debate, and members voted in favour of the WG amendment (Parliamentary Monitoring Group, 2005d). The WG often used the technique of note-passing. Where relationships of trust have been established, MPs will accept expert opinions, or notes reminding them about those opinions.

4.5 Involvement in the costing process

In 2005, Cornerstone Economics began a costing of the Children's Bill, commissioned by the Department of Social Development. Their brief included consultation with civil society, and the CI hosted a workshop to open dialogue between them and the WG. Cornerstone later

⁴⁰ The terms "custody" and "access", found in common law and divorce and maintenance legislation, are associated with parental power over children. Child activists regard them as outdated.

co-opted Sue Philpott to write a situational analysis on children with disabilities for the report (Barberton, 2006), which was indicative of the shift in thinking on children with disabilities. The sector had previously described itself as excluded from government planning; in this instance, its views were fully incorporated at the outset.

4.6 Media dialogue

At the time of the public hearings, the DTT produced a one-page summary of the submission for the media, along with supporting documents⁴¹ such as fact sheets explaining each issue in brief, simple terms. The fact sheets proved to be extremely useful both in ensuring accurate media reporting and making matters easily digestible for MPs. The DTT also took part in the media debate when the Bill passed its second reading in Parliament. Initial media coverage was mostly negative, and focused on a few controversial clauses. In an attempt to widen the debate, the DTT co-ordinator wrote a letter to *The Witness* (a provincial newspaper based in KwaZulu-Natal), highlighting the Bill's importance to children with disabilities and chronic illnesses (Philpott, 2005b).

4.7 Summary

Few organisations continue the conversation once formal law-reform opportunities have passed, but this chapter shows that the DTT clearly took advantage of all opportunities to influence the Bill. For them, the public hearings were but a starting point, and they intervened at critical moments to make sure their issues stayed on the agenda and that MPs based decisions on the available evidence. Throughout the process the DTT listened to MPs' concerns and continued to consult with the disability sector to ensure that responses enjoyed wide support. In addition, they adapted their advocacy strategy by targeting various groups: the MPs, officials on the inter-departmental steering committee, and people in a position to influence the MPs.

_

⁴¹ Fact sheets on assistive devices, health and mental health, social security, abuse and neglect, ECD, and the need for a co-ordinating structure, along with case studies and the full submission.

5. The story behind clause 42(8)(d): Disabled access to children's courts

This section examines the controversy around clause 42(8)(d) of the Children's Bill, and recounts how the DTT, individual MPs and the disability sector worked together successfully to make sure the clause was saved.

5.1 History of the clause

In its initial submission to the National Assembly in August 2004, the DTT maintained that children with disabilities should be able to access children's court proceedings:

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). Particular emphasis should be placed on ensuring physical accessibility as well as access to information.

Disabled Children's Action Group Submission, 2004b: 15

The recommendations were reiterated in the DTT's supplementary submission (Disability Children's Action Group, 2005a) at the policy workshop in April 2005. The presentation caused heated debate but received broad support (Children's Institute, 2005b). After the mini-indaba (described earlier) between the DTT co-ordinator, the drafter and MP Hendrietta Bogopane-Zulu, changes were made to the Bill and sent to the Department of Justice, which presented the revised clause to the committee in May 2005. The amendment – clause 42(8)(d) – read:

42. (8) The children's court hearings must, as far as is practicable, be held in a room which—

•••

(d) is accessible to disabled persons and persons with special needs. 43

The departmental presenter, a chief director⁴⁴, said the provision would be extended to cover sign language interpreters as well.

⁴² Sign language interpreters are required for deaf children so that parents or caregivers are not obliged to interpret for them.

Department of Justice (2005) Proposed amendments to "Chapter 5: Children's Courts" (Children's Bill [B70 of 2003 (Reintroduced)]). Presented to Portfolio Committee on Social Development by Department of Justice, 23 May 2005.

⁴⁴ Chief Director for Protection of the Rights of Vulnerable Groups.

5.2 The eleventh hour briefing and the stand-off between the National Assembly and the Executive

At the urging of the Minister of Social Development, the portfolio committee moved to finish the Bill and, on 31 May 2005, worked into the early hours of the morning to make final touches and reach agreement on outstanding issues. When the MPs reconvened the next morning, they were told to expect the Minister of Social Development and the Deputy Minister of Justice. The Deputy Minister of Justice ordered the committee not to make amendments to the Bill unless these carried Cabinet approval;⁴⁵ and also instructed MPs to insert two amendments on behalf of his department:

You go back to the original Bill on Chapter 4, and then ..., there's two amendments that have to be drafted in this Chapter for that original Chapter as it was accepted by Cabinet ... We're saying to you that we're supportive of only two amendments. If they're going to change anything further, if they're going to do things like bring back things that have been rejected [by Cabinet], like qualifications, training and those issues, then clearly we're saying no.⁴⁶

The committee was particularly confused. Outside the meeting, MP Hendrietta Bogopane-Zulu engaged Deputy Minister de Lange to stress the importance of clause 42(8), but he said the department lacked the budget to make all courts accessible. Hendrietta replied by saying that it was 10 years since the new Bill of Rights promised equality for children with disabilities; so how much longer must they wait? The response from the deputy minister was that access would gradually be realised as the department acquired more funds. Hendrietta argued that the budget was not likely to materialise unless the law placed an obligation on the department to prioritise the issue, and that surely the law should come first before the budget? The deputy minister ended the conversation by saying that he didn't want any confusion, and that this was a direct order.⁴⁷

After this exchange with the MP, Paula Proudlock of the CI also addressed him, pointing out that as a former chair of the Justice Portfolio Committee he himself had often amended Bills tabled by the Executive. His answer was that he would always get ministerial approval before doing so.

MP Hendrietta Bogopane-Zulu stood firm on the disability clauses, and committee proceedings were halted while the ANC and its allies caucused. The instructions from the Executive were clear; the only question was would the committee obey them? After intense negotiation, the committee decided to acquiesce to all the deputy minister's demands, except one. When the committee passed the Bill, it retained the amendment ensuring disabled access to children's courts. The Bill was in turn passed by the National Assembly in June 2005, and the DTT co-ordinator thanked Hendrietta for her stance.

⁴⁵ One political commentator quipped that the two ministers "gave a new meaning to the separation of powers, yesterday ordering MPs not to make changes to the Children's Bill without Cabinet approval" (Quintal, 2005).

⁴⁶ Deputy Minister of Justice, Adv Johannes de Lange, quoted in: Portfolio Committee on Social Development (2005) Transcript of meeting, 1 June 2005. [On file at the Children's Institute]

⁴⁷ The second author was standing next to Hendrietta and the deputy minister during this exchange in the corridor outside the meeting.

Hendrietta's story

My proudest achievement for me, obviously, it's how hard I had to fight for the inclusion of disabled children. The fight and the struggle and finally having them there is my proudest achievement. Because usually you don't have disabled children mentioned as they should be.

Justice [Department] did not take the process seriously. So, by the time the end of the Bill came, obviously their first point of entry will be to lobby the Minister of Social Development who would then lobby us, because of the relationship we would have with him. They were also protecting their prerogative as Justice in terms of the things we are saying is going to cost money. It wasn't a nice meeting, I must say, because the Executive was now stepping into a role that was not theirs. We just had to make it very clear that, look we are the legislators and we are legislating. And we don't think that it is good that you guys bulldoze us. You must reason with us, you mustn't give us instructions. You mustn't order us like we are officials, remove this, put this in. And the Minister of Social Development was fully aware that the best he could do is to play a facilitating role, to beg us; and there, Justice was like, do it, do it, you know. We had to put our foot down and say, we are the legislators and if you think something is going to have a negative impact, you reason with us, you don't order us around.

I have a responsibility as a public representative and as a mother of two disabled children and as a disabled person myself. That was my "aha" moment that I was going to assert my being a public representative and understanding my role as a legislator. That I am there to legislate and government [Executive] can't tell me what I shouldn't legislate for. So it was more a question of ensuring that I do what I am constitutionally represented to do. Represent those that can't represent themselves.

The conflict over clause 42 became a political party issue. I mean as an aggrieved ANC MP, I followed the ANC conflict resolution processes within the party in terms of what is available to me to raise my issues and to facilitate what I feel strongly about. That is how we resolved the process. So I used that, through the ANC, the processes and as ANC Members of Parliament, we had to meet ... So, it didn't get to a point where the portfolio committee had to resolve it. I used the mechanisms. And obviously if I was not getting any joy through my party structures, then I would use the mechanisms that are there for me as a Member of Parliament, instituted by Parliament. But it didn't get to that.

Abridged from interview with MP Hendrietta Bogopane-Zulu, 2006

5.3 Planning for the NCOP process – identifying the need to defend clause 42(8)(d)

The Bill was now referred to the National Council of Provinces (NCOP) for consideration. Since it was a Bill involving national government competencies, whatever amendments were proposed by the NCOP would be returned to the National Assembly for final acceptance or rejection. The path the Bill had to follow meant that the victory over disabled access to courts was fragile and open to future attack, especially given that the deputy minister had refused to yield on the issue.

Further complications arose when the media zoned in on other controversial aspects of the Bill, notably its ban on virginity testing. Public debate raged during the parliamentary recess, and a *The Witness* headline captured the mood: "Uproar as State Moves to Ban Virginity Testing: Bill said to tamper with the heart of African tradition" (Mthethwa & Khumalo, 2005).

5.4 The NCOP public hearings

Like the portfolio committee before it, the NCOP too was under pressure to finish the Bill, and the Select Committee on Social Services wanted to avoid repeating debates that had been resolved in the National Assembly (its focus was on the debate on virginity testing). One MP commented: "If you did not win your battle at the National Assembly, don't bring it here" (Parliamentary Monitoring Group, 2005c).

When the public hearings were advertised, a limitation was placed on who could present: "Stakeholders and interested parties who submitted written submissions to the Portfolio Committee on Social Development on 11-13 August 2004 should not forward the same submission to the above Select Committee, unless they are introducing new issues." 48

Other WG sub-groups found ways around the prohibition by asking network members who had not presented in the first round to champion certain issues, or by presenting new evidence to the committee. The DTT took the decision not to make another submission. It was felt that, if issues arose, the committee could be referred to previous submissions.

5.5 The Department of Justice strikes back – and the NCOP removes clause 42

The Department of Justice attended neither the committee briefings in August nor the public hearings. Other departments did attend, and made recommendations for amendments and presented written submissions.

On 9 November 2005, at the committee's final meeting on the Bill, the Chief Director in the Department of Justice proposed the following amendment:

⁴⁸ From an advert that appeared on the parliamentary website and in the national press.

CLAUSE 42

1. Clause rejected.

NEW CLAUSE

That the following be a new Clause to follow Clause 41:

Children's courts and presiding officers

- **42.** (1) Every court which is established in terms of section 2(1)(f) of the Magistrates' Courts Act, 1944 (Act No. 32 of 1944), is a children's court and has jurisdiction on any matter arising from the application of this Act for the area of its jurisdiction.
- (2) Every –
- (a) magistrate is the presiding officer of the children's court; and
- (b) additional magistrate is an assistant presiding officer of the children's court, for the district of which he or she is magistrate or additional magistrate, as the case may be.
- (3) The presiding officer of the children's court or an assistant presiding officer thereof must perform such functions as may be assigned to him or her under this Act or any other law.⁴⁹

Few MPs had copies of the Bill before them, and the Justice official spoke only of the "new clause". The CI lobbyist passed a note to one of the MPs, pointing out the significance of the change. When he questioned the Justice officials, they responded by saying that although not all children's courts are accessible to people with disabilities, such provisions do not need to be in the legislation; the reform of buildings, they said, is an administrative matter, and can be dealt with in policy.

The committee could not complete its work that day. For various reasons the rest of its formal deliberations were postponed until January 2006, but it happened to be recalled in November to finish the Children's Bill and Nursing Bill. In preparation for this meeting, DTT members phoned MPs on the committee. The chairperson gave assurances that provisions relating to court access for children with disabilities would not be removed, and when the committee reconvened, she wore a DICAG pin on her lapel. Deliberations on the Children's Bill were scheduled for the morning, but the programme was changed at the last minute because MPs had worked on the Nursing Bill all morning and needed to break for lunch. Tired and under stress, MPs went through the Bill with great haste, passing the amendment proposed by the Department of Justice without debate.

When questioned, the chairperson explained the process:

I am sure you're aware that the Bill comes from the department. We are working the Bill there and then we brief the provinces. So we as chairpersons, or we as committee, we can't change anything ... If [the provinces] come with the mandate, they must be considered, but we as a committee, we can't say we want to change one, two, three. We are working on mandates, we are not operating like a national

⁴⁹ Department of Justice (2005) *Proposed Select Committee Amendments To Children's Bill [B70B – 2003]*.

assembly that we can change there and then. We get the mandate from the provinces.

Interview 6, ANC MP, 2006

The comments indicate a misunderstanding of parliamentary procedure. Section 75 of the Constitution defines the process for dealing with national legislation. When dealing with section 75 legislation, the select committee does – and in this case, did – have the authority to amend the Bill. What is important to note is that in the absence of mandates from the provinces the committee relies heavily on the departments. It heard only one viewpoint, the Department of Justice's motivation for the amendment, without reviewing the existing clause, taking evidence from civil society, or even getting a briefing from the portfolio committee on why the clause was inserted in the first place.

An MP admitted that the "committee was not fully aware of the proposed change", adding that departmental officials pushed certain agendas, "not their [own] agendas but the minister's agenda ... people are very scared to lose their jobs ... you can't remove biases because of the way that those people are getting employed" (Interview 7, opposition MP, 2006).

The Constitution vests the national legislative authority in Parliament. However, in practice, most legislation is drafted by the Executive and reviewed by Parliament.

5.6 The last stand in the National Assembly

As the Children's Bill was a section 75 Bill, the NCOP amendments had to be approved by the National Assembly. This gave the DTT a last chance to advocate for the rejection of the amendment to clause 42(8)(d). The CI wrote action briefs for each member of the team and drafted a pro-forma letter outlining the issue.

Mobilising the sector

The DTT contacted key members of the SAFCD for support. A letter was drafted to the portfolio committee and circulated to all networks in the WG, including the SAFCD. Various members endorsed the letter and faxed it to the committee, a measure ensuring that it heard numerous expressions of concern from across the disability sector.

Lobbying phone calls to MPs

The DTT made personal calls to everyone on the committee. They also called MPs on other committees, including MPs Vincent Gore and Wilma Newhoudt-Druchen from the JMC, who in turn called MPs on the portfolio committee and urged them to reject the NCOP amendment.

Using the media, articles, letters, and investigations

A DTT press release was distributed via the CI's media mailing list. An article was published on Health24.com, which in turn was picked up by a journalist from Independent Publishers. When she interviewed the chair of the select committee (NCOP) and was told the clause

was "still in the Bill", 50 it was more evidence that the committee had been duped by the Department of Justice.

How the clause was won

If the National Assembly rejected the NCOP amendment, it would mean adopting a party line that opposed the position of the Department of Justice and of the ANC in the NCOP. Given the political implications, the ANC met to discuss the way forward. The meeting included the chairpersons of the two committees, key party members on the committees, and the Deputy Ministers of Justice, and Social Development. The Minister of Social Development did not attend, and his Deputy did not have a firm position on the matter. Committee chairpersons are expected to back their ministers; in this case, the Deputy Minister of Justice expected the same loyalty.

MPs argued with him until the early hours of the morning, saying that the version of the clause passed by the National Assembly accorded with constitutional imperatives, international law, domestic legislation, and ANC policy. But it was an emotional appeal that finally won the day, an appeal to MPs to support their constituency and "remember where they came from" (Interview 5, ANC MP, 2006).

Disability champions at the meeting (MPs) described feeling battered and bruised by the process, so the DTT mobilised disability activists to show their support at the next portfolio committee session. MPs from the disability caucus, care-givers and parents of children with disabilities, church leaders and WG representatives crowded into the room, and there were loud cheers when the committee voted to reject the NCOP's amendment.

5.7 Summary

This chapter shows the importance of persistence and relationship-building. Individual MPs can champion issues in the face of stiff opposition if they are given motivation for proposed changes and evidence of broad-based support for them. It also shows how an MPs personal experiences and political convictions can motivate her to step into her role as law-maker and stand her ground against executive interference.

⁵⁰ Personal communication, Linda Daniels, *Cape Times*, 2 December 2009.

6. Evaluation of impact

6.1 Evaluation framework

The DTT's advocacy on behalf of the disability sector made an impact on the final version of clause 42, but what effect did it have on the Bill as a whole? In interviews, respondents were asked if the advocacy made any difference and they expressed confidence that it had. Yet can this be proven? We have already outlined the campaign's aims and objectives. Moreover, we previously sub-categorised the objectives into primary ones relating to the Bill's content and secondary ones to do with the process of achieving the primary objectives.

Now, in order to evaluate the campaign's success, we assess the extent to which each group of objectives was met in practice. Secondary objectives are evaluated by using interview responses; primary objectives are evaluated by a comparative analysis of the clauses in the final Act and the DTT's recommendations, along with a review of the timing of these changes.

6.2 Secondary objectives

Promoting the participation of the children's sector in the writing of the Children's Bill

Nonceba Meyiwa and July Nkutha joined the DTT because they recognised that the Bill would affect them and their children. As service users, they are in contact with other parents in their areas; as DICAG members, they are linked to parents nationally. These contacts were used to broaden consultation on the Bill:

We were very much trying to get the voice of the people represented ... As parents we are directly involved in the sector and could raise concerns that they saw in the field and that related to their children.

Interview 15, July Nkutha, DICAG, 2005

Stakeholders indicated that the sector felt included in the process and acknowledged the role the WG and DTT played in facilitating dialogue:

We gave all the support we could; we couldn't have taken the initiative ourselves, unfortunately; but, well, whoever does it, doesn't really matter; eventually we get the result we want, as long as we collaborate in coming up with the position and action as well.

Interview 19, Dr Siva Moodley, DPSA, 2006

Further evidence of the sector's participation is found in endorsements from WG members⁵¹ and organisations in the disability sector: Cape Mental Health, SAFCD, Autism South Africa, and Epilepsy South Africa, DPSA, Down Syndrome South Africa, and the National Council of Persons with Physical Disabilities.

_

⁵¹ Childline South Africa, Dikwankwetla – Children in Action, Johannesburg Child Welfare Society, Molo Songololo, Naledi Lifeskills and Training Centre, RAPCAN, SASPCAN.

In addition, MPs and parliamentary officials commented on civil society's participation in the process; according to portfolio committee members, the number of submissions and presentations was unprecedented:

That was one of the more exciting things as far as I'm concerned, because I compared it to other public hearings [at the time] and I don't believe that [other] hearings attracted as many people, in terms of sheer numbers [of] organisations, as we had coming from various organisations to deal with issues of children.

Interview 8, ANC MP, 2005

Characterising the major challenges facing children

Identifying the problems took effort:

As a sub-group we began with fact sheets, and invited parents and organisations to send real stories or real issues, and gained real experience from the areas. These were consolidated into our submission, and we talked to parents about their direct experiences, and that was how we were able to identify the challenges.

Interview 15, July Nkutha, DICAG, 2005

But these efforts are a vital step in the process:

If the problem was not properly characterised, we did not get good recommendations. We needed to clearly identify problems, and the recommendations would respond to the problems and suggest solutions.

Interview 15, July Nkutha, DICAG, 2005

All of the interviewed departmental officials said the disability submissions gave them new information and highlighted gaps in provision for children with disabilities:

[T]he comments helped us identify, for example, that there's a major gap on disability in the country.

Interview 9, government official, 2005

MPs concurred that the DTT brought the needs of children with disabilities to their attention:

[I]ssues that came forward from NGOs made it necessary for us to rethink our approach to ensure that the legislation fully responds to the needs of children with disability and hence some of the clauses that were introduced to the legislation dealing with that issue.

Interview 10, ANC MP, 2005

Promoting the use of evidence in the decision-making process

The DTT drew on numerous sources of evidence, including statistics, research reports, and constitutional and international law. The most persuasive of these by far were the real-life cases:

I've heard it a couple of times but it still has an impact, from that one guy from the East Rand, I think, [with] disabilities. It's the content, you know, the disability guy with the actual examples are how children are treated.

Interview 11, government official, 2005

Using a co-ordinated approach

To evaluate this objective, we used common messages – that is, recommendations adopted by other sectors – as an indicator of success. Ten of the recommendations proposed by the DTT were included in at least one other submission. Three other recommendations relating to children with disabilities were taken up as proposals by two organisations. In total, 17 of the 36 submissions contained recommendations linked to children with disabilities, 10 of which supported the inclusion of a clause protecting the rights of children with disabilities.

6.3 Primary objectives

Promoting the incorporation and expansion of constitutional rights in the Bill

The ultimate aim was to influence the content of the Bill. Success can thus be judged by the rights incorporated into the Bill and the recommendations adopted by Parliament. Did the DTT meet their primary goal? Does the Children's Act provide the necessary legislative framework for realising the rights of children with disabilities in accordance with South Africa's international and constitutional obligations?

A brief analysis shows that the Act incorporates almost all of the rights and obligations recommended by the DTT⁵² (see Appendix B). Only four of 18 recommendations did not find their way into the Act. Two of the missing elements are a commitment to make special assistance free, as per article 23(3) of the CRC, and the guarantee of physical accessibility to all buildings, subject to available resources, as per article 13 of the ACRWC (clause 42 of the Bill applies to children's court proceedings only).

Below is an analysis of the provisions in the final Bill, with a cross-reference to the DICAG submissions.

_

⁵² This paper does not consider the question of whether the provisions of the Children's Act give effect to these rights since most of the provisioning clauses are in the second Children's Amendment Bill, passed in 2007.

Proposing legislative provisions that could be incorporated into the Bill to help address the major challenges facing children

Definitions

After the mini-indaba between the drafter, the DTT co-ordinator and an MP, the definition of "care" was amended to include a new sub-clause (i) on special needs:

'[C]are' in relation to a child, includes where appropriate – (i) accommodating any special needs that the child may have ...⁵³

There was intense debate over the legality and practicality of changing the terms "access" and "custody" to "care" and "contact". 54 Although lawyers established that such changes were possible and in the best interests of the child, their desirability remained in question. At the committee meeting, DICAG sent a note to one of the MPs and swung the balance of support.

Objects

The DTT called for amendment of the Objects of the Act (Disabled Children's Action Group, 2004b) by adding a sub-clause to ensure assistance for children in especially difficult circumstances (this group includes, but is not limited to, children with disabilities). Cabinet removed the relevant chapter and Parliament did not reinsert it, but – immediately after the mini-indaba (discussed earlier) – it did amend the Objects clause to include two of the recommendations made in the submission:

- 2. The objects of this Act are—
- (f) to protect children from discrimination, exploitation and any other physical, emotional or moral harm or hazards;
- (h) to recognise the special needs that children with disabilities may have ... 55

Inter-sectoral implementation of the Act

Lobbying efforts to reintroduce the SALRC chapter on the National Policy Framework (NPF) were unsuccessful. A view taken in the portfolio committee was that (Parliamentary Monitoring Group, 2006):

... the ANC component of the committee understands that it is not their role, as the committee, to subvert those policy choices, and substitute them with their own, because their understanding is that the committee makes law, they do not determine policy.

Policy determination is viewed as an Executive function over which Parliament does not have authority. However, there was a difference in opinion as to what the NPF would be. The Department of Social Development and Cabinet regarded it as a policy document that would guide the implementation of the Children's Act, whereas civil society was calling for a

⁵³ Children's Act No. 38 of 2005, section 1.(1).

⁵⁴ Children's Act No. 38 of 2005, section 1.(2).

⁵⁵ Children's Act No. 38 of 2005, section 2.

legal obligation on departments to work together for co-ordinated planning and service delivery.

When the WG realised it was the terminology that was problematic for Parliament, not the concept of inter-sectoral collaboration *per se*, they changed their strategy. In his presentation to the policy workshop, July Nkutha called for an inter-sectoral collaboration mechanism. After heated debate, a clause was added to ensure inter-sectoral implementation of the Act. Clause 5 reads:

[A]II organs of state involved with the care, protection and well-being of children must co-operate in the development of a uniform approach aimed at co-ordinating and integrating the services delivered to children.⁵⁶

Although this victory is not directly attributable to the DTT (it was spearheaded by other WG organisations, namely Childline, the CI, the Centre for Child Law and Johannesburg Child Welfare Society), the DTT helped to show the problems that lack of inter-sectoral planning and service delivery caused for children with disabilities. They also helped to redefine the debate and focus on the new terminology that was so pivotal to the success of this campaign.

General principles

New sections were inserted to protect children from unfair discrimination on the grounds of disability and create an enabling environment to respond to the special needs of the child. The DICAG submission to the public hearings made specific recommendations to insert a non-discrimination clause, and this was well supported by other organisations (see Appendix A) However, DICAG alone used the terms "creating an enabling environment" (Disabled Action Children's Group, 2004b). The final amendment inserted in the Act states:

- 6. (2) All proceedings, actions or decisions in a matter concerning a child must—
- (d) protect the child from unfair discrimination on any ground, including on the grounds of the health status or disability of the child or a family member of the child;
- (f) recognise a child's disability and create an enabling environment to respond to the special needs that the child has.⁵⁷

The General Principles of the Children's Act cover the implementation not only of the Act but of all legislation relating to children.⁵⁸ The implications of this change are thus wide-reaching. It effectively means the State has to make provision for children with disabilities when planning *all* services for children.

-

⁵⁶ Children's Act No. 38 of 2005, section 5.

⁵⁷ Children's Act No. 38 of 2005, section 6(2).

⁵⁸ Section 6(1) states that the general principles of the Children's Act guide:

[&]quot;(a) the implementation of all legislation applicable to children, including this Act; and (b) all proceedings, actions and decisions by any organ of state in any matter concerning a child or children in general."

Sue Philpott was at the mini-indaba discussed previously:

[A]t that meeting we basically decided on the disability clauses ... then in the rights section, there was a clause that was [on] non-discrimination against disabled children. And we had felt that just saying 'non-discrimination', what not to do, was not sufficient. We wanted a clause that actually said 'enabling mechanisms to ensure the protection of the rights and the participation of disabled children'. An enabling mechanism goes beyond non-discrimination. And Hendrietta and Ronel [the drafter] took those on board and that was what they decided.

Interview 18, Sue Philpott, DART, 2006

Best interests of the child standard

That Act states that the child's best interests must be applied in all matters concerning the care, protection and well-being of a child. Clause 7 defines the best interests of the child standard, and new sub-sections were inserted, as per the DICAG submission, to ensure that the specific needs of children with disabilities and chronic illnesses are taken into consideration when determining what is in their best interests. Clause 7(1) now reads:

Whenever a provision of this Act requires the best interests of the child standard to be applied, the following factors must be taken into consideration where relevant, namely –

- (i) any disability that a child may have;
- (i) any chronic illness from which a child may suffer ... 59

Children's right to participate

DICAG wanted a provision giving special assistance to ensure that children with disabilities can participate, but it was rejected. However, in section 10 the word "meaningfully" was removed before the word "participate" after MP Hendrietta Bogopane-Zulu argued it could be read to exclude children with mental disabilities. Clause 10 now reads:

Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has a right to participate in an appropriate way and any views expressed by the child must be given due consideration. ⁶⁰

Rights of children with disability

Parliament's insertion of a clause on the rights of "children with disability or chronic illness" was a major victory incorporating many of the rights found in international law that were presented in the DICAG submission to the policy workshop:

11. (1) In any matter concerning a child with a disability due consideration must be given to—

-

⁵⁹ Children's Act No. 38 of 2005, section 7(1)(i) and (j).

⁶⁰ Children's Act No. 38 of 2005, section 10.

- (a) providing the child with parental care, family care or special care as and when appropriate;
- (b) making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have;
- (c) providing the child with conditions that ensure dignity, promote selfreliance and facilitate active participation in the community; and
- (d) providing the child and the child's care-giver with the necessary support services. ⁶¹

The disability sector also lobbied for the introduction of a clause to protect children with disabilities from harmful social and cultural practices (Disabled Children's Action Group, 2005c; Nkutha 2005). Sub-section 3 goes beyond that to cover medical and religious practices too:

A child with a disability or chronic illness has the right not to be subjected to medical, social, cultural or religious practices that are detrimental to his or her health, well-being or dignity. ⁶²

Information on health care

Three amendments were made to this clause. The child now has the right to "information regarding his or her health status" and "the causes and treatment of his or her health status", in addition to information on the treatment of ill-health and disease. ⁶³ A new subsection also ensures that information is presented "in a format accessible to children, giving due consideration to the needs of disabled children". ⁶⁴

An official described how these changes were derived from the DTT's proposals:

Sometimes you use a proposal but you adapt it ... the disability people made a proposal about the child's right to information on health information; it's basically stated the child has a right to information with regard to sexual health and reproductive health and they suggested that a child should also have information on disability and the causes of disability, and we eventually put in 'information on health status and the causes of health status', so disability will be part of the health status and this will then cover the broader thing, not just the very specific thing.

Interview 9, government official, 2005

Access to court proceedings

Two amendments facilitate the participation of children with disabilities in children's court inquiries, and there is no doubt that these provisions were the result of the DTT's sustained campaign (see Section 5).

⁶² Children's Act No. 38 of 2005, section 11(3).

_

⁶¹ Children's Act No. 38 of 2005, section 11.

 $^{^{63}}$ Children's Act No 38 of 2005, section 13(1)(b) and (c).

⁶⁴ Children's Act No. 38 of 2005, section 13(2).

Clause 42(8)(d) enables physical access:

The Children's Courts hearings must, as far as is practicable, be held in a room which: ...

(d) is accessible to disabled persons and persons with special needs. 65

Clause 61 ensures disabled children have the opportunity to express their views:

The presiding officer in a matter before a children's court must –

(a) allow a child involved in the matter to express a view and preference in the matter if the court finds that the child, given the child's age, maturity and stage of development and any special needs that the child may have, is able to participate in the proceedings and the child chooses to do so \dots 66

National Child Protection Register

Clauses 111 to 128 on the National Child Protection Register were originally tagged as part of the section 76 Bill (the second Bill). When the clauses moved into the first Bill, the DTT called for provisions ensuring that data on disabilities were captured, and the following was inserted:

Contents of Part A of Register [National Child Protection Register]

114. (2) Part A of the National Child Protection Register must reflect—

(a) in the case of reported incidents referred to in subsection

(1)(a)—

(iii) whether the child has a disability and if so, the nature of the disability;

(iv) whether the child has a chronic illness and if so, the nature of the chronic illness;⁶⁷

The wording was taken directly from the DICAG submission to the policy workshop (Disabled Children's Action Group 2005c). This amendment will help ensure that data on child abuse and neglect can be disaggregated to show the number of children with disabilities. Such information will be essential for monitoring and tracking whether the higher risk of abuse and neglect that children with disabilities face is reduced over time as services to children with disabilities improve.

Recommendations not included in the Children's Act

Property rights

There was broad support for the protection of property rights, but the committee advised that it should be addressed in legislation pertaining to succession, the administration of estates and guardianship.⁶⁸ At this assurance, the sector decided not to pursue the matter.

⁶⁵ Children's Act No. 38 of 2005, section 42(8)(d).

⁶⁶ Children's Act No. 38 of 2005, section 61(1).

⁶⁷ Children's Act No. 38 of 2005, chapter 8.

Definition of a child in need of care and protection

The DTT were persuaded by MPs' arguments that children with disabilities are not in need of statutory protection and that most need support programmes within the family rather than alternative care.

Sign language

DICAG recommended that parental responsibilities to children with disabilities include the duty to learn to communicate with such children, but this was rejected largely because of its unenforceability.

Children in especially difficult circumstances

The sector called for the re-insertion of Chapter 16, which put an obligation on government to devise strategies for assisting children in especially difficult circumstances, which by definition include children with disabilities. The chapter was excised by Cabinet. The excision was defended by the Department of Social Development on the grounds that such a strategy constitutes policy and that, as policy is an executive function, it cannot be included in legislation.

Fourteen out of 18 recommendations were incorporated into the Act. On the issues of children in need of care and protection and the responsibility of parents to learn sign language, the dialogue with MPs and officials led the DTT to review their proposals. The committee made a commitment to address the protection of property rights in other legislation. Hence, the only real "loss" was on the strategies to assist children in especially difficult circumstances.

6.4 Secondary benefits

Advocacy activities had additional benefits that went beyond amending the Bill. The DTT identified them as the development of a best practice model of advocacy; the revival of disability sector networks; and the formation of relationships with key decision-makers (Disability Task Team, 2005b).

Kashifa Abrahams⁶⁹ described how the DTT helped "revive" the disability sector:

The Children's Bill presented an opportunity to address disability issues in a truly integrated manner, as it traversed so many areas for children. The INDS was the last opportunity to do that ... Since the decline of the SAFCD, there hasn't really been any other unified body to address key policies issues for people with disabilities, let alone children who are disabled ...

⁶⁸ Legislation protection property rights: The Department of Justice claims that it is responsible for these matters and legislative provisions should be made by amending the Intestate Succession Act No. 81 of 1987, and the Administration of Estates Act No. 66 of 1965.

⁶⁹ At that time, Kashifa Abrahams was part of a team conducting an evaluation of DICAG.

The work through the Children's Bill forced the disability sector to almost revive the movement and to reflect on the essence of the social model of disability in practical terms ...

E-mail correspondence, Sue Philpott, June 2005

The continuous promotion of children's rights also produced attitudinal shifts:

I think it's been a process of conscientisation; the advocacy process in and of itself has helped raise awareness of children's rights in the sector and change the attitudes of decision-makers and government official to children with disabilities.

Interview 18, Sue Philpott, DART, 2006

These are sustainable benefits that will assist future campaigns in the disability sector. It is interesting that this sub-group wants to expand the advocacy model. In his interview, July Nkutha reiterated how important it is to keep the process going, to tackle other issues and engage in other legislative processes using the same model:

It should not just be for the Children's Bill. Working together is key and we need to identify other projects for the group to take forward ... If the project ends, it would be a tragedy.

Interview 15, July Nkutha, DICAG, 2005

We underestimate these achievements if we simply count the proposed amendments that were included in the Act. The DTT's work resulted in major gains for children with disabilities and the sector as a whole. For the first time, children with disabilities were placed at the centre of mainstream legislation and the sector's momentum was revived at the same time. In the next section we examine the essential elements of that success.

7. Essential ingredients – what is in the mix?

The Children's Bill Working Group (WG) continuously strove to improve the effectiveness of its advocacy campaign. In 2004, 2005 and 2006, evaluation interviews were conducted in which respondents were asked to reflect on the campaign and identify essential ingredients. What follows is a list of such ingredients, along with selected interview commentary. The campaign had two strands – support from a central hub and activities by sub-groups – and they are treated separately for the sake of clarity.

7.1 A co-ordinated campaign with a central hub

Expert support from the Children's Institute

The CI facilitated consultation and built sub-groups' capacity for doing their own advocacy. This role was central to the campaign's success:

We appreciate the outstanding technical, practical and advisory help they [the CI] have given ... We are in no doubt that, without this support, we would not have come to Parliament this week.

Disability Task Team Letter 2003

As the co-ordinating structure, the CI offered numerous forms of support:

Knowledge-sharing:

There were things that they knew that we didn't know as a disability sector, and that is why it was important to work as a team, and to work together with different people that work with children.

Interview 16, Sandra Ambrose, DICAG, 2006

 Legal advice and interpretation – legislation requires translation for non-specialist audiences:

They made that information [so] you could read ... and understand it ... it wasn't big words.

Interview 16, Sandra Ambrose, DICAG, 2006

 Technical assistance – this related to evidence-gathering and producing submissions and presentations:

They made sure that the submissions contained the relevant issues that had to go in, that the articulation was correct.

Interview 17, Nonceba Meyiwa, DICAG, 2006

Organising workshops – many CSOs lack capacity to hold workshops, whereas the CI could provide an administrative base and experienced co-ordinators and facilitators:

[T]hey ran a workshop at our council and they played a big part in giving us material, assisting us with a lot of information.

Interview 16, Sandra Ambrose, DICAG, 2006

• Building partnerships – collaboration with other organisations produces synergy:

[You are] on an island on your own ... But when you stand together ... you stand a better chance of being heard.

Interview 16, Sandra Ambrose, DICAG, 2006

Moral support:

We got moral support, we got human, they gave themselves.

Interview 16, Sandra Ambrose, DICAG, 2006

• Encouragement – organisations were given encouragement to engage with national debate:

I had thought that my work was confined to a provincial level and I did not have the skill to critique policies and identify gaps.

Interview 15, July Nkutha, DICAG, 2005

Sometimes we do not believe in the potential that we do have to influence things!

Report by Sue Philpott, 2006c: 1

 Parliamentary information – briefings were given on how the system works and mock hearings boosted presenters' self-confidence:

We prepared together and there was a sense of camaraderie ...

Interview 18, Sue Philpott, DART, 2006

Tracking the debate in Parliament:

They had their ear to the ground, you know; they are so informative.

Interview 16, Sandra Ambrose, DICAG, 2006

Targeting, MP profiles and contact details:

They went out and got information for us; they got us linked up with ... politicians: they got us linked up with the different MECs ...

Interview 16, Sandra Ambrose, DICAG, 2006

E-mail updates about dates of hearings, etc.:

I think providing us with information that we needed particularly in terms of the advocacy process and what was happening in parliamentary processes ..., advice, direction, encouragement.

Interview 18, Sue Philpott, DART, 2006

• Involving people in the ceremonial events – it made them feel special:

It was quite an experience, you know, to be a big part.

Interview 16, Sandra Ambrose, DICAG, 2006

The support of a central organising body and the disability sector were critical. Characterising challenges and developing positions took extensive consultation, time, money and dedicated work by a co-ordinator. Defining the rights and drafting proposals required support from legal experts. Following the debate and knowing how and when to react required an ongoing, expert presence in Parliament, and providing that expert support required dedicated funding. The funding also allowed for core activities that NGOs could not normally engage in, such as holding workshops, transporting presenters to public hearings, and maintaining a presence in Parliament.

Being part of a larger campaign

Being part of something bigger built confidence and unity of purpose, and decision-makers noticed its favourable effects:

[The WG] are forcing other NGOs to think, and they were bringing them on board and there was a ... kind of a camaraderie of child rights organisations, but also others ... that work with children and all of them started to speak the same language. It was well researched, it was well thought-through and people came with alternatives to the table.

Interview 11, government official, 2005

What stood out for MPs was that marginalised groups were able to participate; empowered by involvement in something bigger, these groups could have their stories heard:

Children's Institute really provided a lot of leadership. What was interesting for me ... was the pulling in of parents of disabled children. That has never happened. Usually you find disabled children [have] been left out. And for me, I think that was one of those 'Aha!' moments. I think they [the CI] had really done very well in leading that process. Children's Institute providing the required leadership in the

administration and the co-ordination; in providing that leadership they also made space for members of the working group to retain their individual autonomous status as organisations. That for me also gave them that 'Aha!'

Interview 5, ANC MP, 2006

Common messages emphasise points

One strategic ploy used effectively was repetition: having multiple organisations repeating the same argument at the same event, or presenting the same arguments in different formats over time. Parliamentary researchers, staff and drafters found it irksome, but it worked with the MPs – the people holding decision-making power:

What was also amazing was, without fail, every NGO spoke about the National Policy Framework, which I thought was quite clever – that, you know, you guys had organised yourselves. It was good.

Interview 14, Opposition MP, 2005

The importance of a unified stance

A unified stance makes for effective communication and public participation:

Over the years I think the public's concerns via the NGOs have consolidated, you know, in the beginning it was very much more individual lobbying than anything else; now that I don't think is there so much anymore. ... I appreciate the consolidation of NGOs speaking with one voice. I can't tell you how horrific public hearings used to be.

Interview 12, Opposition MP, 2005

When you get different messages or conflicting messages it's going to do [harm] because the sector has to be unified in their approach.

Interview 19, Dr Siva Moodley, DPSA, 2006

Membership of the WG enabled DTT members to gain insight from experienced campaigners and increase the opportunities for raising disability issues by ensuring that other organisations endorsed DTT submissions and included disability messages in their own submissions. Being part of a larger group gave them knowledge, impact, confidence and a sense of solidarity.

7.2 Essential ingredients in the sub-group campaign

Decision-makers and members of the DTT and the disability sector at large identified several factors that contributed to the success of the DTT campaign. The support from the CI and WG was an essential ingredient, but respondents cited other ingredients that related specifically to this campaign. It was vital to possess **resources**, a **dedicated co-ordinator**, **funding** and a strong **administrative base**. The CI and DICAG provided such a base, and through it, were able to secure and manage the funds for the campaign. The CI spent on average R1 million per annum on the collective campaign, including dedicated support to the DTT, and the DTT spent an additional R105,000 in 2005.

Having financial resources and an administrative base enabled the DTT to pursue the further, essential practice of **consulting constantly** with its sub-sector through SAFCD and other key organisations. These consultations embraced not only organisations working with children with disabilities and chronic illnesses but parents and children as well. For one DTT member, the inclusion of parents was the most "significant" factor of all in their success. Parents were deeply committed to the issues and ready to fight for the recognition and protection of their children's rights. Moreover, parents also speak the same language as MPs:

If we don't get parents to understand what that means and why the Bill is advocating for whatever, you can't get it passed, because parliamentarians are parents too.

Interview 20, Petronella Linders, National Youth Commission, 2006

A virtuous circle of communication developed. The more the DTT consulted, the more their members grew in confidence and made an impact; as these successes were reported back to the sub-sector, so more people were encouraged to participate. Not only did consultation with others give the DTT confidence in their message, it also gave them legitimacy in the eyes of others.

The DTT wanted their audience to make specific recommendations to amend the Children's Bill. They learnt it was important to identify and describe the relevant issues. **Characterising the challenges facing children** was the first step for the public and MPs alike:

They gave us a further insight as to what are the challenges that confront ... people that have to ... fulfil some of the responsibilities to children. And that perspective is very useful to enable us to see in what way we could possibly assist, in the way we would formulate the legislation ...

Interview 10, ANC MP, 2005

The WG used legal experts to help formulate recommendations as legislatives amendments: **Proposing legislative solutions** made it easier for drafters to adopt changes and also ensured that nothing was lost in translation. A further benefit was that such demonstrable expertise enhanced the group's credibility with MPs and reassured the latter that the legislation was practical.

Presenting in Parliament was essential. Despite the travel costs it entailed, members had to be present at the public hearings to explain the submission and help MPs understand it more fully through an opportunity to question the authors:

Unless you have interacted with the person, or the people, that does the written submission you may not get the full context the submissions have raised. And that written submission alone does not provide the platform for engagement which oral submissions do; so I think that on their own they are not adequate.

Interview 10, ANC MP, 2005

The personal interaction benefited civil society too:

For parliamentarians it was very important because they got to cross-examine us and we got to know their way of thinking.

Interview 17, Nonceba Meyiwa, DICAG, 2006

It was important to recognise the different needs of target audiences. DTT made two submissions — a technical submission and a case study. MPs do not have time to read lengthy technical reports and prefer hearing vivid stories. Sometimes *what* was said was less important than *how* it was said:

I don't look so much at the actual words because they are unimportant; it's actually the feeling behind the words that matter to me. Now I will listen with sympathy because it fashions my thought processes.

Interview 12, Opposition MP, 2005

It is essential to **check the summary of submissions and correct any omissions**. Few, if any, MPs sit through public hearings in their entirety, or read all submissions. As one official pointed out, "the real debates happen in the portfolio committee meetings" (Interview 11, government official, 2005). There, MPs rely almost exclusively on an official summary of the submissions; and because the summaries can have omissions, it is critical that MPs have accurate information brought to their attention. Even so, drafters facilitating the discussion used the summary selectively, a practice making it all the more necessary **to track the debate** and engage directly with MPs to ensure that key points remain on the agenda:

There wasn't really time to go to the committee and put all the comments on the table and have discussions on all of them – that was simply not possible ... we selectively mentioned some of the comments that we received; we did not mention everything.

Interview 9, government official, 2005

Writing an executive summary for submissions helps ensure that the researchers summarise and present the most important information.

Maintaining a presence in Parliament was also identified as an essential ingredient. MPs have queries and questions; having someone in Parliament meant that the DTT could respond to them. Since it is not possible to have a team of experts on hand to answer all the questions, the advocacy co-ordinator took a **spokesperson list** so that she could connect MPs to people with relevant expertise; these persons should be kept briefed on current issues and be ready to respond.

In the campaign's early phases it was possible to give detailed responses to questions and even present new evidence to the MPs. The DTT maintained dialogue with MPs by various means, sending them notes during debates or writing extended briefings shortly afterwards.

MPs said they found this extra information useful, and parliamentary staff commented on the importance of maintaining dialogue by using **different products** over a period of time, such as "opinion papers now and again, or short research reports to the committee chairperson" (Interview 15, parliamentary officer, 2005).

Operating in a law-reform process with tight timeframes means that time is of the essence. Sometimes the committee would change its schedule and MPs would be alerted unexpectedly to attend meetings. **Anticipating possible responses** to the debate helped the DTT prepare for these moments:

Issues need to be clear quickly. We have to have reached a position before the debate. We also need to plan counter-arguments in advance and have them ready when we start engaging. It is not a good idea to have to go back and respond a couple of days later.

Interview 15, July Nkutha, DICAG, 2005

Sometimes there was only one opportunity to influence the debate, and many of the DTT's successes came about because someone was physically present to intervene at deliberations:

You also have people in the committee which is helpful; the idea there, passing notes to members of Parliament, is a good idea. Because as that issue comes up, there is a moment, and then it passes because there is always such a time problem.

Interview 3, Opposition MP, 2005

There were times when the debate dragged on through the night. Being present was necessary to maximise opportunities for influence; but it also demonstrated commitment:

[T]hey never lost momentum. ... I mean, it will be two o'clock in the morning and we will all be dragging for coffee, and they will be there. That level of commitment was very positive for me. It actually affirmed the seriousness that they take children.

Interview 5, ANC MP, 2006

MPs have a responsibility to consult with their constituencies and educate themselves about the topics they address in committees: This presents opportunities for informal engagement. The DTT found that **face-to-face meetings** allowed them to get a better understanding of the individual MPs' queries and discuss how particular recommendations related to the vision of each political party:

I think they should engage parliamentarians directly. You know there's always a lunchtime, there's always an hour, you know that you can steal somewhere. It's no good saying you're too busy to interact.

Interview 12, Opposition MP, 2005

Conversations with MPs should not be restricted to the parliamentary precinct. MPs were asked to rank the usefulness of different stages of the parliamentary process. In terms of influence, the **study tour** was rated just ahead of the public hearings:

Because they did something different that no other process would and that was to give us a first-hand appraisal of the situation on the ground. And an opportunity to interact with service providers, social workers on the ground, and get to hear from

them, which is a very rare occasion. To hear from them what are the real challenges that they are encountering. Speak to communities, you know communities; speak to children themselves, see the facilities see the challenges ... nothing else can take the place of that and so they were useful.

Interview 10, ANC MP, 2005

The study tours were organised by the provincial departments of social development, and NGOs and CBOS had little control over whether they were included in these formal tours. But the same positive impact was gained from **constituency visits** organised by the DTT:

It's had a very profound impact on yourself in terms of urgency with regards to certain issues, significance and appropriateness of the initiative, you know, policies ...

Interview 10, ANC MP, 2005

Everyone interviewed emphasised the importance of **building relationships with decision- makers:**

Getting the MPs to assist us in supporting our position in specific ways ... was made easier because we were not complete strangers.

Interview 18, Sue Philpott, DART, 2006

They built a good relationship with Hendrietta. They were able to inform her properly, about what the issues are and she was then prepared to go out there and put her neck on the line, if I can put it that way, to ensure that that clause is kept in the Bill.

Interview 20, Petronella Linders, National Youth Commission, 2006

MPs are selective about which issues they champion, so campaigners must **target MPs according to their interests.** The MPs targeted by the DTT were either parents of children with disabilities or themselves people with disabilities, and could thus identify closely with the issues the sub-group was raising.

It also helped to be acquainted with the targeted MPs and know their individual strengths and inclinations:

So that you don't spend time trying to talk to me about religious issues and I am not interested in religion. So, when a particular Bill comes, they need to learn to know their members and the strengths they have.

Interview 5, ANC MP, 2006

Another way to influence MPs was to lobby the people to whom they speak – in other words, working, and building relationships, with the decision-makers' support staff. Parliamentary research staff are subject specialists and tend to grasp arguments more quickly than MPs; they summarise information for MPs and pass on useful documents. The **portfolio committee clerk** writes a weekly letter to the MPs on the committee and can send out information or invitations to members to visit organisations during constituency week.

It was also sometimes useful for organisations to send information to the **researcher**, who is able to recommend that the committee consider particular issues:

I have said to the chairperson, 'Madame Chairperson, I really think that we should do x or y or z based on this information that I got from the Children's Institute or from Community Law Centre'.

Interview 15, parliamentary officer, 2005

Referring to what she termed "critical incidents", Sue Philpott described the contact that was made with the **executive drafting team**:

Given that the committee had not consistently given clear instructions to the drafters, there was scope for interpretation – and this is where the input of the task team was critical. In addition, the fact that there was a telephone call to follow up [on] the written submission enabled a number of issues to be clarified.

Disability Task Team Report, 2005b: 13

The lobbying load was shared not only with the sector and the WG, but with other **influential organisations** and **MPs from other committees**. **Individuals** also played an important role – they could take advantage of informal opportunities for advocacy:

I am fairly senior within the youth commission; I was able to speak to people like Hendrietta, Lewis and Mike, parliamentarians themselves, knowing them personally and it wasn't a structured approach or anything like that; it was more about calling them up, informal conversations and having the opportunity to see them in meetings of the commission; I would ask them: How far is the process, are they supporting it?

Interview 20, Petronella Linders, National Youth Commission, 2006

Although it is better to engage continuously with all the decision-makers, sometimes it was necessary to **exert pressure** before they would change the Bill. The Department of Social Development published the draft Bill for comment in September 2003, but made no changes to the Bill in response to submissions. Asked why, an official replied:

I think they basically just published it to cover all angles, I don't think they seriously published it for comment.

Interview 9, government official, 2005

Having failed to persuade the Department of Social Development to make amendments to the Bill, the DTT appealed to the MPs. When the committee rejected a government proposal, the same official complained and appealed for civil society to talk to the government:

I don't think any state department is ever unwilling to listen and to take ideas on if there can be improvements.

Interview 9, government official, 2005

Strategists had to decide when to keep dialogue open, when to target particular individuals, and when to exert external pressure. The **news media** can be used judiciously, either to keep the public informed or apply pressure as a measure of last resort. It is a fine balancing

act. A point may be made, but to the detriment of good long-term relationships with a target group:

For some other reason they opted to go to the media, and it really upsets.

Interview 4, parliamentary officer, 2005

Finally, there were times when it had to be accepted that it was unproductive to continue a campaign. Strategists need to **realise when an argument has been exhausted**. One example was the reinsertion of Chapter 16:

Civil society sometimes barks at trees that would never bend, and in the process of doing that, they alienate and irritate members and communication breaks. When communication breaks, then members don't hear them anymore The [WG] were strategic enough to read the mood of the members So they didn't waste time and energy, they would just switch to the next point, and that was another positive thing.

Interview 5, ANC MP, 2006

8. Conclusion

The purpose of this paper was to document the DTT's advocacy campaign, evaluate the impact it had, and examine the factors contributing to its success. Evaluating its impact shows that the campaign was very successful. Not only were the views of the disability sector represented throughout the debate, but the majority of the legislative solutions proposed by the DTT were incorporated into the final text of the Children's Bill. The campaign also had unexpected benefits, ranging from the personal growth of the individuals involved to the revival of the disability sector. Analysis of the campaign reveals that a combination of factors was critical to its success.

The DTT prepared for the public hearings on the Children's Bill by conducting widespread consultation with the disability sector. They gathered evidence of the challenges facing children, researched the obligations on the State, and led the sector to consensus on possible solutions to the challenges. They overcame their fears and presented two submissions in Parliament, one a technical proposal from the sector, the other the story of a parent. Many organisations end their engagement in law reform after the public hearings. The DTT maintained their campaign over the period of a year and a half, using all the opportunities available to them, and creating their own.

Campaigners need to do more than make their points during a public hearing. Advocacy is a two-way conversation: They need to follow the debates closely, listening carefully to the MPs, and then need to respond to queries and concerns. Such continuous engagement demonstrates strength of commitment and builds relationships. As the DTT established their credibility, so the relationships deepened and led to greater levels of trust. These relationships proved to be critical when the Executive ordered the portfolio committee to remove the amendments that would facilitate the participation of children with disabilities in court processes affecting them.

The DTT used their extended network to show the demand for reform and drew on the media to apply additional pressure. MPs changed the legislation despite opposition from the Executive because they had personal experience of exclusion, felt supported by a network of people with the same experiences of exclusion, and were provided with evidence.

This study demonstrates that advocacy activities must extend beyond formal opportunities. Lobbyists must target individuals carefully and choose appropriate times and places to meet; vary the representatives and the mode of engagement. The DTT was successful because they used multiple modes of engagement: constituency visits, study tours, meetings, telephone calls, sms-es and notes.

The DTT also presented their evidence in a variety of formats. To show that a problem is widespread, academic research is invaluable, but because MPs do not have time to read multiple reports, short case studies allowed them to understand the issues quickly and draw parallels with the challenges faced by themselves and their own constituents. The fact that the DTT's proposed changes were written in legal language meant they could be easily inserted into the Bill by the drafters without any need for interpretation.

The DTT could not have won success by working alone; the support of a central organising body and of the disability sector was vital to their achievement. The central body initiated and sustained the general Children's Bill campaign both financially and politically.

This study shows that advocacy is clearly a process of education, dialogue and relationship building. If at first you don't succeed, try again, but vary your tactics and strategies. The rewards of persistent and imaginative campaigning were that a small, dedicated team were able to move children with disabilities from the sidelines to centre stage of social service delivery.

Appendix A: Analysis of recommendations adopted by other organisations

All the Working Group submissions were analysed to see if organisations had either repeated, or endorsed, a recommendation made by DICAG. The following contained recommendations or endorsed the DICAG position:

- Alliance for Children's Entitlement to Social Security, Submission on the Children's Bill [B70-2003], to the Portfolio Committee On Social Development, 27 July 2004
- Centre For Applied Legal Studies, Education Law Project, Law And Transformation Programme, Submission to the Portfolio Committee Hearings on the Children's Bill, July 2004
- Children's Institute, Submission Number 1 On The Children's Rights Chapter Of The Children's Bill, University Of Cape Town, 27 July 2004
- Children's Bill Working Group, Joint Submission On The Children's Bill, 27 July 2004
- Dikwankwetla Children in Action, Children are the Future Give Them Their Rights: Submission On The Children's Bill To The Portfolio Committee On Social Development, July 2004
- Early Learning Resources Unit and South African Congress for Early Childhood Development, Submission on the Children's Bill [B70-2003] to the Portfolio Committee on Social Development, 27 July 2004
- Johannesburg Child Welfare Society, Submission On Aspects Of The Children's Bill Relating
 To Substitute Family Care, July 2004
- Joint HIV/AIDS Sector, Submission On Section 75 Of The Children's Bill [B70-2003] Presented To The Portfolio Committee On Social Development, 27 July 2004
- RAPCAN, Submission To The Parliamentary Portfolio Committee On Social Development The Children's Bill Prevention Is Better Than Cure, July 2004
- South African Council Of Churches, *Children's Bill [B70-2003 (Reintroduced)] Submission To The Department Of Social Development, 27 July 2004.*
- South African Human Rights Commission, *Children's Bill [B70-2003], Submission to the Parliamentary Portfolio Committee on Social Development, 27 July 2004*
- South African National Council For Child Welfare, Submission To The Parliamentary Portfolio Committee For Social Development On The Children's Bill 12 August 2003 Section 75 Bill, July 2004
- Soul City/ Buddyz, Children's Bill Submission, July 2004
- South African Society for the Prevention of Child Abuse and Neglect, *Children's Bill:*Submission On Child Protection, Incorporating Prevention And Early Intervention
 And Children In Especially Difficult Circumstances, July 2004
- Youth Action Group, It's Your Move Joint Submission, On Section 75 Of The Children's Bill [B70-2003] Presented To The Portfolio Committee On Social Development, 27 July 2004

Breakdown of support for each recommendation:

DICAG proposal	ORGANISATIONS SUPPORTING THE	
	RECOMMENDATION	
Reinsertion of the rights clause	ACESS (p. 10); Children's Bill Working Group(p. 3); RAPCAN (p. 6); CALS (p. 9); HIV(p. 6); SA National Council for Child Welfare (p. 6); Children's Institute (pp. 10 & 37); SACC (p. 2); Soul City/Buddyz (p. 6)	
Reinsertion of the unfair discrimination clause	ACESS (p. 10); Children's Institute (p. 24); SACC (p. 2)	
Equal treatment for children with disabilities	Youth Action Group called for children to "be treated equally, regardless of disabilities" (p. 8); Dikwankwetla – Children in Action: "The Bill needs to be mindful of addressing needs of ALL children, instead of separating them into groups such as the disabled, those infected by HIV/AIDS." (p. 7)	
Right to participation	Children's Institute (pp. 10 & 29)	
Information on health care and access to contraception	Soul City/Buddyz (pp. 11 & 12)	
Assistive devices for children with disabilities	JCWS recommended the reinsertion of clause 347 removed from the SALRC draft which provided for a "means-tested subsidy to enable those with disabilities to obtain assistive devices" (p. 5). ACESS called for the extension of the care dependency grant to children with moderate disabilities (p. 22). Other organisations called for the reinsertion of the right to health care, which includes the right to: "(d) have access to appropriate assistive devices that are necessary to enable the participation of children with disabilities and chronic illnesses in community life" (CI, pp. 10 & 34).	
Early childhood development	 ELRU and SA Congress for ECD made a joint submission which had two pages dedicated to children with disabilities. They advocated for: an inclusive approach to ECD; a range of programmes that could accommodate children with different types of impairment; funding and training for family programmes run by parents of children with disabilities. They outlined the role that the ECD sector could play in terms of: prevention of illnesses and injuries leading to disability; early identification and intervention for children with disabilities and chronic illnesses; and appropriate referral of children identified who have health or social needs (pp. 23 – 24). 	

Call for the reinsertion of the strategies	ACESS (p. 16) Children's Bill Working Group (p. 5);
dealing with children in especially	Soul City/Buddyz (p. 10); SASPCAN (p. 2)
difficult circumstances	σου, σιτη σασαγε (ρ. 10], σποι σπιν (ρ. 2)
National Policy Framework	Most organisations in the Working Group asked
National Folicy Hainework	for the NPF to be reincorporated into the Bill;
	•
	however, some specifically argued for a NPF to address the needs of children with disabilities.
	They included SASPCAN (p. 9); Soul City/Buddyz,
	(pp. 6 – 7) and the SAHRC:
	"Issues that the National Policy Framework could
	address include:
	The integration and prioritisation of the needs of
	children with disabilities within all spheres of the
	implementation of the Bill" (p. 4)
	"The National Policy Framework should also
	make reference to children with disabilities and
	ensure that the implementation of the Bill takes
	account of the special needs of children with
	disabilities." (p. 9)
Children's Courts	In order to promote the creation of a barrier-free
	court system for children with disabilities, the
	SAHRC recommended the following:
	"Clause 42 – Children's courts and presiding
	officers:
	That an additional sub section be added to clause
	42(7) of the Bill which states that court hearings
	must be held in a room which is accessible to
	children with disabilities." (p. 9)
Harmful social and cultural practices	Soul City/Buddyz (p. 7) called for a debate on
	harmful social and cultural practices:
	"The birth of a child with disabilities, especially
	when the impairment is visible at birth, is a
	traumatic experience for any family. Issues of
	guilt, rejection, denial and anguish are emotions
	that the family has to deal with daily. This is
	exacerbated by the cultural norms surrounding
	the child's birth. The issues should be debated
	and a solution sought with reference to Clause 12
	(Harmful social and cultural practices)."
Financial support for care-givers	Both ACESS (p. 18) and JCWS (p. 5) called for
	means-tested grants to increase the ability of
	care-givers to provide for children with
	disabilities and chronic illnesses.
Financial support to foster parents care	JCWS called for the removal of "financial
for children with disabilities	obstacles in the way of families who would
	otherwise be willing to care for children, including
	the charging of fees for essential public services,
	such as health and education, and the extra costs
	of caring for a child with special needs, for
	example those arising from physical or mental
	disabilities or chronic illness" (p. 4).

Appendix B: Analysis of Children's rights in the Children's Act

	Africa's international and constitutional	Children's Act No. 38 of 2005
•	tions. The right: to family care or parental care, or appropriate alternative care	Section 2(b)(i), section 11(1)(a)
•	to social services	Section 2(b)(ii)
•	to be protected from maltreatment, neglect, abuse or degradation	Section 2(b)(iii)
•	to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community	Section 6 (2)(f), section 11(1)(c)
•	child's best interests should be the primary consideration in matters all affecting the child	Section 2(b)(iv), section 7, and section 9
•	to equality	Section 6 (2)(c)
•	to protection from discrimination	Section 2(f), section 6 (2)(d)
•	to freedom of expression and the right to participate in decisions affecting them	Section 6(5), section 10
•	to protection against harmful social and cultural practices	Sections 11(3) and 12
•	to have special needs recognised	Section 6 (2)(f), sections 7(1)(i) and (j), section 11(1)(b)
•	to special care and appropriate assistance	Sections 11(1)(a) and (d)

Appendix C: List of the Children's Bill Working Group Members

Aids Legal Network

Aids Law Project

Alliance for Children's Entitlement to Social Security

Association for Persons with Disabilities

Black Sash

Caring Schools Network

Catholic Institute for Education

Centre for Child Law, University of Pretoria

Child Advocacy Programme

Child Welfare South Africa

Childline South Africa

Children First

Children's HIV/AIDS Network

Children's HIV/AIDS National Network for SA National AIDS Council

Children's Institute, University of Cape Town

Children's Rights Centre

Children in Distress Network

Congress of South African Trade Unions

Community Law Centre

Disabled Children's Action Group

Disabled People South Africa

Disability Action Research Team

Early Learning Resources Unit

Gender Advocacy Programme

Human Sciences Research Council

Johannesburg Child Welfare

Lawyers for Human Rights

Legal Aid Clinic, University of Cape Town

Molo Songololo

Networking AIDS Community Of South Africa

National Alliance for Street Children

National Association of Child and Youth Care Workers

National Child Rights Committee

National Early Childhood Development Alliance

National Welfare, Social Service and Development Forum

National Youth Commission

Network Against Child Labour

Resources Aimed at the Prevention of Child Abuse and Neglect

South African Democratic Trade Union

SAVE the Children UK

SAVE the Children Sweden

South African Society Prevention of Child Abuse and Neglect

Soul City

South African Congress for Early Childhood Development

South African Council of Churches

South African Human Rights Commission

South African Society for the Prevention of Child Abuse and Neglect

Southern African Catholic Bishops' Conference Parliamentary Office

Umtata Child Abuse Resource Centre

Towards the End of Child Labour

References

Drafts of the Children's Bill

South African Law Reform Commission (2002) Children's Bill, (Minister of Social Development), [B-2002].

Children's Bill [B70 of 2003 (Reintroduced)] – Bill tabled in Parliament.

Children's Bill [B70B of 2003] – Bill passed by the National Assembly, 22 June 2005.

Children's Bill [B70C of 2003] – Amendments proposed by the NCOP, 13 December 2005.

Children's Bill [B70D of 2003] – Bill passed by the National Assembly, 14 December 2005.

Department of Justice (2005) Proposed amendments to "Chapter 5: Children's Courts"

(Children's Bill [B70 of 2003 (Reintroduced)]). Presented to Portfolio Committee on Social Development by Department of Justice, 23 May 2005.

Children's Act No. 38 of 2005.

Other Legislation

Constitution of the Republic of South Africa Act No. 108 of 1996. Promotion of Equality and Prevention of Unfair Discrimination Act No 4. of 2000.

International Treaties, Resolutions and General Comments

- Office of the High Commissioner of Human Rights (1989) Convention on the Rights of the Child, UN Assembly Resolution 44/25.
- Organisation for African Unity (1990) *African Charter on the Rights and Welfare of the Child.*OAU Doc. CAB/LEG/24.9/49.
- United Nations (1966) International Covenant on Economic, Social and Cultural Rights, 999
 UNTS 3
- United Nations (1994) General Comment 5, Committee on Economic Social and Cultural Rights, HRI/GEN/1/Rev.1.
- United Nations General Assembly (1993) Standard Rules on the Equalization of Opportunities for Persons with Disabilities, A/RES/ 48/ 96/, 85th Plenary Meeting, 20 December 1993.
- United Nations Committee on Economic Social and Cultural Rights (1997) *Children with disabilities. Resolution 1997/20.* Adopted at the 36th plenary meeting, 21 July 1997.

Children's Institute Updates and Briefings

- Children's Institute (2004) *Advocacy Strategy: Child Rights.* Presented to the Working Group, 1 December 2004.
- Children's Institute (2005a) Checklist for Sub-group Advocacy. University of Cape Town.
- Proudlock P, Nicholson J & Dyason B (2004) *The Children's Bill Resource Pack*. Children's Institute, University of Cape Town.
- Paula Proudlock (2003) *Progress Report on the Children's Bill.* Children's Institute, University of Cape Town, 25 October 2003.
- Proudlock P (2005) *Description of the Children's Bill Project.* Children's Institute, University of Cape Town, 24 March 2005.

- Jamieson L & Proudlock P (2005) *Children's Bill Progress Update: Report on amendments made by the Portfolio Committee on Social Development.* Children's Institute, University of Cape Town, 27 June 2005.
- Jamieson L (2005) Children's Bill Progress Update: Report on Select Committee on Social Services deliberations on the Children's Bill and proposed amendments as at 09 November 2005. Children's Institute, University of Cape Town.

Disability Task Team Reports

- Meyiwa N (2006a) *Report 2: Writing the case study and presenting at the public hearings in Parliament.* September 2006.
- Meyiwa N (2006b) Report 4: Meetings with the MPs in Parliament, and constituency visit to Nigel; writing the case study and presenting at the public hearings in Parliament. September 2006.
- Philpott S (2006a) Report 1: Background report and description of the disability sector. 19 September 2006.
- Philpott S (2006b) Report 3: Policy Workshop. 19 September 2006.
- Philpott S (2006c) *Report 5: Building relationships with decision-makers.* 19 September 2006.
- Philpott S (2005a) Discussion with Ronel van Zyl. 12 May 2005.
- Disability Task Team (2005a) *Children's Bill Working Group Disability Sub-Group Advocacy Plan, March 2005.*
- Disability Task Team (2005b) Disability Task Team of the Children's Bill Working Group Final report of the activities for the period January June 2005.

Minutes

Disability Task Team (2005c) Disability planning meeting minutes, 15 March 2005.

Disability Task Team (2005d) Key messages on the Section 75 Children's Bill, March 2005.

- Disability Task Team (2005e) Meeting of the Disability Task Team of the Children's Bill Working Group, Children's Institute, 20 May 2005.
- Disability Task Team (2005f) Minutes of Meeting with Louis Nzimande and Mike Masutha, SP3/19/2005.

Submissions to Parliament by the Disability Task Team

- Disabled Children's Action Group (2003) Submission to the Department of Social Development on the Children's Bill: Sub-sector: Children with disabilities & chronic diseases, 24 October 2003.
- Disabled Children's Action Group (2004a) Executive summary of submission on the Children's Bill, August 2004.
- Disabled Children's Action Group (2004b) Submission to the Portfolio Committee on Social Development on the Children's Bill: Section 75[B70-2003 (Reintroduced)], 13 August 2004.

- Disabled Children's Action Group (2005a) *Draft submission from the Disabled Children's*Action Group to the Portfolio Committee of the Department of Social Development,

 March 2005.
- Disabled Children's Action Group (2005b) *Key messages on the Section 75 Children's Bill, March 2005.*
- Disabled Children's Action Group (2005c) Submission on the Children's Bill to the Portfolio Committee of the Department of Social Development, April 2005.
- July Nkutha (2005) Key Messages on the Section 75 Children's Bill: Presentation to the Portfolio Committee on Department of Social Development, April 2005.
- Meyiwa N (2004) Case study on a child with a chronic illness. DICAG, 13 August 2004.
- Philpott S (2005b) *Discussion document on terminology: "children with disability or chronic illness"*. Disability Task Team of the Children's Bill Working Group, April 2005.

Submissions to Parliament by Other Organisations

- Alliance for Children's Entitlement to Social Security (2001) Submission on the Children's Bill [B70-2003] to the Portfolio Committee On Social Development. 27 July 2004.
- Centre For Applied Legal Studies, Education Law Project, Law And Transformation Programme (2004) *Submission to the Portfolio Committee Hearings on the Children's Bill.* July 2004.
- Children's Institute (2004) Submission Number 1 On The Children's Rights Chapter Of The Children's Bill. University Of Cape Town, 27 July 2004.
- Children's Bill Working Group (2004) Joint Submission On The Children's Bill. 27 July 2004.
- Dikwankwetla Children in Action (2004) *Children are the Future Give Them Their Rights:*Submission On The Children's Bill To The Portfolio Committee On Social
 Development. July 2004.
- Early Learning Resources Unit and South African Congress for Early Childhood Development (2004) Submission On The Children's Bill [B70-2003] to the Portfolio Committee on Social Development. 27 July 2004.
- Johannesburg Child Welfare Society (2004) Submission On Aspects Of The Children's Bill Relating To Substitute Family Care. July 2004.
- Joint HIV/AIDS Sector (2004) Submission On Section 75 Of The Children's Bill [B70-2003].

 Presented to the Portfolio Committee On Social Development, 27 July 2004.
- RAPCAN (2004) Submission To The Parliamentary Portfolio Committee On Social Development The Children's Bill Prevention Is Better Than Cure. July 2004.
- South African Council Of Churches (2004) *Children's Bill [B70-2003 (Reintroduced)].*Submission To The Department Of Social Development. 27 July 2004.
- South African Human Rights Commission (2004) *Children's Bill [B70-2003]. Submission To The Parliamentary Portfolio Committee on Social Development.* 27 July 2004.
- South African National Council For Child Welfare (2004) Submission To The Parliamentary Portfolio Committee For Social Development On The Children's Bill, 12 August 2003 Section 75 Bill. July 2004.
- Soul City/ Buddyz (2004) Children's Bill Submission. July 2004.
- South African Society for the Prevention of Child Abuse and Neglect (2004) *Children's Bill:*Submission On Child Protection, Incorporating Prevention And Early Intervention

 And Children In Especially Difficult Circumstances. July 2004.

Youth Action Group (2004) *It's Your Move: Joint Submission on Section 75 of the Children's Bill [B70-2003]*. Presented To The Portfolio Committee On Social Development, 27 July 2004.

Newspaper articles

Quintal A (2005) Don't amend Children's Bill. The Mercury, 2 June 2005.

Mthethwa B & Khumalo S (2005) Uproar as State Moves to Ban Virginity Testing: Bill said to tamper with the heart of African tradition. *Sunday Times*, 10 July 2005.

Philpott S (2005d) Letter to the Editor. The Witness, 29 June 2005.

Miscellaneous

- Barberton C (2006) The Cost of the Children's Bill Estimates of the cost to Government of the services envisaged by the Comprehensive Children's Bill for the period 2005 to 2010. Pretoria: Cornerstone Economic Research. Report for the Department of Social Development.
- Department of Justice (2005) *Proposed Select Committee Amendments To Children's Bill* [B70B 2003].
- Children's Institute (2005b) Minutes of the Children's Bill Policy Workshop, 13 14 April 2005.
- Dhai A (2003) 'Ethical & societal issues in the care and management of the intellectually disabled child as they grow up'. Presented at a workshop of the South African Association for Scientific Study of Mental Handicap, Johannesburg General Hospital.
- Disability Task Team (2003) Letter to Marian Jacobs, director of the Children's Institute, August 2003. [On file at the Children's Institute]
- Dutschke M (2006) *Defining children's constitutional right to social services*. A Project 28 Working Paper, July 2006. Children's Institute, University of Cape Town.
- Lamprecht L (2003) 'Sexuality in children with intellectual disabilities'. Presented at a workshop of the South African Association for Scientific Study of Mental Handicap, Johannesburg General Hospital.
- Office on the Rights of the Child (2005) 'Children's Bill and Related Legislation: Implications for State Departments and other Institutions, Part Two'. Presented to the Portfolio Committee on Social Development, 19 January 2005.
- Office of the Deputy President (1997) White Paper on Integrated National Disability Strategy, November 1997. Pretoria: Government Printers.
- Parliamentary Monitoring Group (2005a) Minutes of the Portfolio Committee on Social Development meeting, Children's Bill Deliberations, 23 May 2005.
- Parliamentary Monitoring Group (2005b) Minutes of the Portfolio Committee on Social Development meeting, Children's Bill: Joint Presentation By Departments On The Interdepartmental Steering Committee, 19 January 2005.
- Parliamentary Monitoring Group (2005c) Minutes of the Select Committee on Social Services meeting, Children's Bill: Discussion; Nomination of Central Drug Authority Candidates: Briefing, 06 September 2005.
- Parliamentary Monitoring Group (2005d) Report of the Portfolio Committee on Social Development meeting, 20 May 2005.

- Proudlock P (2006a) Letter to the Portfolio Committee on Social Development, 15 March 2005. [On file at the Children's Institute]
- Proudlock P (2006b) Letter to the Portfolio Committee on Social Development, 24 March 2005. [On file at the Children's Institute]
- Portfolio Committee on Social Development (2005) Transcript of meeting, 1 June 2005. [On file at the Children's Institute]
- South African Law Reform Commission (2003) *Memorandum on the Objects of the Children's Bill.*



Tel: +27 21 689 5404 Fax: +27 21 689 8330

E-mail: info@ci.org.za Web: www.ci.org.za