

Submission on the White Paper on the NHI

NATIONAL HEALTH INSURANCE FOR SOUTH
AFRICA: TOWARDS UNIVERSAL HEALTH
COVERAGE (Version 20)

to the Director-General: Health
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by the Disabled Children's Action Group (DICAG)



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Introduction

The Disabled Children's Action Group (DICAG) was established in 1993 and is a mass membership organisation of parents¹ of children with disabilities. DICAG focuses on parent empowerment and capacity building, as well as advocacy and monitoring the implementation of government policies.

DICAG has two key programmes - *development* and *advocacy*. The development programme seeks to empower parents of children with disabilities with knowledge and life skills to be able to respond to their children's rights and needs and to empower children with disabilities to be self-advocates on their own issues. The advocacy programme of DICAG seeks to promote and protect the rights of children with disabilities and ensure that government and human rights bodies formulate and implement policies that will enable the full inclusion and participation of children with disabilities, towards creating a "Society for All".

This submission highlights some of the most pressing challenges of children with disabilities in the public health sector and then makes comments and recommendations in respect of various clauses of the White Paper on the NHI. These are made in the spirit of working towards a truly universal health system, in which the Department of Health, together with other key partners is able to provide health services that ensure access to health for *all* children.

Children with disabilities and the public health sector

With respect to health services, children with disabilities need two things. First, they need access to child health services that are provided for all other children. Children with disabilities need to be immunized, they need curative care when they are sick and their parents need to know about breastfeeding and how to promote good nutrition. Provision of such services is an obligation of the State, as according to the Convention on the Rights of Persons with Disabilities (CRDP) 25 (a)

*States parties shall provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to all other persons... including population-based public health programmes. This requires the removal of all barriers to access and participation, including access to transport to information and universal access and design.*²

Secondly, children with disabilities need access to specific services, such as rehabilitation and assistive devices. Again this is an obligation of government, as according to the CRPD 25 (b), the State as a signatory undertakes to

*Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, as services designed to minimise and prevent further disabilities.*³

¹ The term 'parent' is used to refer to the primary caregiver of a child with a disability, which may not be the biological parent of the child.

² *UN Convention on the Rights of Persons with Disabilities (2008)s*. CRPD Art 9, RSA (2016) White Paper on the Rights of Persons with Disabilities p.87.

³ This is also reflected in Article 23 of the CRC, in which the State is obliged to recognise the special needs of children with disabilities and ensure they have effective access and receive health care services and rehabilitation services, which should be free of charge wherever possible.

Despite the South African government's ratification of the CRPD, children with disabilities face many pressing challenges with respect to the health sector. These include the following:

- Poor availability of rehabilitation services, which is compounded by lack of clarity on referral pathways.
- Transport which is unaffordable and inaccessible, making it difficult and expensive for parents to seek health services for their children. Parents may have to pay a double fare to take both their child and their buggy or wheelchair in a taxi.
- Health facility infrastructure remains largely inaccessible with steps, narrow doorways and lack of disabled-friendly toilets. Long queues and overcrowded waiting areas are barriers that may prevent a parent of a child with a condition such as autism from being able to access health services.
- Parents continue to struggle to access the necessary assistive devices for their children, including buggies, hearing aids and Augmentative and Alternative Communication devices. Given a child's rate of growth, timely provision is essential, and yet many parents wait for months (and even years) for devices. Maintenance and repair of devices is also an associated challenge.
- Negative attitudes towards children with disabilities and their parents are widespread within the health sector, posing a disincentive for parents to seek help early. This is compounded with lack of knowledge about disability and available services on the part of health care staff, many of whom are not able to give accurate information about types of disabilities or support that a parent might need (including counseling).

It is hoped that the NHI, with its vision of universal health care will address many of these challenges thereby ensuring that children with disabilities have access not only to health services directed to all children, but also to those that are required specifically because of their disabilities.

It must be noted that there are many policy-related documents that speak to the NHI White Paper in respect of children with disabilities, the most recently released of which is *White Paper on the Rights of Persons with Disabilities*. We appeal not only for the alignment of these policies, but implementation strategies that dovetail in respect of approaches and M & E systems.

CLAUSE	COMMENT	RECOMMENDATIONS
CHAPTER 1 INTRODUCTION AND BACKGROUND		
(7)	We welcome this provision which emphasises that health care services should be closest to where people live (See CRPD 25 (c))	
(21)	To address the problem of limited human resources, we agree with the idea of contracting of private practitioners to include therapists such as OTs, PTs and SLTs and audiologists.	These therapists should address overall barriers to learning, not only physical (e.g. cognitive barriers); and not be limited to school going children.
(33)	The NHI should use terminology which is consistent with the CRPD	We recommend replacing 'people living with disabilities with 'people with disabilities'.
(35)	We value the use of community service therapists in extending rehabilitation services to rural and under-served areas. However, we have a concern that they are not experienced, often not well supervised and there is a high turnover with poor handover. These factors serve to undermine the quality of rehabilitation services offered to children with disabilities.	Management structures and monitoring processes need to be strengthened around community service therapists.
(41) Footnote 3	<p>Many parents of children with disabilities could be facing catastrophic health care expenditure as a result of extended period of dependency of their children and the high costs associated with disability.</p> <p><i>Ithumeleng looks after Thabo, a child of her sister, who has a severe disability. Thabo is 6 years old and attends a stimulation centre. He is unable to eat, sit or walk on his own. Ithumeleng receives a Care Dependency Grant of R1 410/month, which is to cover Thabo's basic needs, but she spends over R1 200/month on large-size nappies. There is also a need for mattress protectors and wipes as well as transport to get to therapy. Food and clothes also need to be purchased - making the financial demands on parents of children with disabilities very heavy.</i></p>	
CHAPTER 2 DEFINITION, FEATURES AND PRINCIPLES OF THE NHI		
2.2 Features of the NHI (52) (i)	We appreciate that rehabilitative care is included in the PHC continuum, here as well as in clause 158 ⁴ The CRPD (26) provides for habilitation and rehabilitation, noting that these services must begin at the earliest possible stage and be based on the multidisciplinary assessment of individual needs and strengths.	Rehabilitation services should be provided as close as possible to where people live and work not only to ensure that they are accessible, but also so that they are able to address both impairments and activity limitations of children with disabilities,

⁴ See CRC Clause 24 (1), where rehabilitation is considered part of health.

		as well as unique environmental and social barriers faced by children with disabilities and their families.
2.3 Principles (56) Equity	We welcome the inclusion of reference to equity, which may require that additional resources are allocated to children with disabilities to ensure that they enjoy the same outcomes as other children in terms of access to services.	Consideration should be given to the White Paper on the Rights of Persons with Disabilities which holds that disability equitable planning ‘requires that disability considerations be mainstreamed in all planning processes with a particular focus on (i) equality of outcomes (ii) universal design (iii) the removal of barriers (iv) reasonable accommodation measures and (v) redress’ (p.106).
	The White Paper on the Rights of Persons with Disabilities emphasizes the importance of early childhood development for young children with disabilities (p.82).	We recommend that inclusion of another principle in this list – that of early intervention . This is in line with obligations of the State in respect of the CRPD (Article 26 (b) which is to provide habilitation and rehabilitation services in such a way that they ‘begin at the earliest possible stage’. This is also in line with the NDP, which emphasises the need to build on existing child survival programmes to include early childhood development (p.303).
CHAPTER 3 PROBLEM STATEMENT		
(64)	It is not clear whether ‘equipment’ includes assistive devices, and if these considered something to be provided for.	Identification of the health needs of children with disabilities must include assistive devices. These are a critical requirement for children with disabilities. CRPD 26 (3) States parties shall promote the availability, knowledge and use of assistive devices, designed for persons with disabilities, as they relate to habilitation and rehabilitation
3.1.1 Quality of healthcare services (75)	The attitudes of health care personnel towards disabled children and their parents often result in negative experiences. <i>Sindi was a teenager when she gave birth to her first child. When her daughter was born, it was a normal delivery and Sindi was totally unprepared when told by a nurse that her child would never walk. There was no counselling and no advice on where she could get support. She was devastated, not understanding what</i>	All health care workers should be trained in disability sensitization.

	<i>was happening and not in a good place to be able to support her child.</i> We are aware of the negligence resulting in severe disabilities among children ⁵	
(76)	The current health system is also characterised by a lack of emphasis on early intervention and (re) habilitation.	Early intervention should be an underlying principle of the NHI (see Section 2.3).
3.1.5 Human resources (79)	Shortage of health professionals also applies to rehabilitation service providers. The extent of this shortage is detailed in the <i>Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020</i> ; and included in Table 1 which shows current vacancy rates among therapists.	
3.1.7 Out of pocket payments (85)	Parents take their children to clinics or hospitals, where they are assessed for assistive devices. However, children often have to wait for long periods before getting the assistive devices that they need. <i>Jabulani is a 5-year old boy with cerebral palsy affecting his whole body; he is unable to walk and needs help with feeding. His family applied for a buggy for him in 2014, when he was three, but they have still not received it. When he goes to the clinic and for therapy, Jabulani has to be carried on his mother's back. The fact that Jabulani does not have an appropriate assistive device for mobility is preventing his attendance at an ECD centre and limiting opportunities to develop his abilities.</i>	It is critical that assistive devices be provided and maintained not only at no cost, but <i>timeously</i> for young children with disabilities, as without them their development is impeded.
3.2 Burden of disease (98), (99) (100)	We welcome the recognition of the need to address the social determinants of health. This needs to take cognisance of the close relationship between disability and poverty. For example, stunting of children caused by malnutrition, results in poor schooling outcomes. The Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020 provides a useful diagram illustrating the link between poverty, ill-health and disability (p.7)	
(102)	As maternal and child mortality rates decrease, we can expect a high number of children with disabilities to survive.	The health care system needs to be responsive to this emerging trend and move from a focus on child survival to one on child development.
CHAPTER 4 RATIONALE AND BENEFITS OF NHI		
(114)	It needs to be noted that the benefits of the NHI go beyond economic gains, but help	

⁵ See McKerrow, N (2015) *Litigation is killing the Health System*. Paper presented at the 6th Child Priorities Conference, University of KwaZulu Natal, Pietermaritzburg.

	to restore the dignity of human beings.	
CHAPTER 5 NATIONAL HEALTH INSURANCE COVERAGE		
(118)	It is not clear how vulnerable groups will be prioritised.	There is a need for dis-aggregation of disability in all M & E systems in order to inform responsive planning, budgeting, implementing and reporting on services for children with disabilities. This is in accordance with the White Paper on the Rights of Persons with Disabilities.
(120) Registration	‘Designated public facilities’ should be as versatile as possible. It is not clear as to what information will be included on registration and how children with disabilities will be identified.	Consider having mobile facilities that are able to go to places where the children are. We recommend including the disability status of the child, if these children are to be prioritised.
5.3 Service coverage		
(127)	This list is not comprehensive.	Include also Occupational Therapists, Speech-Language Therapists and Audiologists.
(139)	It is not clear as to whether nappies are considered to be a ‘health product’; nor whether it includes orthotics and prosthetics and other assistive devices.	We recommend that nappies and other consumables that are necessary for the health of the child be provided.
CHAPTER 6 ORGANISATION OF THE HEALTH CARE SYSTEM		
(159)	We appreciate the approach of developing the ‘Ideal Clinic’.	The criteria for an ‘Ideal Clinic’ need to be spelled out, and include the criteria of being ‘disability friendly’ and ‘child friendly’.
(160)	It is good to see referrals being mentioned, and that consideration is given to transportation. It is positive that referrals are to be made upwards and downwards and implying that there will be feedback about the outcomes of referral.	Transportation needs to be accessible. The referral systems linked to the NHI should form part of a national integrated referral and tracking system as outlined in the White Paper on the Rights of Persons with Disabilities (p.82).
6.1.1 Municipal Ward-Based PHC Outreach Teams		
(163)	The work of CHWs through these teams provides an important mechanism by which to provide health services as close as possible to where children live.	The work of these teams should be linked to the principle of early identification. Following referral, CHWs need to follow-up to ensure that children have got the necessary services. CHWs need to take a sensitive approach in the community, to encourage parents to come forward for help and address issues of trust and partnerships.
6.1.2 Integrated School Health Programme		
(169)	It is not clear as to whether this provision includes special schools. However,	Provision needs to be made for screening and referral for children

	it does not address the needs of children who are of school-going age, but are not in schools, but are in informal partial care centres. In addition, it does not provide for screening for pre-school children.	pre-school age, as well as those that are not in mainstream schools. There should be a general focus on 'screening for barriers to learning'. This screening should be used in conjunction with the Department of Education tool on Screening, Identification, Assessment and Support (SIAS).
(171)	Reference is made to referral of children with vision and hearing problems.	There needs to be clarity on whether children are referred within the health system or within the education system or between them. It is important to clarify how the referral process works.
6.1.3 Contracting private health providers		
(174)	It is positive that progress has been made in establishing the District Clinical Specialist teams.	We recommend including a rehabilitation specialist in this team to ensure adequate provision of early intervention and rehabilitation services in the district
6.1.4 Contracting private health care providers		
(176)	We understand 'private health practitioners' (see clause 179) to include therapists. Their role is to promote early childhood development of all children and to undertake early intervention in order to reduce/remove barriers to learning.	Refer to 'barriers to learning' rather than only 'physical barriers to learning' Correction of 'bearers to learning'
(179)	It is good to see the inclusion of therapists here; the contracting of therapists may be necessary if they are to be involved in School Based Teams or on District Specialist Teams.	
6.2 Strategies to enhance effectiveness of health system		
(186)	We welcome the establishment of Clinic Committee, with guidelines as to how they will be constituted and function.	We recommend that the disability sector be represented on these Clinic Committees, through self-representation of disabled people or parents of disabled children.
6.3 Hospitals and specialised services		
6.3.1 Definitions of services to be delivered in reorganised hospitals	It is not clear how rehabilitation services fit in to reorganised hospitals, including specialist units such as spinal cord units. There is provision only for psychiatric hospitals.	<i>The Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020</i> details rehabilitation services that are to be provided at each level of care, including schools and hospitals. It is recommended that the NHI White Paper be in alignment with this Framework, as well as the recommendation of the <i>White Paper on the Rights of Persons with Disabilities</i> for the establishment of integrated, multi-sectoral, provincial habilitation and rehabilitation centres (p.86).
6.6 Enhancing human resources for health		
(225)	<i>The Framework and Strategy for Disability and Rehabilitation</i>	In line with the HRH strategy for the health sector (p.77), it is critical to

	<p><i>Services</i> indicates very high vacancy rates for Occupational Therapists, Physiotherapists and STA's per province (p.9) The HRH strategy for the health sector notes the low level of absorption of 'Allied Health professions (physiotherapy and occupational therapy) into the public sector as a result of lack of public sector posts.⁶</p>	<p>effectively manage human resources in order to ensure that rehabilitation staff are attracted, retained and motivated within both public and private sectors. There is also a need to promote access to health professionals in rural and remote areas. We also recommend development of a strategy to strengthen community-based rehabilitation services at community level, including training of mid-level workers to support children with disabilities and their families.⁷</p>
<p>CHAPTER 7: FINANCING OF NHI</p>		
		<p>One of the underlying premises is that the NHI will give priority to the most vulnerable within our society. We would like to see budgets developed on the basis of need, rather than replicating from a previous year. For example, a particular hospital should budget for the number of wheelchairs or buggies needed by children in the area, based on up-dated data available at local level.</p> <p>It is also important for budgets such as those for assistive devices to be ring-fenced, or they are in danger of being diverted and used for 'more urgent/important' items, such as surgical supplies.</p>
<p>CHAPTER 8: PURCHASING OF HEALTH SERVICES</p>		
<p>8.4. Treatment guidelines</p>		
<p>(337) & (338)</p>	<p>There are clear guidelines in place for IMCI but not for screening and early intervention for young children with disabilities or developmental delays.</p>	<p>There need to be guidelines in place to ensure screening of children with respect to development, as well as for early intervention and/or referral.</p>

⁶ Dept of Health. (2012). Human resources for health South Africa: 2012/13-2016/17.

⁷ Dept of Health. (2012). Human resources for health South Africa: 2012/13-2016/17 p.101.

Bibliography

- Dept of Basic Education and UNICEF. (2015). Study on children with disabilities from birth to four years: Dept of Basic Education & UNICEF.
- Dept of Health. (2012). Human resources for health South Africa: HRH strategy for the health sector 2012/13-2016/17.
- Dept of Health. (2015). *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020*
- Dept of Social Development, Dept of Women, Children and People with Disabilities & UNICEF. (2012). Children with disabilities in South Africa: a situation analysis 2001-2011. Pretoria: DSD, DWCPD, UNICEF.
- Jacklin, L. (2013). The future is in our hands. In Stephen, CR and Bamford, LJ (eds), *Saving Children 2010-2011 A seventh survey of child health care in South Africa*. Pretoria: Tshepesa Press.
- National Planning Commission. (2011). National Development Plan: vision for 2030.
- Proudlock, P., Lake, L., Jamieson, L., & Draga, L. (2013). Legislative and policy developments 2012/2013. In L. Berry, L. Biersteker, A. Dawes, L. Lake & C. Smith (Eds.), *South African Child Gauge*. Cape Town: Children's Institute, University of Cape Town.
- RSA (2016) *White Paper on the Rights of Persons with Disabilities*
- Schneider, M., Couper, J., & Swartz, L. (2010). Assessment of accessibility of health facilities to persons with disabilities: Report submitted to the Directorate: Chronic diseases, disabilities and geriatrics. Pretoria: Dept of Health.
- Saloojee, H. (2011). National health insurance and health system restructuring - does it offer anything to children? *South African Journal of Child health*, 5(3).
- Sherry, K. (2015). Disability and rehabilitation: essential considerations for equitable, accessible and poverty-reducing health care in South Africa. In Padarath, A, King J & English R (eds), *South African Health Review 2014/15* Durban: Health Systems Trust.

Acronyms

CHWs Community Health Workers

CRC UN Convention on the Rights of the Child

CRDP UN Convention on the Rights of Persons with Disabilities

IMCI Integrated Management of Childhood Illnesses

OT Occupational Therapist

PT Physiotherapist

SLT Speech Language Therapist

Table 1: Vacancy rates per province (2015)

Province	Occupational Therapist		Physiotherapist		Speech-Language Therapist and Audiologist	
	Posts filled	Vacancy rate	Posts filled	Vacancy rate	Posts filled	Vacancy rate
EC	75	54%	111	45%	40	42%
FS	69	30%	68	36%	12	63%
GP	271	16%	230	14%	149	9%
KZN	236	9%	327	9%	154	14%
LP	193	3%	58	5%	67	14%
MP	96	54%	75	63%	49	68%
NC	63	28%	59	34%	33	21%
NW	70	13%	85	14%	26	16%
WC	140	5%	143	3%	66	3%
SA	1 213	22%	1 256	23%	596	27%

Source: Department of Health. Occupational Categories; February 2015.

Cited in Dept of Health. (2015). *Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020*