



SAIDA

Southern African Inherited Disorders Association

Reg. No. 001 029 NPO

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Comments: Draft National Disability Rights Policy

The Southern African Inherited Disorders Association (SAIDA) is a non-profit membership organisation representing patient support groups, and focuses on advocacy, education, research and support activities.

Congenital disorders (CDs) or birth defects are a leading cause of disability and death worldwide. CDs are not equally distributed globally, with 90% occurring in middle and low income countries, including South Africa, contributing to 95% of CD related deaths worldwide. According to the March of Dimes report of 2006¹, 3.3 million children under five years of age die from CDs every year and an estimated 3.2 million of those who survive are disabled for life. Since most CDs are caused by genetics, CDs are a leading cause of disability and death in children. In industrialised countries that have controlled infectious diseases and completed the epidemiological transition, CDs cause between 20-25% of childhood deaths and result in many more persons living with disability. As South Africa recovers from the HIV/AIDS and concomitant TB epidemics and other communicable diseases are better controlled, the previously “buried” health issue of CDs is emerging and the true extent of their contribution to disability and mortality – and to the burden of disease, will be revealed.

SAIDA’s specific comments on the NDRP draft:

1. Although other priority groups are specified in the document, including women and children there is no mention of the congenitally disabled. The rights of the congenitally disabled need to be mainstreamed in the NDRP, inline with the Convention on the Rights of Persons with Disabilities. These rights need to be prioritised in accordance with World Health Assembly (WHA) Resolution WHA63.17 of 2010², which urges member countries,

¹ Christianson A, Howson CP, Modell B. March of Dimes: Global Report on Birth Defects, the Hidden Toll of Dying and Disabled Children. White Plains, NY: March of Dimes Birth Defects Foundation, 2006:85.

² World Health Organization. Sixty-Third World Health Assembly – Birth Defects. Geneva: WHO, 2010. http://apps.who.int/gb/ebwha/pdf_files/WHA63/A63_R17-en.pdf (accessed 11 September 2013).

including South Africa, to prioritise CDs and undertake necessary activities related to their care and management. By not contextualising those born with congenital disabilities, including those of late onset such as Huntingtons Disease and Alzhiemers, this ignores and maginalises the issue of CDs. SAIDA recommends that the congenitally disabled and are specified in this document and CDs recognised as as priority health issue, as is required by South Africa as a signatory to Resolution WHA63.17.

2. SAIDA would like to see the human rights and dignity of people with congenital disorders³ – the congenitally disabled - recognised in this document through the provision of relevant healthcare, specifically the medical genetic services they require. The current NDRP mentions rehabilitation treatment for people with disability, but in many cases a proper diagnosis is required before further treatment, including rehabilitation, can be prescribed. Diagnosis and ongoing care for the congenitally disabled needs to be emphasized in the document (note: this does not refer to prevention which we understand is excluded in the remit of the NDRP). Current medical genetic services required to support the majority of persons with disability, including accurate diagnosis and referral, are inadequate and have been compromised as a result of competing health priorities (HIV/AIDS, TB) and the resulting reallocation of funds and capacity over the past decade. For their rights and dignity to be upheld, this needs to be rectified.
3. SAIDA supports the emphasis on the NDRP on the funding of representative organisations of persons with disabilities (10.2) and the recognition of Representative Organisations of Persons with Disabilities and the participation of these organisations in the government-civil society interface.

Yours sincerely,



Helen Malherbe
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³ Christianson AL. Attaining human dignity for people with birth defects: A historical perspective. S Afr Med J 2013;103(12):1014-1019. [http://dx.doi.org/10.7196/samj.7277]