Mainstreaming Disability and the Family

> *"People with disabilities are excluded from the mainstream of society and experience difficulty in accessing fundamental rights… Because the emphasis is on the medical needs of people with disabilities, there is a corresponding neglect of their wider social needs. This has resulted in severe isolation for people with disabilities and their families".*
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> *SA Integrated Disability Strategy[1]*

1. Introduction[2]

While South Africa ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007, and despite various policies and laws that protect the rights of persons with disabilities, the majority of people with disabilities in South Africa have been excluded from the mainstream of society.

Very briefly, a disability can be defined as 'a functional limitation or restriction of an individual's ability to perform an activity'.[3] However, while such a definition is accurate, it does not describe the complexity of most disabilities. The World Health Organization (WHO) defines disability as 'an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations'.[4] Moreover, it is clear from this definition that disability cannot be regarded only as a health problem. 'It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives'.[5] Overcoming the difficulties faced by people with disabilities requires interventions which remove environmental, economic, educational and social barriers.[6] This is especially so for people who experience more than one disability.

Chronic pain, cognitive disorders and mental disabilities, while not immediately apparent, are nevertheless disabilities. The degree of functional impairment may be limited or substantial. Cerebral Palsy, for example, is "a disorder of voluntary movement and co-ordination due to the imperfect development of, or damage to certain areas of the developing brain. The extent to which individuals are disabled depends on the severity of the brain damage. The condition is life-long and there is no cure".[7]

On 3rd December 2014, the International Day of Persons with Disabilities, the WHO announced that "over one billion people, about 15% of the world's population, have some form of disability." 80% of those people live in low- and middle-income countries, where often access to basic health and social services is limited for all citizens. However, the impact on people with disabilities is more profound; and poverty exacerbates disability.

According to the statistics derived from the 2011 census, the national disability prevalence rate is 7.5% in South Africa. Disability is more prevalent among females compared to males (8.3% and 6.5% respectively), and the instance of disability increases with age.[8]

It is essential to remember that a person with disability is not defined by their condition and reference to their disability should be prefaced by that person's name – not the other way around. There has been a gradual shift in the understanding of disability. Many derogatory terms previously used to describe disability are falling into disuse – 'retarded', 'cripple', 'spastic', 'dumb', 'mental', 'idiot'. One such example of this increased sensitivity is the term 'spastic', which refers to stiff and rigid muscles which results in

compromised mobility, is now correctly referred to as 'cerebral palsy'. It should also be remembered that the term 'disabled' is an adjective and not a noun.[9]

2. A Rights-Based Approach to Disability

The United Nations Convention on the Rights of Persons with Disabilities was ratified by South Africa in April 2008. It sets out the legal obligations of states to promote and protect the rights of persons with disabilities, and emphasizes the importance of mainstreaming disability issues. Furthermore, it defines disability as an evolving concept, stressing that disability results from interaction between the person with impairment and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.[10] The focus is on the 'enabling' of those with disability by providing facilities, services and assistive devices that that mitigate the effect of the disability. The appropriate intervention can mean that the disability is no longer 'disabling'.

In terms of the SA Bill of Rights[11] which guarantees the fundamental human rights and equality of all citizens, legislation and policy which gives substance to these rights must be developed. The *National Policy on the Provision of Social Development Services to People with Disabilities* focuses on the delivery of social development services to people with disabilities; it seeks to complement the existing national and international legislative and policy frameworks; and incorporates the principle of mainstreaming disability.[12] Among the guiding principles is the development of significant support systems for families caring for a person with disability. "Families have inherent capacities and strengths that sustain them in times of prosperity as well as adversity".[13] The key question that the policy tries to answer is "How can people with disabilities in our society benefit equally and equitably from our service provision"?[14]

People with disabilities have the same health needs as non-disabled people – for immunization, cancer screening, dental checkups etc. However, they also may experience a narrower margin of health, often because of poverty and social exclusion, and they may be vulnerable to secondary conditions, such as pressure sores or urinary tract infections and the exacerbation of scoliosis due to immobility. The common cold easily becomes pneumonia. Furthermore, many conditions and chronic illnesses are, by their nature, degenerative.[15]

Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need. Their needs may require the co-ordination of various health and social services which are not necessarily available at the same institution, or are simply too far away.

3. Access to Grants

There are different types of social grants for children with disabilities. The Care Dependency Grant (CDG) is applied to severely disabled children. The applicant must be South African citizen, permanent resident or refugee; must be resident in South Africa; and the child must be under 18. A medical/assessment report confirming permanent, severe disability must be submitted. The applicant and spouse must meet the requirements of the means test, and the care-dependent child/children must not be permanently cared for in a state institution.[16] Families of children with mild to moderate disability may receive full tax rebates on disability-related costs, but may not apply for the CFG.[17]

The Disability Grant is payable to a South African citizen, permanent resident or refugee between 18 and 59 years of age. A medical/assessment report confirming disability must be submitted. There is a means test, and the applicant must not be maintained or cared for in a state institution.[18] A permanent Disability Grant may be provided until the 60th birthday, at which point it will be converted to an Older Person's Grant.[19] The Care Dependency Grant, the Disability Grant and the Old Age Grant each amount to R1 350 per month.

4. Inclusive Education

Nelson Mandela reminded us that "d*isabled* children are equally entitled to an exciting and brilliant future."**[20]** Inclusive education for children with disability is a child-centered approach which seeks to accommodate children with disability in mainstream schools. However, such an approach is sensible to the challenges this involves, and focuses on the 'best interests of the child'. Schools must be adequately resourced, with appropriate steps taken to accommodate children with disability. **"Segregation in childhood leads to difficulty integrating into adulthood. Inclusion

promotes resilience and independence, and promotes caring and acceptance by non-disabled children".[21] Furthermore, it is not possible to have easily accessible special needs schools for all children with disability. However, there are children who need more specialized education and care that is beyond the capacity of mainstream schools. Thus, for example, the Western Cape Cerebral Palsy Association (WCCPA) provides therapeutic services for children with cerebral palsy, and also operates a school.

The Vatican Charter of the Rights of the Family asserts that "children who are handicapped have the right to find in the home and the school an environment suitable to their human development".[22]

5. Employment Opportunities

The lack of employment opportunities for persons with disability beyond school going age often results in social isolation and loneliness. In 2013 5.6 million people were employed in South Africa in the formal sector. However, only 50 867 (0.9%) of those employed were people with disabilities.[23] In 1998 the projected target for the employment of those with disability was set at 4% by 2004, but only 0.4% was achieved. The most recent target is 2% by 2015. The Department of Labour has done little to encourage the employment of persons with disability in spite of legislating asserting the equality of opportunity for all. This is compounded by the lack of post-school educational opportunities and the absence of disability-specific legislation.[24] But there are exceptions – for example, the WCCPA offers employment opportunities for adults with cerebral palsy.

6. Provision of Assistive Devices

The provision of appropriate assistive devices and services to all those with disability is key. Be it spectacles, hearing aids, walking frames, wheelchairs, or computer programmes that facilitate communication, assistive devices are key to the enablement of those with disability.

Ideally, a wheelchair for a person with quadriplegia should be custom made so as to provide the correct measurements for the user's height, weight and degree of mobility and so provide as much support and comfort as possible. A child would need to have successive wheelchairs as he or she grows. Wheelchairs in rural areas have to transverse difficult terrain, resulting in punctured tyres. Access to transport that is able accommodate wheel chairs is also a necessity.

7. Conclusion

Mainstreaming disability is about overcoming barriers that 'dis'able. It requires supporting families to better enable them to care for their disabled member. This support may be very practical, such as the finance required to make adjustments to the family home for a wheelchair; or the provision of respite care which gives the primary caregiver a break when the disabled family member requires 24-hour care. Social work services should be available to do case management and counselling. Mainstreaming disability is fundamentally about transformation – of our buildings, transport systems, schools and other educational facilities, health care and social services, as well as our language. In undertaking this transformation we realize not only the equality which all are afforded in the Constitution, but our God-given dignity as well.

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[1] South Africa's Integrated Disability Strategy White Paper, 1997
[2] The SACBC Parliamentary Liaison Office, the Western Cape Department of Social Development, and NICRO held a Roundtable Discussion on 'Mainstreaming Disability and the Family' on 21st November 2014. The roundtable was addressed by Ms Patisa Momoza, Programme Manager of Services to Persons with Disability of the Western Cape Department of Social Development; Ms Caroline Taylor from Inclusive Education; and Ms Gadija Koopman, the Director of the Western Cape Cerebral Palsy Association. This Briefing Paper owes much to their respective presentations and to the discussion which followed.
[3] Websters' Online Definition
[4] WHO www.who.int/topics/disabilities

[5] WHO www.who.int/topics/disabilities

[6] WHO www.who.int/topics/disabilities

[7] Presentation by Gadija Koopman, 21st November 2014.

[8] Statistics South Africa, 9th September 2014

[9] National Educational Association of Disabled Students, 2014

[10] The United Nations Convention on the Rights of Persons with Disabilities, 13th December 2006

[11] The Constitution of the Republic of South Africa, 1996

[12] Presentation by Patisa Momoza, 21st November 2014

[13] The National Policy on the Provision of Social Development Services to People with Disabilities, 2013

[14] Ibid.

[15] Such examples include Huntington's disease; muscular dystrophy; multiple sclerosis; macular degeneration.

[16] http://www.sassa.gov.za/index.php/social-grants/care-dependency-grant

[17] An example of such expenses would be the purchase of nappies.

[18] http://www.sassa.gov.za/index.php/social-grants/care-dependency-grant

[19] http://www.blacksash.org.za/index.php/your-rights/social-grants/item/disability-grant

[20] www.education.gov.za/LinkClick.aspx?

[21] Presentation by Caroline Taylor, 21st November 2014

[22] Charter of the Rights of the Family, 22nd August 1983

[23] Presentation by Caroline Taylor, 21st November 2014

[24] South Africa's Integrated Disability Strategy White Paper 1997