

# ESR

## REVIEW

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### Ensuring rights make real change

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# Editorial

This is the third issue of the *ESR Review* for 2011. It is a special issue that focuses on and explores the interplay between access to socio-economic rights in the context of persons with disabilities and the needs of persons with disabilities to have economic and social security. Such a focus is timely and appropriate in light of ongoing legal and policy initiatives by South Africa to give effect to the international standards and norms protecting persons with disabilities.

One of the main international instruments in this regard is the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), which was adopted in 2006. South Africa ratified the CRPD and its optional protocol on 30 November 2007. However, South Africa is yet to fully domesticate the Convention. In March 2011, it emerged from the deliberations by the Parliamentary Portfolio Committee on Women, Youth, Children and People with Disabilities that South Africa had not adequately incorporated the CRPD into its legal framework, consequently weakening the effect of the Convention in South Africa. It also emerged that South Africa had not yet submitted a state report to the UN Committee on the Rights of Persons with Disabilities as required under the Convention.

Legislation that protects vulnerable citizens (including persons with disabilities) reflects a society that respects and cares for its people. It is important to affirm that progressive legislation can be an effective tool to promote and protect the rights of persons with disabilities. Professor Michael Perlin acknowledges that 'viewing disability as a human rights issue requires us to recognize the inherent equality of all people, regardless of abilities, disabilities, or differences, and obligates society to remove the attitudinal and physical barriers to equality and inclusion of people with disabilities'. (Perlin, 2011 – see 'New publications', p 22)

At the regional level, the continent is yet to adopt a treaty on the rights of people with disabilities. A draft African Disability Protocol is currently being negotiated by African Union (AU) member states. It is therefore appropriate that this issue of the *ESR Review* begins with some reflections by Juliet Mureriwa on the potential of the draft African Disability Protocol in claiming socio-economic justice for persons with disabilities. Henri Nkuepo then examines the status of women with disability and acknowledges that they are the most vulnerable among the vulnerable with regard to their right to health.

At the national level, the courts in South Africa have been at the forefront of interpreting relevant constitutional obligations and providing remedies to persons with disabilities. In this regard, Nkatha Murungi provides an overview of the duty to provide

basic education for children with severe and profound intellectual disabilities by analysing the recent case of *Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa and Government of the Province of the Western Cape*.

This is followed by Yvette Wiid's review of the practical implications of the Social Assistance Amendment Bill 2010 for persons with disabilities. From an advocacy angle, Sarah Rule and Bongwe Zuma evaluate the implementation of the CRPD through human rights forums in KwaZulu-Natal. Christina Nomdo, Alexander Henry and Sandra Ambrose then review the potential of children with disabilities to contribute to policy analysis and advocate for children with disabilities to become socio-economic rights activists.

This issue also contains a brief on two new publications: one being the World report on disability and the other a book on persons with disabilities.

We acknowledge and thank all the guest contributors to this issue. We trust that readers will find it stimulating and useful in the advancement of socio-economic rights, especially the rights of persons with disabilities in our society.

Gladys Mirugi-Mukundi, editor

## Some reflections on the draft African Disability Protocol and socio-economic justice for persons with disabilities

Juliet Mureriwa

*The focus on the rights of persons with disabilities on the African continent dates back to the 1980s. It can be traced to an African regional conference on the International Year of Disabled Persons (1981) held in Ethiopia. However, the idea of an Africa-specific disability rights instrument is fairly new. The first call by the African Union for such an instrument was only made in 2003. The African Union has observed that the rights of persons with disability are not adequately protected, and has called upon its member states to develop a protocol on the protection and promotion of the rights of persons with disabilities (Resolution ACHPR/Res.143 (XXXV) 09, adopted during the 45th ordinary session of the African Commission on Human and Peoples' Rights, 13–27 2009, Banjul, The Gambia).*

In 2009, the African Commission on Human and Peoples' Rights (the African Commission) took up the call and established a Working Group on the Rights of Older Persons and People with Disabilities, which put together two draft instruments at a seminar of experts held in Accra, Ghana: one on older persons and the other on persons with disabilities. A subcommittee established at the meeting formally adopted the draft Protocol on the Rights of People with Disabilities in Africa in November 2009 (the Accra Draft).

Many of the inadequacies of the Accra Draft relate to the fact that its adoption was not preceded by sufficient conceptual and analytical thinking (Viljoen, 2011). Its

socio-economic clauses are weak and are a watered-down version of the international disability instrument. Its deficiencies are exacerbated by the fact that the drafting process did not include disabled people's organisations (DPOs) and mainstream civil society groups working on disability rights, including the African Union's very own disability rights secretariat, the Secretariat for the African Decade for Persons with Disabilities (SADPD).

In an effort to allow deeper reflection on the draft, the SADPD's Advocacy Technical Team, comprising African DPOs, disability rights experts and academics, did a lot of advocacy work, including at the African Commission level, in order to defer the finalisation of the draft so as to allow an inclusive process before a disability instrument was adopted. The African Commission's working group is now expected to have broad and inclusive consultations with the disability movement, DPOs, African states and relevant stakeholders to determine the need for any further human rights instrument to cover disability, including the possible protocol, a convention or other formal elaboration.

It is against this background that the protection of the socio-economic rights of persons with disabilities on the continent should be understood. Ideological developments that preceded the Accra Draft are also important in understanding the justification for including and prioritising socio-economic rights in the disability instrument that is adopted.

The idea of socio-economic justice dates back to the twin international covenants on human rights of 1966: the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR). However, international ideological debates on the two covenants led to socio-

There is a critical need to address the negative impact of poverty on the lives of people with disabilities

economic rights being relegated to an inferior status. The African Charter on Human and Peoples' Rights (the African Charter), adopted in 1981, was an innovative departure from international ideological thinking as it was able to proclaim that civil and political rights and socio-economic rights were indivisible.

The preamble to the African Charter proclaims the necessity for the African continent to pay particular attention to developmental rights and affirms that civil and political rights cannot be disassociated from socio-economic rights in their conception as well as universality. The satisfaction of socio-economic rights thus guarantees the enjoyment of civil and political rights. It is therefore of utmost importance that any rights instrument adopted should respect and uphold both categories of rights.

In Africa, persons with disabilities are among the poorest of the poor, so an African disability instrument should pay adequate attention to socio-economic rights. The interaction between poverty and disability cannot be overlooked, and therefore the importance of poverty eradication as a means both to prevent disability and to provide effective redress for persons with disabilities is crucial (Matsebula, 2003). Poverty aggravates the poor living conditions of people with disabilities in developing countries. For this reason, the disability instrument that is adopted must clearly provide that persons with disabilities should have an equal share in the improvements in living conditions resulting from social and economic development. A fight against poverty and underdevelopment in Africa is dependent on, among other things, how successfully socio-economic rights are concretised in important human rights instruments.

As noted in the preamble to the United Nations Convention on the Rights of Persons with Disabilities of 2006 (CRPD), the majority of persons with disabilities live in conditions of extreme poverty. The clause on adequate standard of living and social protection (article 28) of the Accra Draft does not address the issue of poverty reduction programmes for persons with disabilities, or what measures states should take to safeguard and promote the realisation of this right, especially the continuous improvement of the living conditions of persons with disabilities. Nor is anything said about ensuring that persons with disabilities have access to clean water.

It is therefore imperative to recognise the critical need to address the negative impact of poverty on their lives.

The disability instrument that is adopted should speak directly to the linkages between poverty, disability and development – that is, access to education, health services, employment opportunities, an adequate standard of living and social security.

Persons with disabilities should have the right to enjoy a decent life, as normal and full as possible, and free from discrimination. This right lies at the heart of the right to human dignity and should be zealously guarded and forcefully protected in the disability instrument, in accordance with the well-established principle that all human beings are born free and equal in dignity and rights (see, generally, *Purohit v The Gambia* (2003) AHRLR 96).

The clause on the right to health (article 8) is vague as it does not oblige the state to take all appropriate measures to ensure that this right reaches fruition. There are no measures provided to ensure that persons with disabilities 'get [the] excellent free and affordable health care' granted in article 8(f). There is no mention in this clause of services designed to minimise and prevent further disability or early identification and intervention as appropriate.

The devastating impact of HIV and AIDS on persons with disabilities is another aggravating factor in relation to socio-economic injustice. High levels of poverty, increased exposure to sexual abuse, lack of accessible means to education on prevention and care, and the inaccessibility of medical services expose persons with disabilities to a greater risk of contracting HIV and AIDS and often leave them with less access to health services (Groce, 2005).

In its final form, Africa's disability instrument should reflect the fact that women and girls with disabilities in Africa face multiple forms of discrimination and are at a greater risk of violence, abuse, neglect and exploitation. Their situation should be specifically highlighted. Socio-economic rights are generally difficult to access on the continent, due to resource constraints, among other things, but women and girls with disabilities are the worst affected. The socio-economic condition of women with disabilities is aggravated by a lack of respect for women's property rights, access to and ownership of productive resources, and cultural practices that favour patriarchal inheritance norms.

The disability instrument that is adopted should also clearly recognise that children with disabilities must have full enjoyment of their human rights and fundamental freedoms, just as much as other children, especially the right to education. It is universally accepted that education is the key to sustainable development. Therefore no child, with disabilities or without, ought to be denied his/her fundamental right to education. However, the right to equality is meaningless if children with disabilities continue to be segregated, institutionalised and denied access to quality education.

Even South Africa, which is seen as a beacon of hope for the upliftment of social-economic rights on the continent and has one of the most advanced constitutions in the world, is struggling with social justice for persons with disabilities. However, its rich socio-economic rights jurispru-



dence provides a ray of hope. In the recent case of *Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa and Government of the Province of the Western Cape* 2011 JDR 0375 (WCC), which is examined in detail elsewhere in this issue of the *ESR Review* (see p 10), the Western Cape High Court found that the state's failure to provide quality basic education to children with mental disabilities was an infringement of their right to education, their right to equality, their right to dignity and their right to protection from neglect. The Court held that there was no justification for the state's failure and that the children's rights had been violated by stigmatisation. It was further held that the state's failure to provide education to these children also violated their right to protection from degradation, as the children's education depended on the chance charity of a non-governmental organisation (NGO) programme with no long-term sustainability. The Court ordered the state to take reasonable measures to ensure that all children with intellectual disabilities in the province got access to affordable and quality basic education. The significance of this decision lies in the Court's provision of a structural interdict as a form of relief: it ordered the state to report back to the Court on its progress towards implementing the order.

The challenges persons with disabilities face are linked to the socio-economic realities of the African continent. Therefore the advantage of an Africa-specific disability instrument is its capacity to ensure that special attention is devoted to the specific socio-economic needs of African persons with disabilities. It would address the Africa-specific contextual realities while extracting the best out of the universally agreed disability principles embodied in the CRPD and regional human rights treaties such as the African Charter. In addition, it would signal Africa's concern and determination to undo the decades of neglect and often severe socio-economic rights violations suffered by persons with disabilities on the continent (Viljoen, 2011).

The Accra Draft lacks a proper implementation clause, without which the socio-economic rights set out by the protocol are just paper rights which will not change anyone's life. Article 2, which is supposedly the implementation clause, says nothing about implementation. There is nothing in this provision to ensure that states set up focal points within governments that will ensure the implementation of the protocol, and will also act as the governments' coordinating mechanisms facilitating related action in the various disability sectors.

Despite the CRPD's ratification by at least 50% of African states, the lives of persons with disabilities on the continent have remained largely unchanged. The key to changing their lives, even with an African disability rights instrument, is to ensure that such an instrument includes a clear and enforceable strategic plan on domestication and implementation.

As the disability movement lobbies and builds consensus on the form of the resultant instrument, there is a need to ensure that socio-economic justice does not fall off the

radar. The civil and political rights that are being put at the forefront will be meaningless if there are no poverty reduction strategies in place to lift the lives of persons with disabilities above the poverty line. Their right to life will be meaningless if they have no food to eat or access to essential health services. What good is the right to vote to a man whose handicap denies him the ability to farm and provide for his family? What good is the right to non-discrimination to a woman with albinism denied employment because of her skin pigmentation? Human rights instruments that condemn socio-economic rights to an inferior status go against the spirit of the African Charter and the Constitutive Act of the African Union, which seeks to lift the continent out of poverty and dependency. Any African state that chooses to ignore the socio-economic needs of its people is a danger to itself.

Persons with disabilities on the continent should not be content with half measures regarding their socio-economic rights. No one ought to be satisfied with perfunctory relief offered by governments and NGOs on the assumption that the socio-economic circumstances of persons with disabilities are a permanent condition. African states should therefore adopt and develop programmes that encourage quality inclusive education, work and self-sufficiency rather than dependency. A lack of education and of sustainable employment opportunities is a potent mixture that can lock people into perpetual poverty. Social justice moves beyond the relief of immediate needs and dependency and seeks to change the conditions and social structures that cause or aggravate the dependency.

A comprehensive African disability rights instrument that upholds socio-economic rights will make a significant contribution to redressing the profound socio-economic disadvantages of persons with disabilities and promoting their participation, not only in the socio-economic sphere, but also in civil and political life, with equal opportunities for everyone. Therefore African states should be obliged to take measures to the maximum of their available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realisation of socio-economic rights for persons with disabilities.

Finally, the resultant disability instrument should be adequately informed by Africa-specific content, cogent philosophy and universal human rights principles (SADPD Communiqué to the African Commission dated March 2011). Above all, it should represent the personal experiences of persons with disabilities in Africa.

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See generally: <http://www.africandecade.org.za>.

## Women with disability

### The most vulnerable among the vulnerable with regard to their right to health

#### Henri Nkuepo

*'Disability' is one of those words whose definition tears apart scholars and policy-makers. Even people regarded as 'disabled' disagree with the definitions of the word, arguing that they are the product of disadvantage and restrictions imposed by society to exclude them from mainstream activities (UPIAS, 1976: 14). Sadly, that is true, since the definition of the word 'disability' always has a negative connotation. 'Disabled' is also seen as a derogatory word; hence the use of 'persons with disabilities' in most discourses. According to the Convention on the Rights of Persons with Disabilities (CRPD), a person with disability is one who has a long-term physical, mental, intellectual or sensory impairment which may hinder her/his full, effective and equal participation in social activities (article 1).*

This definition is universally accepted. However, many countries, including South Africa, have not included it in their national laws, or continue to use the word 'disability' instead of 'impairment'. The South African Social Assistance Amendment Bill of March 2010 proposed a definition

based on article 1 of the CRPD, but did not use all the wording of article 1. The United States has a comprehensive national definition of 'person with disability' in the Americans with Disabilities Act (ADA), as revised by the ADA Amendments Act of 2008. It provides that a person with disability is an individual who has a physical or mental impairment that substantially limits one or more major life activities of such individual; who has a record of such impairment; or is regarded as having such impairment (section 12102). Based on this definition and that in the CRPD, this paper will use the word 'impairment' instead of 'disability'. Thus, a woman or girl with impairment is one who has a physical or mental impairment that substantially restricts her in performing one or more major life activities.

Being mentally or physically restricted in certain life activities does not mean that one does not have the right to take part in such activities or to be equal to others who have the full capacity to perform them. People with impairments are discriminated against because of their physical or mental impairments. This is particularly true for women and girls in Africa, for whom physical or mental impairment is generally seen as a death sentence. Women with impairments are victims of double discrimination or injustice. First, they are women in a patriarchal society and therefore regarded as inferior to men (gender inequality); and second, women who are impaired are discriminated against by both other women and the society in which they live.

This paper focuses on the socio-economic rights of women with impairments and particularly their right to health care, beginning with an overview of the situation in South Africa. It acknowledges the efforts made by the South African government thus far with regard to the rights of people with impairments, but argues that the legislation in place is gender-neutral and that the use of the word 'disability' misleads and contributes to delaying the translation of South African laws into reality. It further sets out some policy initiatives, based on a policy paper written by Carolyn Frohmader in 2010 for Women with Disability Australia, that could help address issues around the right to health care of women with impairments in South Africa.

### Women with impairments and the right to health care

First and foremost, it is important to stress that the right to health care is not about being in good health. It is rather a fundamental right that includes both 'freedom' and 'entitlement' (Frohmader, 2010). In other words, the right to health care includes the freedom 'to control one's health and body including sexual and reproductive freedom; the right to participate in decisions about one's health; and the right to be free from interference, such as non-consensual medical treatment and experimentation' (Frohmader, 2010). Based on this definition and with regard to women with impairments in South Africa, the question is: What makes them the most vulnerable among the vulnerable?

First of all, women with impairments have medical needs three times greater than those of the average person, because: they need to seek medical care for their impairments; in addition to having reproductive needs and concerns, like other women, they are biologically more vulnerable and need extra medical care, which varies depending on the type of disability; and they have to be constantly examined, especially those who cannot speak or explain their health condition, to see if they have any psychological disturbance as a result of violence or health problems.

Second, South African women with impairments, like all other women, are vulnerable and subject to violence. Research shows that the rate of violence against them is higher; they are extremely vulnerable to gender-based violence, and they have limited access to the criminal justice system and to gender-based violence support services (Naidu et al., 2005). As a result, they end up with infectious diseases, HIV and AIDS, and undesired pregnancies. Not knowing the transformations happening to their body or sometimes unable to communicate or explain those transformations, and lacking money to go to hospital, they are often forced to live with those problems.

Third, it is argued that women and girls with impairments are generally forced to undergo sterilisation for various reasons; including menstrual management and personal care (Wilson et al., 1994), prevention of pregnancy and pregnancy caused by sexual violence (Austral-

Women with impairments have medical needs three times greater than those of the average person

ian Family Law Council, 1994). This is a global and general issue, and South Africa is not spared.

In addition, women with impairments are usually frustrated by health care practitioners. Nokwanele Mgwili and Brian Watermeyer have examined a situation affecting impaired women in the Eastern Cape, where nurses oppress and punish them because of their impairments (Mgwili and Watermeyer, 2006). Impaired pregnant women are also traumatised by questions from health care practitioners like: 'How are you going to give birth?' and 'How are you going to hold your baby?' (Mgwili and Watermeyer, 2006). The case presented by these authors shows how women with impairments decide to think less about founding a family or having more children. Hence their chances of having a normal family are reduced.

While there is no regulation in place in South Africa to address the problems faced by women with impairments, the government has made some efforts to assist people with impairments. For example, the Integrated National Disability Strategy of 1997 recognises the contribution that people with impairments make in society, and provides that they should be mainstreamed in all aspects of the government and in all sectors. The strategy recognises that women with impairments in South Africa are discriminated against and are more likely to be illiterate, poor, destitute and malnourished, and to have a smaller chance of establishing a family. However, it says nothing about their health needs and how the government addresses them. Other pieces of legislation, such as the Employment Equity Act, the South African Schools Act and the Mental Health Care Act, do not have specific provisions on the right to health care of women with disabilities.

The South African Constitution recognises the right of everyone to have access to health care services and reproductive health care, and it calls on the state to take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of the right to health care (Constitution of the Republic of South Africa, section 27). Based on the argument discussed above – that the medical needs of women with impairments are three times greater than those of an average person – one can argue that this constitutional mandate is insufficient to realise equal access to health care services, because it assumes that all South Africans are equal and should have equal access to health care services. However, while all South Africans are indeed equal, they have different health needs, and measures adopted to address these

- A national health policy that focuses specifically on people with impairments would be very important in improving the status of this group ●●

needs should therefore be tailored to bring those who are more vulnerable, such as women with impairments, up to the same level. The need to pay particular attention to the vulnerable can be deduced from the test of 'reasonableness' used by the South African Constitutional Court in *Government of the Republic of South Africa and Others v Grootboom and Others* 2000 (11) BCLR 1169 (CC). The Court, considering the case of those most in need, held: 'Those whose needs are the most urgent and whose ability to enjoy all rights therefore is most in peril, must not be ignored by the measures aimed at achieving realisation of the right.'

The expression 'within its available resources' in section 27(2) of the Constitution is also generally criticised as a limitation on the extent of realisation of rights. This expression is used by governments as an excuse to procrastinate in the progressive realisation of rights (Stubbs, 1997). A state can offer the excuse that it is not making enough progress in realising the rights because it does not have sufficient resources (SAHRC, 2008). In *Soobramoney v Minister of Health, KwaZulu Natal*, 1997 (12) BCLR 1696 (CC), the Constitutional Court held that the state did not have enough resources to ensure full realisation of the right of the appellant. This excuse should not be used when it comes to realising the right to health care of women with impairments. The government should make sure that those women enjoy the highest attainable standard of physical and mental health as provided by the International Covenant on Economic, Social and Cultural Rights (ICESCR).

The Constitution further provides that the government has an obligation to protect, promote and fulfil the right to health (section 27(2)). This implies, among other things, that the government should refrain from undertaking actions (e.g. programmes, policies or laws) that inhibit or interfere with the ability of women with impairments to enjoy their right to health care and from denying or limiting their equal access to health care services, for instance through causing bodily harm, unnecessary morbidity and preventable mortality (Frohman, 2010). The government is required to protect that right from violation by third parties, to provide appropriate services to enable these women to enjoy their right to health care as a matter of priority, and to ensure equal access to health care facilities without discrimination (Frohman, 2010). The government must thus adopt appropriate legislative and administrative, budgetary, judicial and promotional measures to facilitate the complete re-

alisation of the right to health care of women with impairments (Asher, 2004).

The first priority of the South African government in terms of its obligations should be to ensure that women with impairments and other vulnerable people have access to at least the basic level of their socio-economic right to health care (SAHRC, 2008). This is what is referred to as the minimum core obligation, based on an interpretation of the obligations of states under the ICESCR given by the United Nations Committee on Economic, Social and Cultural Rights (ESCR Committee).

But what is the minimum core obligation of the government with regard to the right to health care of women with impairments? In order to answer this question, it is important to look at the constitutional obligation imposed on the government and to decide whether that obligation is sufficient to meet the needs of women with impairments. Thus, the minimum core obligation of the South African government with regard to the right to health of women with impairments is to ensure that those women, first, have access to health care services for their impairments and, second, have the same basic health care services as other South Africans enjoy.

## Recommendations

A point to note from the outset is that the authorities in South Africa do not have recent statistics on the exact number of South African women with impairments, as the last population census took place ten years ago. Without knowledge of the extent of a problem, it becomes difficult to resolve it. It is therefore important for the government to ensure that the necessary statistics are documented during the current (2011) population census.

In addition, South Africa needs to adopt appropriate legislative, administrative and other measures specifically aimed at ensuring implementation of the right to health care of women with impairments and modifying or abolishing existing customs and practices that constitute discrimination against these women. For example, a national health policy that focuses specifically on people with impairments would be very important in improving the status of this group. Such an initiative would widen the scope of measures available to women with impairments and would help both those women and their advocates fight against violations of their rights.

The South African government should also put in place programmes to educate women with impairments, particularly about their reproductive health care. This is because the large majority of these women do not get the appropriate information or treatment regarding their reproductive health care rights. For instance, it is argued that they have no information about sexuality, birth control, sexually transmitted diseases, pregnancy and motherhood from mainstream health care facilities (Degener, 2000).

Furthermore, the issue of health care for women with impairments should be mainstreamed in medical schools. This is because research shows that medical practitioners



are often human rights violators, to the extent that they administer degrading and humiliating treatment to impaired women (Degener, 2000). It is also important to establish a specialised programme for medical schools based on the health care of women with impairments. This would help attract practitioners who are passionate about the issue to help these vulnerable people. Such practitioners can be trained and placed in hospitals around the country.

## Conclusion

This paper has sought to demonstrate that physical and/or mental impairments prevent women from fully enjoying their right to health care. Women with impairments are victims of a double discrimination: first as women in a patriarchal society, and second as impaired people. They

are also discriminated against by other women. The legislation in place in South Africa is inefficient, gender-neutral and mostly designed without consideration of the vulnerability of these women. The South African Constitution may be highly innovative, but its section 27 is not adequate to the challenges that these women face.

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## The duty to provide basic education for children with severe and profound intellectual disabilities

Nkatha Murungi

*Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa and Government of the Province of the Western Cape 2011 JDR 0375 (WCC)*

*The applicant in the case of Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa and Government of the Province of the Western Cape was a body comprising various non-governmental organisations (NGOs) that care for children with severe and profound intellectual disabilities in the Western Cape. The applicant's case was that the state's financial provision for children with severe or profound intellectual disabilities was much less than that provided for other children, that such provision was inadequate to cater for the educational needs of these children, and that the money was only available when NGOs provided the facilities. (Children with an IQ of 20 to 35 are considered severely intellectually disabled, while those with an IQ below 20 are deemed to have profound intellectual disability.) It was argued that these circumstances infringed the rights of the children concerned to education, equality, human dignity and protection from neglect and degradation.*

It was agreed by all the parties that the state did not make any direct provision for children with intellectual disabilities, and that children with severe and profound disabilities who could not access special care centres run by NGOs received no education at all. In addition, it was not in dispute that the amount that the state, through the Department of Health, paid to the NGOs was both insufficient for the purpose and less than both the amount paid for children with mild to moderate intellectual disabilities, and that paid for children without a disability. Both parties recognised that the needs of children with severe and profound intellectual disabilities were much greater than those of children who did not have a similar degree of impairment or any impairment at all.

The respondents' case was that there was a policy in place, documented in White Paper 6 of 2001 and the National Strategy on Screening, Identification, Assessment and Support (SIAS), which did not exclude children with severe and profound intellectual disability. Furthermore, argued

the respondents, a lot had been done to streamline education in the country in terms of the Constitution, and several measures aimed at improving the welfare of children, such as social grants, had been adopted, thereby increasing the number of children with disabilities attending school.

The government argued that the current state of affairs was justified by the fact that the Department of Education was still reeling from the legacy of the apartheid education system (para 8). It also argued that the children concerned were unlikely to benefit from any kind of education in view of the extent of their disability. Counsel for the respondent argued that the right of the affected children to education, being a socio-economic right, should not be seen in isolation, but together with other socio-economic rights such as housing, food, water, health care and social security (para 16); and that in view of the scarcity of resources, certain children would be left out of the education system, and would have to depend on the life skills imparted by their parents.

Before the case was filed, the applicants had held several meetings with the Western Cape Departments of Education, Health and Social Services in an attempt to improve the circumstances of the children concerned, but were not satisfied with the response of the departments, noting lack of progress on the measures agreed upon during the deliberations.

### Summary of the decision

The Western Cape High Court found the respondents in breach of their duty to uphold the rights of children with severe and profound disabilities to a basic education, protection from neglect and degradation, equality and human dignity. The respondents were ordered to take reasonable measures (including interim measures) to give effect to the rights of these children; to ensure that every child in the Western Cape who had severe or profound intellectual disability was accorded affordable access to basic education of adequate quality; and to provide funding for organisations which provided education for such children in special care centres in the Western Cape (para 52). The Court also issued a structural interdict against the respondents, directing them to deliver to the applicant and to file to the Court a report under oath as to the implementation of the order within 12 months of the order, which means November 2011.

### Issues arising

A number of issues arising in this case are significant for the protection of socio-economic rights, and the right to education, in the context of disability in particular. These include responsibility for upholding rights, the prioritisa-

tion of competing socio-economic rights, the nature of the state's duty in relation to the provision of basic education, and the effects of the ratification of the United Nations Convention on the Rights of Persons with Disabilities of 2006 (CRPD) on the education of children with disabilities in South Africa.

On the duty borne for implementation of education, the Court was of the view that while the state might currently rely on organisations such as members of the Western Cape Forum for Intellectual Disability to provide education for the children concerned, their involvement did not absolve the state from its constitutional duty to provide education (para 24). To put the involvement of non-governmental non-profit organisations in this regard in context, the care and education of children with disabilities has often been a function of charitable, religious and NGOs, a phenomenon that is found in many countries and regions. The trend is largely attributable to the charitable model of thinking about disabilities that dominated this field in the past.

The role of non-governmental actors in education is recognised internationally. The World Conference on Education for All, held in Jomtien, Thailand, in 1990, adopted the World Declaration on Education for All, which laid the foundation for education that is inclusive of all people, including persons with disabilities. The declaration stated that national authorities had a responsibility to provide basic education for all, but would need partnerships with NGOs, the private sector, local communities, religious groups, and families to deliver this responsibility. SIAS envisages a role for non-governmental or non-profit organisations in providing services and support for children and families with disabilities, either voluntarily or under contract with the state (at 17).

One of the fundamental implications of the human rights model of thinking about disability is that it is now incumbent upon the government to ensure the realisation of the rights of people with disabilities without discrimination. It is not enough for the state to allow the establishment or operation of institutions for the education and care of children, such as the applicant in this action. The state must take positive measures to fulfil its responsibility, particularly because where such organisations cannot accommodate all the eligible children, as in the present case, the duty of the state to make education available and accessible to them is breached.

As to the prioritisation of rights in the face of competing demands, the respondent argued that it had limited resources and competing demands for their distribution, and that the right to education should not trump other rights such as housing, food, water, health care and social security (para 17). Indeed, the hefty demands imposed on the government by various socio-economic needs cannot be denied. In addition, sufficient justification cannot be made for prioritisation of education in general above other socio-economic rights, save for the argument that education is an empowerment right that fundamentally influences the realisation of many other rights (Beiter, 2006: 18).

However, international jurisprudence points to a differentiated duty with respect to primary education. In the view

of the United Nations Committee on Economic, Social and Cultural Rights (ESCR Committee), free and compulsory primary education ought to be prioritised in resource allocation (General Comment 13 on the right to education UN doc. E/C.12/1999/10, para 51). In addition, the right to basic education under section 29 of the South African Constitution is not limited to the progressive realisation and availability of resources, as are the rights to housing, health care, food, water and social security. Thus the state's argument that education should be considered in light of competing demands only arises in respect of the provision of further education. The children in the present case were, however, claiming basic education.

The respondents relied heavily on White Paper 6 to justify the current circumstances with respect to the affected children. They averred that once this policy was fully implemented, which as projected would be in ten years' time, the children concerned would be able to access education. Yet the respondents did not rebut the submission that under the SIAS strategy, which forms part of the implementation of White Paper 6, children who required more than 'moderate and high levels of support' (levels 4 and 5 needs) would not be educated. Implicitly it was conceded that even after the policy was fully implemented, there would be children with severe and profound intellectual disabilities still excluded from the schooling to be provided by the respondents, solely on the grounds of the extent of their impairment.

Denial of access to education in this manner would be manifestly in violation of the Constitution, the Children's Act and South Africa's commitments under international law. Both the Constitution (section 9(3)) and the Children's Act (section 6(2)(d)) proscribe discrimination in rights on the basis of disability. The Children's Act, in section 11(1)(b), further requires that in matters concerning a child with disabilities, due regard be paid to making it possible for the child to participate in educational activities. South Africa ratified the CRPD in 2007. In article 24(2)(a), this convention binds states parties to ensuring, among other things, that children with disabilities are not excluded from the general education system on the basis of disability.

This means that their education, even when conducted outside regular schools, must be an integral part of mainstream education planning. In essence, funding and resource allocation and planning towards education must factor in the education of all children, including those with severe and profound intellectual disabilities. The state practice challenged in this case has the potential to exacerbate the exclusion of children with severe and profound intellectual disabilities from contact with other children, and thereby undermine the goal of inclusion. It is clear that there is a discrepancy between the standard required in international law and that established under White Paper 6. The policy predates the CRPD and ought to be revised accordingly.

Progressive realisation of the right to education of children with disabilities as contemplated by the policy is also worth some thought. The right to basic education under section 29(1)(a) of the South African Constitution is not subject to resource availability over a period of time. In addition,

the implementation of the right to free primary education is an immediate obligation under international law. South Africa maintains a system of user fees for primary schools, with conditional exemptions. Some commentators indeed argue that use of the term 'basic' as opposed to 'primary' education under section 29 of the Constitution is a deliberate move to shield the state from international demands to make primary education free and compulsory (Woolman and Bishop, 2008: 24.)

But in any case, basic education is broad and primary education is but a facet thereof, which the state is still bound to provide free for all by virtue of its commitments under the United Nations Convention on the Rights of the Child (CRC). Consequently, suggesting delivery of education for children with disabilities on a progressive basis while not applying the same standard to children without disabilities is, in effect, discriminatory. What remains is to establish whether such differentiation is fair or not, and if not, whether it is justifiable.

We will not delve into this debate here, but it may be useful to emphasise that the debate on whether or not the realisation of primary education for children creates immediate or progressive duties is continuing. The prevailing view is that primary education yields immediate obligations for states. This view is supported by the ESCR Committee in General Comment 13 on the right to education. Article 4(2) of the CRPD obliges states parties to take measures to the maximum of their available resources with a view to achieving socio-economic rights progressively. However, the CRPD's article 7(1) requirement that states parties ensure the enjoyment of the rights on an equal basis with other children brings into play the standards established under other international instruments such as the International Covenant on Economic, Social and Cultural Rights and the CRC, which establish an unlimited duty to provide free and compulsory primary education. According to article 4(2) of the CRPD, where immediate obligations are already established in international law, progression does not apply.

The submission that the children in question were unlikely to benefit from any amount of education implies an understanding of education in the narrow sense of formal education. It is difficult to say that a child is incapable of benefiting in any respect whatsoever. A child's education is aimed at, among other things, the fullest possible development of their personality, talents and mental and physical abilities. In addition, education is generally evaluated on the basis of four elements: availability, accessibility, acceptability and adaptability. Adaptability in educa-

tion requires the education provided to be responsive to the needs of each student. To achieve this, the curriculum must be flexible enough to accommodate diverse needs. Thus, to argue that a student is incapable of benefiting from education is an implicit admission of both inflexibility and unwillingness to adjust the curriculum to the learner's needs, which is a violation of their right to education.

It should also be noted that though the case was mainly about the implementation of the right to education, the core of the argument was allegations of unequal treatment of the children concerned. The applicant argued that the manner in which state funds were allocated for education discriminated against children with severe and profound disabilities. The outcome might have been different if the underlying question had related to the government's approach to education in general. Evidently, the Court did not address itself to the implementation of the right to education for children with disabilities in general, but focused on the education of one category of children with disabilities relative to others: those with less severe disabilities, other types of disabilities or no disability at all.

### The effects of the decision

This case reaffirmed the responsibility of the state to ensure non-discrimination on the basis of disability in the allocation of resources for the implementation of rights. The actual impact of the case on decision-making in the provincial government can perhaps be assessed when the report is filed in November 2011.

The decision is of persuasive value to other courts at the national level. It is also a milestone towards realising the educational rights of children with severe and profound intellectual disabilities. While this decision is of immediate benefit to children under the care of the applicant, it is equally important for children and organisations in similar circumstances all over South Africa. It can be applied to trigger responses from other departments in the various provinces.

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The full judgment can be accessed at <http://www.fedsas.org.za/english/Hofuitprake.aspx>

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## The practical implications of the Social Assistance Amendment Bill 2010 for persons with disabilities

Yvette Wiid

*Arguably one of the most important rights in the Bill of Rights of the South African Constitution is the right to equality. Section 9 of the Constitution provides that 'everyone is equal before the law, and deserves equal protection of the law'. In addition to the right to equality, numerous other rights have been identified as playing a major role in protecting the quality of life of South African citizens and residents. These rights are socio-economic rights and include the right to housing, water, basic health care, access to social security, and life (see Khoza and others v Minister of Social Development and others 2004 (6) SA 504 (CC) for the inclusion of permanent residents in the scope of application of socio-economic rights in South Africa). According to Strydom (2006: 247), the right to equality is the guarantee to all citizens and permanent residents of South Africa that they may enjoy the socio-economic rights enshrined in the Constitution equally.*

As a result of the importance attached to the socio-economic rights contained in the Constitution, many pieces of legislation exist which aim to protect and facilitate these rights. Examples are the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000, the Labour Relations Act 66 of 1995, the Unemployment Insurance Act 63 of 2001, the Social Assistance Act 13 of 2004 and the Prevention of Illegal Eviction from and Unlawful Occupation of Land Act 19 of 1998. All these are laws of general application and apply to all citizens and residents of South Africa.

While these extensive general legislative measures exist to ensure the equal treatment of South Africans, there is an obvious dearth of legislation and policy relating to the protection of the socio-economic rights of persons with disabilities. One may argue that the laws of general application mentioned above are sufficient for the protection of the rights of persons with disabilities as well as those without disabilities, but it is important to bear in mind that persons with disabilities have, in many instances, different needs and find themselves in different circumstances to those of the average South African without any disability.

In 2006, the United Nations recognised the need to make specific provision for the protection of the rights of persons with disabilities and adopted the Convention on

the Rights of Persons with Disabilities (CRPD) and its Optional Protocol of 2006. South Africa signed and ratified this Convention in 2007 and is consequently bound by its provisions. The most important is article 4, which places an obligation on all states that have ratified the Convention to implement necessary legislative measures to provide for the rights of persons with disabilities. As a result of this obligation, the first tentative step towards implementing disability-specific legislation was taken by the South African legislature.

Legislation making provision for the rights of persons with disabilities includes: the Social Assistance Act, which allows a 'person with a disability' to apply for the state-administered disability grant; the Employment Equity Act 55 of 1998, which provides that the employment prospects of a person with a disability may not be curtailed because of the disability; and the Promotion of Equality and Prevention of Unfair Discrimination Act, which provides that no person may be discriminated against on the basis of their disability.

One of the most problematic aspects of all these laws is that none includes a satisfactory definition of either 'disability' or 'person with a disability'. The Social Assistance Amendment Bill 2010 included a definition of 'disability' that was intended to clarify the concept, and thereby make the identification of a person with a disability easier. It is submitted that easier identification of a person as having a disability would in turn make the protection of that person's rights in terms of the legislation dealing with the rights of persons with disabilities easier. It is obviously impossible to protect the rights of a person with a disability if one does not know what a disability is.

While the attempt to define a person with disability in the Social Assistance Amendment Bill is a laudable effort, the definition itself, as well as its practical ramifications, has been met with heavy criticism from various sectors. The definition of a disability in terms of clause 1 of the Social Assistance Amendment Bill is as follows:

'disability', in respect of an applicant, means a moderate to severe limitation to his or her ability to function as a result of a physical, sensory, communication, intellectual or mental disability rendering him or her unable to—

- (a) obtain the means needed to enable him or her to provide for his or her own maintenance; or
- (b) be gainfully employed ...

This definition would be used when determining whether an applicant is deemed to have a disability for purposes of being awarded the state-administered disability grant,

- A national health policy that focuses specifically on people with impairments would be very important in improving the status of this group ●●

which forms part of South Africa's social security system. The right of access to social security is one of the socio-economic rights that are guaranteed in terms of section 27 of the Bill of Rights.

The definition proposed in the Bill is clearly more developed than the definitions of a person with a disability in existing legislation, although elements of the current definitions can be found in this proposed definition. While it seems to be worded carefully and is much more detailed than any of the existing definitions, it is the consequences of the introduction of this definition that are worrying.

One of the more important criticisms of the proposed definition was put forward by the AIDS Law Project (ALP) (ALP 2010a). The ALP criticised the definition for vagueness, in that the term 'disability' is used to define 'disability'. The definition is therefore not only vague, but also unclear. Many of the current problems relating to the awarding of the disability grant result from the lack of clarity relating to certain practicalities in determining the eligibility of the applicant. One example that the ALP points out is that doctors involved in the process of determining the extent of a person's disability are unsure of their duties in this regard.

Another problem surrounding the awarding of the disability grant that relates to the definition of disability as proposed in the Bill is the lack of guidelines for officials from the South African Social Security Agency (SASSA) dealing with applications for the grant. The ALP points out that this results in the outcome of any particular application being based on the subjective opinion of the SASSA official dealing with it. This situation is undesirable, as the outcome of an application for the disability grant should be based on a set list of criteria applicable to all applicants, not on the approach of a particular official.

The South African social security system makes provision for the payment of permanent and temporary disability grants. For that reason, it would be useful if the particular disability of an applicant could be classified as temporary or permanent by the doctor involved in the application process. This is not the case at the moment. Many doctors are unsure whether they should specify the temporary or permanent nature of the applicant's disability, and this has led to problems in the disability grant system. Many recipients of the grant who were awarded it on a temporary basis are made to reapply year in and year out. Where it is patently clear that a recipient's condition is not going to improve to such an extent that they

will no longer need the grant, the recipient should not be made to reapply for the grant, as the application process is often a drawn-out and costly exercise. One must also bear in mind that recipients do not receive the grant while they are in the process of reapplying, which leaves them without an income for that time.

Persons in receipt of the disability grant and the older person's grant are currently permitted to apply for a supplementary grant when they require additional care for themselves at their own home. This supplementary grant is known as the grant-in-aid. The definition of 'disability' in the Bill, read with clause 6, effectively excludes anyone in receipt of the older person's grant from applying for the grant-in-aid. Clause 6 provides that a person is only entitled to receive the grant-in-aid if he/she has a disability and requires 'regular attendance by another person'. Many older persons are not necessarily considered persons with disabilities, according to the definition in the Bill, but require 'regular attendance' because of their age and resultant frailty. Since these older persons are not considered as having disabilities for purposes of the Bill, they are effectively disqualified from applying for the grant-in-aid. The exclusion of frail or ill older persons from applying for the grant-in-aid must be remedied, as it may be argued that the effective barring of these older persons from accessing the grant-in-aid amounts to unfair discrimination in terms of section 9 of the Constitution.

It is submitted that the definition proposed in the Social Assistance Amendment Bill is not ready to be passed into law in South Africa, since there are too many uncertainties and perceived absurdities with the definition as it currently reads. It is further submitted that the Bill only addresses one aspect of the rights of persons with disabilities, namely the right of access to social security. Any legislative attempts to promote and protect the rights of persons with disabilities should not be limited to the protection of one socio-economic right, but rather extend beyond that. Disability-specific legislation should therefore not address one problematic aspect of the protection of the rights of persons with disabilities, as the Social Assistance Amendment Bill does, but provide clarity as to what exactly the rights of a person with a disability are. In other words, any attempt to protect the rights of persons with disabilities in legislation should deal with as many rights and aspects of those rights as is practically possible.

Should the Social Assistance Amendment Bill be promulgated as it currently reads, South African law will still be addressing the rights of persons with disabilities in a piecemeal fashion in separate pieces of legislation. It is therefore in the interests of legal certainty and to the benefit of persons with disabilities that the protection of their rights be dealt with in a comprehensive and unambiguous manner. In accordance with the provisions of the CRPD, it is submitted that the most appropriate manner in which to provide for the rights of persons with disabilities in South Africa is the introduction of disability-specific legislation that is not only well considered but also well constructed.

The legislation should not only provide for a definition of 'disability' or 'person with disability', but also address the numerous ancillary issues that have been raised in the wake of the Social Assistance Amendment Bill, and have been the cause of much debate. It is important that any disability-related legislation be drafted in consultation with experts in disability law, as well as representatives from the 'disabled' community such as Disabled People South Africa and the Disability Workshop Development

Enterprise, so that the outcome of such consultation is a workable piece of legislation that makes adequate and clear provision for the protection and equal treatment of persons with disabilities.

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## Human rights forums and the Convention on the Rights of Persons with Disabilities in KwaZulu-Natal

Sarah Rule and Bongwiwe Zuma

*South Africa ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in November 2007. It was one of the first 20 countries to do so. But there was no fanfare, no nationally visible celebration and limited or no media coverage. Ordinary people with disabilities in South Africa's KwaZulu-Natal province were mostly unaware of the significant change in the disability context and whether it would have any impact on their lives.*

As in other parts of the world and of South Africa, people with disabilities in KwaZulu-Natal are a marginalised group, particularly vulnerable to poverty. Statistics South Africa identified a 5% disability prevalence rate in KwaZulu-Natal in the 2001 census, totalling 470 588 people with disabilities in the province (Lehohla, 2005). This same report described the deprivation and disadvantage people with disabilities experienced in South Africa. For example, in the 35–39 age group, 52.2% of non-disabled people were employed whereas only 25.9% of people with disabilities were employed. The percentage of households headed by people with disabilities who lived in traditional dwellings was significantly higher than the equivalent in households headed by people without disabilities (Lehohla, 2005),

probably indicating that the households headed by people with disabilities were in rural areas. Other indicators, such as access to piped water and electricity for lighting, also indicate significant deprivation in households headed by people with disabilities in KwaZulu-Natal.

Not only do people with disabilities in KwaZulu-Natal experience material deprivation and disadvantage, but, according to anecdotal evidence, a number of them also experience violations of their rights. Lack of access to education and the absence of appropriate places of safety for children and teenagers with disabilities are two of the violations described in the Umgungundlovu Disability Forum's 2010 shadow report to the United Nations Committee on the Rights of Persons with Disabilities.

Within the broader context of KwaZulu-Natal, and specifically that of vulnerable groups such as women, the elderly and people with disabilities, the Office of the Premier initiated human rights forums in ten districts of the province. Each forum consists of 20 members from civil society: representatives of organisations such as widows' forums and parents' groups, and traditional leaders. The members of the human rights forums were volunteers and, prior to the current project, had received some training from the Office of the Premier.

The mandate of the human rights forums is to raise awareness of human rights within their district, to receive complaints of violations of people's rights and to

deal with these complaints through referral to appropriate resources.

### **Purpose of the project**

The current project was initiated in order to inform the human rights forums specifically of the rights of people with disabilities as enshrined in the CRPD and in the South African Constitution and domestic legislation. The aim was also to engender appropriate attitudes towards people with disabilities so that forum members would be able to assist such people in their districts in a non-discriminatory manner.

### **Description of the project**

The project was undertaken as a partnership between government and civil society. A non-governmental organisation (NGO) called Community Based Rehabilitation, Education and Training for Empowerment (CREATE) initiated the project and is working with the Chief Directorate: Human Rights in the Office of the Premier and the Legal Resources Centre to achieve the project's aims. All partners contribute to the development of training materials and provide facilitators for the two modules of the course.

Participants in the training thus far have included 110 members of six human rights forums in KwaZulu-Natal. Their educational levels range from no education to high school. Most of the participants speak isiZulu as their home language and are from remote rural areas where resources are difficult to access. Most are unemployed or are volunteers in organisations representing young people, senior citizens, traditional leaders and traditional healers.

The course that was designed for the project consists of two modules. The first module raised awareness of human rights and disability. The second dealt specifically with interventions that the human rights forum members could make when they came across violations of the rights of people with disabilities. In Module 1, the participants learned about the South African Constitution, the CRPD, Chapter 9 institutions and the context for the promotion and respect of the rights of people with disabilities, including the Millennium Development Goals, South Africa's national outcomes and the provincial strategic objectives. Module 2 focused more specifically on the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000. In this module, participants learned about taking cases to the equality courts, as well as the more generic skills of networking and report-writing.

The content of the course was designed to facilitate a clear understanding of the difference between government and party-political initiatives. This is particularly important in KwaZulu-Natal, where membership of opposing political parties may be seen as sufficient reason to ignore the human rights orientation of the South African government. It was also felt that the training should help human rights forum members understand the importance of participating in and promoting the inclusion of people with disabili-

ties in development activities in their communities. This would encourage respect for and fulfilment of the rights of people with disabilities. Learning about the national outcomes and provincial strategic objectives would also equip the forum members with tools to monitor whether local councillors were acting in line with government priorities. It is hoped that information about the Promotion of Equality and Prevention of Unfair Discrimination Act and procedures to take cases to the equality courts will also enable the forums to act against violations of the rights of people with disabilities.

The language of training has mainly been isiZulu, the home language of most participants, with the manuals being available in isiZulu and English. These manuals are designed for participants who do not have a high level of literacy. Training takes place in the districts targeted, with a four-day workshop for each module.

The project continues: as at September 2011, Module 1 has been run in five mainly rural districts, as well as Umgungundlovu, the district in which Pietermaritzburg is situated. The four-day workshop for Module 2 has only been conducted in Umgungundlovu and uThukela districts thus far. In order to ascertain the knowledge and attitudes of participants, a baseline questionnaire is administered prior to Module 1 training. This is followed by an evaluation immediately after Module 1 and a repeat of the initial questionnaire some months later.

### **Initial outcomes of the project**

Although the project is not yet complete, the training has already produced some interesting results. Subsequent to the Module 1 workshops, participants have kept in contact with CREATE and a number of them have reported on outcomes of the training. The data from the questionnaires is incomplete because not all of the human rights forums have been trained yet. Therefore the findings discussed in this article are from reports on activities that forum members have undertaken rather than from the baseline assessments.

Having learned about the civil and political rights of people with disabilities, a member of the Umgungundlovu human rights forum based in a rural area was very quick to act on his training. Immediately after attending the first module of the course, he arranged for 40 people with disabilities to register with the Independent Electoral Commission as voters. Thanks to the myths and stigma prevailing in the community, people with disabilities had not been aware that they were entitled to vote. These people with disabilities were able to vote for the first time in the local government elections in 2011.

One forum member, the parent of a child with a disability, was particularly interested to learn about article 16 of the CRPD, which sets out the right to freedom from exploitation, violence and abuse. Together with other parents in her community, she had emphasised that the sexual abuse of children with disabilities was a major issue of



concern. This forum member is now working together with the district municipality's disability focal person and social workers from the Department of Social Development to address the problem.

Module 2 of the training has also proved to be a catalyst for action on disability rights. Several human rights forum members have reported violations of the rights of people with disabilities in their areas to CREATE. For example, in one district, a forum member reported that males with disabilities had not been allowed to participate in traditional cultural activities because of their disabilities. In another area, widows had been enticing boys with intellectual disabilities to have sex with them in the belief that it would 'cure the widow's bad luck'. The Legal Resources Centre is currently investigating whether it would be appropriate to take any of the cases of violations of human rights of people with disabilities reported subsequent to training to the equality court.

Human rights forum members are also beginning to locate abuses of the rights of people with disabilities within the wider context. In uThukela district, where *ukuthwala* (the abduction of girls and forced marriage) has recently been acknowledged as a problem, a forum member identified girls with intellectual disabilities and those with epilepsy as being at particular risk in this practice. The forum member has taken action to get two NGOs to address parents and to assist an orphan girl whose home was destroyed in the process of *ukuthwala*.

From the reports of human rights forum members on their activities after attending training, it appears that the course has stimulated at least some of them to identify situations in which people with disabilities in their communities face discrimination or violations of their rights. An increasing body of evidence will become available as the course is completed for all ten human rights forums in KwaZulu-Natal, and as baseline and follow-up questionnaires are analysed. Even at this stage of the project, however, several pertinent issues have arisen which may have wider implications.

## Disability rights and the role of government and civil society

The initial outcomes of the project reported on in this article illustrate the situation described by Mji et al. (2009: 3):

In South Africa the majority of people with disabilities are not yet experiencing meaningful change in their quality of life, access to equal rights and level of community integration, despite a favourable policy environment.

While the national and provincial governments are responsible for creating this positive policy environment, having ratified the CRPD, the role of government in implementing the CRPD and the policies designed to enact it needs to be explored.

Article 4 of the CRPD commits the state to taking appropriate measures to modify or abolish practices and

● ● Many officials in provincial and local government, as well as traditional leaders, lack knowledge of the CRPD ● ●

customs that discriminate against people with disabilities (United Nations, 2006). Through the reports of human rights forum members, both the local and provincial levels of government are becoming aware of discriminatory practices in parts of KwaZulu-Natal. Although government should be committed to addressing this discrimination, it has become apparent that many officials in provincial government departments and in local government, as well as traditional leaders, lack knowledge of the CRPD. Considering the stipulation in the Convention (United Nations, 2006: articles 4 and 8) that the state is responsible for raising awareness and promoting the training of staff that provide services guaranteeing the rights of people with disabilities, it could be said that the government has not fulfilled its mandate.

The current project illustrates that a partnership between government and civil society organisations can work to address discrimination against people with disabilities. Human rights forum members, through their contact and networking with government officials, are also raising awareness of the rights of people with disabilities in the public sector.

The human rights forums themselves were initiated by the Office of the Premier, although they have become independent of government. This raises the vexed question of the continuation of these forums. Without support from the government, forum members, who are mostly unpaid volunteers in community-based organisations, struggle to fund their work of promoting human rights, identifying cases of violations of human rights and referring people to appropriate resources. If the state were to fund these forums, would a member feel able to report cases where a government department or official had violated the rights of a person in their community? There are no easy answers. NGOs typically rely on donors, who may not fund operational expenses, so helping each human rights forum become a non-governmental organisation may not be a sustainable option. Although in this project the human rights forums are beginning to show the impact they can have on people with disabilities and their communities, their future is not assured in the long term.

The project reported on in this article illustrates that, while not uncomplicated, it is possible for a partnership between civil society and government to contribute to the promotion of the rights of people with disabilities and to

intervene when those rights are violated, even if the state itself is partly responsible for those violations.

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## The potential of children with disabilities to contribute to policy analysis

### Supporting children with disabilities become socio-economic rights activists

Christina Nomdo, Alexander Henry and Sandra Ambrose

*The Children's Act 38 of 2005 affirms the right of children to participate in all decisions affecting their lives. However, societal perspectives on the capacities of children inhibit the realisation of this right. An inordinate amount of attention is given to what children are 'unable' to do, instead of supporting the potential of their abilities (Lansdown, 2001). This is true for children in general and, in particular, for children with disabilities.*

This reflection provides some insights into the requirements for supporting children with disabilities when they act as socio-economic rights activists. It particularly relates to the involvement of children from the Disabled Children's Action Group (DICAG) in the Children Participating in Gov-

ernance (CPG) initiative coordinated by IDASA's Children's Budget Unit (CBU) from 2004 to 2006 (Nomdo, 2007).

### Children Participating in Governance Project

The IDASA facilitators ... demonstrated so much commitment and dedication when working with the diverse group of children, even the children with disabilities. (Written input by Sandra Ambrose, 7 October 2011)

The CPG project was initiated by the CBU in 2004. The project was titled Children Participating in Governance: Budget Monitoring within a Rights-Based Framework. The fundamental rationale of the project was that children's participation in governance ensures that their perspectives, experiences and priorities inform economic policy and budget allocations, among other things.

The project was designed to have two phases of execution: a training phase and an advocacy campaign. The

training programme built the capacity of child peer facilitators who, in turn, conducted workshops on the following three topical areas:

- linking budgets and rights;
- budget analysis as a monitoring tool; and
- developing a strategic budget advocacy campaign.

The process followed by the CPG project ensured full and equal participation of children with disabilities, and is discussed below.

## Partnering with DICAG

As one of the project leaders the process was very informative. I've experienced people's different beliefs and their cultural differences. I've gained so much knowledge from the facilitators as well as from the children and in the process it strengthened my leadership skills. (Written input by Sandra Ambrose, 7 October 2011)

DICAG was initiated as a programme under the auspices of Disabled People South Africa in 1993, and became an independent organisation in 1997. Even though DICAG was initiated to help parents of children with disabilities become advocates, the child participation ethos of the organisation has always been strong.

DICAG was one of four partner organisations in the CPG project. Like the other partners, DICAG was selected because of the commitment of the adults in the organisation to child participation. In the case of DICAG, these adults included the national coordinator, parents, facilitators, translators and interpreters. The adults ensured that the children were protected, supported in relation to their special needs, stimulated and integrated fully into the project. Their commitment was unwavering throughout the two-year training phase. The relationship between the initiating organisation and DICAG was very productive, allowing frank feedback and critique of project implementation.

## Selecting participants

The training phase of the CPG project required the selection of a group of five peer facilitators and 20 participants from the DICAG group. An important lesson from DICAG during the peer facilitator selection process related to the contentious issue of chronological age and its relationship to level of functioning. The CBU had decided that children up to 18 would participate in the project. DICAG argued quite strongly that chronological age meant very little to children with disabilities, among whom impairments negated age-appropriate functioning. Their selected peer facilitators were aged 14 to 20.

However, evolving capacity was not only applicable to DICAG participants. All the children in the peer facilitator group had varying levels of education and familiarity with the English used for instruction, so the adult trainers opted to present information as simply as possible in the form of games.

[For] almost all of us at the workshop, English was not our first language or our mother tongue and we had to talk English nearly all the time because it was the only way we could communicate. (Personal journal of peer facilitator, 20 May/June 2005)

For the DICAG group, it was necessary to adapt the information levels used to accommodate the different levels and styles of learning. One of the peer facilitators from DICAG helped the adult trainers adapt some materials. Some members in the DICAG group had difficulty concentrating for long periods and did not do well when discussion was the learning method used. They fared much better with role playing and drawing. For example, at one workshop the adult facilitators supported two parallel sessions for the DICAG children. One parallel workshop focused on budget analysis skills and the other on helping children who had been confined to their homes become familiar with the use of money. This was more empowering than the 'one size fits all' option – but it did require much more preparation, as well as plenty of patience.

Children, especially children with disabilities, are not a homogeneous group and thus require individualised support. The children in the project each required support according to their physical, emotional and intellectual make-up. For example, the two hearing-impaired peer facilitators selected by DICAG required at least two interpreters to keep pace with the rate of training. Some of the children from the other organisations required emotional support to deal with home stress. It was important to build a good support team for the project to ensure that all the children's needs were met.

## Children with disabilities leading social change

I'm raised by a disabled mother, but I have never worked closely with disabled teenagers.... At first it wasn't easy because we [have our prejudices] but today I stand in AWE of the things I've learnt from them and how they conquer thing[s] [even though they have] disabilities. (Personal journal of peer facilitator, February/March 2005)

The peer facilitation group consisted of approximately 20 children representing Molo Songololo's Cape Town-based children's group called It's Your Move; the Junior City Council of Cape Town; the Life Hunters children's group supported by Practical Ministries based in Port Shepstone, Kwa-Zulu Natal; and DICAG, which had national representation. The project coordinators expressly selected children's groups that would be proxies for urban, peri-urban and rural contexts. Children in the group spoke English, Afrikaans, Zulu, Xhosa or Sotho and subscribed to various cultural, religious and traditional belief systems. During the two-year training phase, the children had several opportunities to get to know each other as they met for at least a week at a time on three different occasions and in different contexts: Cape Town, Port Shepstone and Johannesburg.

The integrated composition of the peer facilitation group was reported to be the factor with the most important impact on the consciousness of the children involved. The children very quickly overcame prejudices and biases about working in an integrated group. They focused almost immediately on satisfying their curiosity about the others. The experiences of difference intrigued all the children. For example, boys and girls wanted to develop more personal relationships, and children from urban and rural contexts wanted to understand each other's life experiences.

## Gearing up for advocacy

Some of our municipal officials are interested [in] this project. This will surely break the concrete that I assumed was between children and government. (Personal journal of peer facilitator, 23 August 2005)

The first two training workshops concentrated on the concepts of socio-economic, civil and political rights; how government works; and the budget system and structure. The final workshop with peer facilitators focused on advocacy

skills and provided some opportunities to engage in child rights advocacy. The work coincided with the presentation of the national budget. The CPG peer facilitators attended a joint forum for the budget where the National Assembly and the National Council of Provinces questioned the national minister on budget policy.

During the same week, the children participated in civil society activism for the extension of the child support grant to 18-year-olds. The children took part in a march that delivered a petition to Parliament and participated in a media campaign. A small group worked with the IDASA facilitators to draft a response to the 2006 national budget in terms of the realisation of children's rights.

## Children with disabilities as rights activists

All the CPG child participants were asked to contribute to the policy on inclusive education. They provided their input during discussions and debates. The DICAG children in particular provided their input by means of role play and drawings as well as more conventional methods of discussion. One DICAG child participant was interviewed specifically to relate her experiences of mainstreaming inclusive

### The story of Alex Henry

#### Who I was at the start of the project

I'm Alex Henry and I'm 21 years old and am confined to a wheelchair due to cerebral palsy. However, I lead an active mainstream lifestyle. I live in the City of Cape Town in the suburb of Strandfontein adjacent to Mitchells Plain... I am currently (in 2005) completing the last of two years of my secondary education at a further education and training College. I actively engage with peers in mainstream activities of a social nature. Like all adolescents I occasionally indulge my vices. Inevitably these peers become my support system.

I think I started with the Disabled Children's Action Group in 1997 as a member because my mom was using them as a support system. She found out that there was a youth outing over a long weekend and this is how I became a member. I went to Parliament and represented my school under the DICAG banner: lobbying government from a disability point of view. I became a founding member of the youth steering committee where I enjoyed the benefits of national travel in 2000. Before leaving high school I went to Sweden on a study tour under the banner of the South African Council on Disability (which is now defunct).

I think I was selected for this project [CPG] because I'm outspoken. Part of my dream is to show disabled youth [that] yes, it may take you a longer time, but you can get what you want and where you want to be. Yes, I work hard but I am still not where I want to be. I want to be completely mainstream and independent. Disability should not be an issue. (Personal journal, August 2005)

#### Integrating into the peer facilitators' group

Because I am able to interact across the board on different levels and I have verbal and reasoning abilities,

they forget I am disabled. It is to my advantage because they don't get 'choked up feelings inside'. So they are able to tell me what they don't like about me without being afraid of offence. With others, they are overly tactful which will spark a vendetta/argument in the future. (Personal journal, 20 February 2005)

Kusela, who is loud and fun-loving, ... wants to include me in her own special way. She makes a person feel mainstream. She is not one to throw a pity-party for me. From the beginning there was Louise. She virtually became my human computer because of her friendliness towards me. I felt at ease working with her [she helped to make notes during the workshops]. (Personal journal, July 2005)

#### Experiences of facilitation

The difficulty is that my constituency might not be able to fully participate due to their various disabilities. However, I will adapt my facilitation skills to accommodate everyone but I may have problems in adapting content (especially the concepts).

I am thinking of meeting with a special needs teacher to explain my job as a facilitator and the content I am expected to share. I will then request help from the teacher to break down these concepts in order for everyone to understand. (Personal journal, 20 February 2005)

#### Impact of the project on my life

... it almost set me up for life today, hence I'm a trainer. When I pushed for my job that I now have, in the back of my mind [I had]... that I could cope with classroom dynamics.

Without me knowing the project was a vital for me too because at the very least I have been able to keep up my economic status. (Written input, 12 October 2011)



education. This input formed part of an IDASA policy analysis document (Wildeman and Nomdo, 2007).

The DICAG group was able to attend the 2006 budget speech by the Minister of Finance, as DICAG is always invited. In addition, however, thanks to the personal advocacy of one of DICAG's peer facilitators, two child advocates from the group were able to ask the Minister and Director-General of Finance questions on national television about the introduction of fee-free schools and accessible transport for young people going to work.

## Conclusion

Children can become effective rights advocates and agents for change when they are provided with appropriate support from peers and adults. The CPG project trained 100 children to understand and implement rights advocacy. DICAG adults and child representatives successfully participated in a two-year training initiative to build capacity to analyse government policies and budgets from a child rights perspective.

The key insights relating to supporting children with disabilities in becoming rights activists include the following:

- Adult partners are required to support, protect and facilitate the integration of children.
- The evolving capacities of children need to be taken into account.
- Games, drawings and role plays facilitate learning and dialogue.
- Working in an integrated group helps children break down prejudices and the stereotyping of children with disabilities.
- The children involved found policy advocacy relating directly to their own life experiences most interesting. All they needed to raise their opinions with confidence was support.

Christina Nomdo is the executive director of Resources Aimed at the Prevention of Child Abuse and Neglect (RAPCAN), based in Cape Town. Alexander Henry is an activist with the Disabled Children's Action Group (DICAG). Sandra Ambrose is DICAG's national coordinator.

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## New publications

### World Health Organization, 2011: *World report on disability*

The *World report on disability* was launched by the World Health Organization (WHO) and the World Bank in June 2011. This, the first such report, is based on the Convention on the Rights of Persons with Disabilities. It makes a major contribution to our understanding of disability and its impact on individuals and society, and it highlights the various barriers that people with disabilities face: attitudinal, physical and financial. The report documents the current situation of people with disabilities, highlighting gaps in knowledge and stressing the need for further research and policy development.

The report recommends that policy-makers, research-

ers, practitioners, advocates and volunteers involved in disability take action at the local, national and international levels. It advocates the inclusion of persons with disabilities in their communities in terms of access to health, rehabilitation, support, education and employment.

The report points out that working-age persons with disabilities experience significant labour market disadvantages and worse labour market outcomes than those without disabilities. Global data from the World Health Survey shows that employment rates are lower for disabled men (53%) and disabled women (20%) than for non-disabled men (65%) and women (30%). This indicates that people with disabilities are more likely to be unemployed and thus experience higher rates of poverty than non-disabled people.

For further details on the report, go to [http://www.who.int/disabilities/world\\_report/2011/en/index.html](http://www.who.int/disabilities/world_report/2011/en/index.html).

**M Perlin, 2011.** *International human rights and mental disability law: When the silenced are heard.* Oxford University Press, New York

This book draws attention to the conditions of persons with mental disorders, who are particularly vulnerable to abuse and violation of their rights. Mental disability law is one of the least understood areas of the law. The book sheds light on conditions of persons with mental disability by stimulating the debate on a social policy issue that remains a low priority for most nations.

It explores the mistreatment of persons with mental disabilities around the world by examining and analysing the growing field of international mental health law, using

examples from Western and Eastern Europe, South America, Africa and Asia.

The book highlights the interconnectedness of international human rights and mental disability law. It further argues that persons with mental disabilities should be treated with liberty, dignity, equality and entitlement, as they seek to be treated.

For further details, go to <http://www.oup.com/us/catalog/general/subject/Psychology/Clinical/?view=usa&ci=9780195393231>

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## Call for contributions to the ESR Review

The Socio-Economic Rights Project of the Community Law Centre (University of the Western Cape) welcomes contributions to be published in the *ESR Review*. The *ESR Review* is a quarterly publication that aims to inform and educate politicians, policy-makers, NGOs, the academic community and legal practitioners about key developments relating to socio-economic rights at the national and international levels. It also seeks to stimulate creative thinking on how to advance these rights as a tool for poverty alleviation in South Africa and abroad. Contributions on relevant experiences in countries other than South Africa, or on international developments, are therefore welcomed.

Contributions should focus on any theme relating to socio-economic rights, on specific rights or on socio-economic rights in general. In addition, we are currently seeking contributions on:

- the role of Parliament in advancing socio-economic rights;
- the African Commission and socio-economic rights;
- using international law to advance socio-economic rights at the domestic level;
- South Africa's reporting obligations at the UN or African level, or both, in relation to socio-economic rights.

Contributions should be sent in electronic format (MS Word) to [serp@uwc.ac.za](mailto:serp@uwc.ac.za) or [gmirugi-mukundi@uwc.ac.za](mailto:gmirugi-mukundi@uwc.ac.za). Previous editions of the *ESR Review* and the complete guide for contributors can be accessed online: [www.communitylawcentre.org.za/clc-projects/socio-economic-rights](http://www.communitylawcentre.org.za/clc-projects/socio-economic-rights)