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Children in Difficult Circumstances: A South African Perspective

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ABSTRACT Throughout the world, a great many children face severe hardships, particularly those who are encumbered with disabilities. Although commendable legal and policy reforms have been introduced in an attempt to cater for the needs and the best interests of children, at present their effectiveness is being hindered by the inability of those structures which are tasked with meeting the needs of children to provide adequate support for their optimal well-being and development. Consequently, the gains which are to be expected from reforms in terms of legislation and policy frameworks remain theoretical gains, as actual practice tends to resist the successful implementation of these reforms to provide adequate assistance to children with disabilities. Some of the significant shortcomings of practice are evident in the shortage of educational institutions with the requisite specialised skills and humane environments to cater for children with special needs and the financial difficulties which the additional costs which are entailed in enabling these children to achieve an acceptable standard of living in their adult lives. It is the considered opinion of the authors of this paper that both the government and other relevant stakeholders need to make a coordinated and concerted effort to ensure that rates of dropping out of schools are minimised, families are strengthened and schools equipped with support systems to accommodate disabled children.

INTRODUCTION

In South Africa, disability is still surrounded by stigma and prejudice (Cooper and Gilbert 2016). For parents, having a disabled child tends to be associated with punishment, failure and, in extreme cases, a belief of having been cursed. Parents of disabled children often experience exclusion within their communities and the birth of a disabled child is often accompanied by rejection on the part of either one or both parents. In rural areas, it is commonplace for men to leave their wives after the birth of a disabled child, as the wife is often believed to be blamed for the disability. In addition, not only is the abandonment of families into which disabled children are born often not frowned upon, indeed, it is largely condoned by local rural communities. In urban areas, in which men also frequently leave their wives after a disabled child is born, it would appear that in many cases the men are seeking to escape the pressures which are associated with caring for a disabled child, rather than from the stigma which may be associated with his or her birth. However, in both sets of circumstances the consequences for the abandoned mother are the same. The vast majority of disabled children are brought up in single-parent households (Loft 2011). For example, in one special school which catered for 200 children, only 20 of the children had fathers (Lansdown 2002).

As a result of the negative attitudes which surround them, disabled children are frequently hidden from view, kept in back rooms and their existence and their human rights largely denied (Lansdown 2002: 8). In order to ensure that the provisions for social justice which are enshrined in the United Nations Convention on the Rights of the Child are honoured, disabled children and their parents need a variety of support structures that will help them to overcome the difficulties with which they have been encumbered and to take their rightful place in their societies. The United Nations Education Fund (UNICEF) has identified disabilities with respect to sight and hearing as being the most common in South Africa. In addition, statistics have shown that one in ten children with disabilities is afflicted by multiple disabilities. In terms of gender, disabilities tend to be more pronounced among males than females, while orphans and children living in institutions or on the streets are at a particularly high risk of suffering from disabilities. The precarious situation of disabled children is particularly evident in the findings of the Statistics South Africa Community Survey of

2007 that children with disabilities are less likely to have access to housing, water and sanitation than their non-disabled peers and that these conditions cause a great deal of stress and strain for these children and for their families (UNICEF 2012: 11).

The relevant literature reveals that of the order of 110 300 learners with disabilities attend ordinary public schools in South Africa and that there are 423 special needs schools throughout the country to attend to the needs of these children, with 105 000 learners benefiting from these schools. However, the literature also reveals that among those disabled children who attend schools, the rates of dropping out are significantly higher than those of children who are not disabled (UNICEF 2012: 11). Elphick et al. (2015) explains that although South Africa has demonstrated a considerable commitment to disabled children through legal and policy reforms during the past two decades, the implementation of inclusive education for them remains an uphill and arduous task. Examples which have been drawn from a study which was published in the Childhood Journal reveal that parents and caregivers of children in the economically poor township of Orange Farm, which is approximately 45 km south of Johannesburg, spend between R600 and R900 approaching seven different schools to complete various assessments and to seek admission for their children (Elphick et al. 2015: 108). Unfortunately, the study also found that there are no local schools in the community which cater for the needs in terms of educational support of children with moderate or high levels of disabilities. The reasons which are advanced for refusing admission to these children range from a lack of space in the schools, insufficient facilities such as ramps or continence care and insufficient skills to accommodate children with disabilities (Elphick et al. 2015).

Rates of impoverishment are very high for a very significant portion of the households which house children, which makes it imperative for policies to prioritise the needs of children in South Africa (Wilkinson 2011). Poor people are at a particularly great risk of impairment or disability and the birth of a disabled child or the occurrence of a disability in a family often exerts a negative influence on the morale of families which are affected, frequently thrusting them still deeper into poverty. As a consequence, not only is there a particularly high proportion of disabled people among the very poor, but there are also steadily-increasing numbers of families living at the poverty level as a result of disabilities (UNICEF 2013). The International Labour Organisation (ILO) and the UN Development Programme (UNDP) maintain that a key indicator of poverty is the degree to which people are excluded from having access to basic goods and services (Integrated National Disability Strategy White Paper 1997). Poor people do not have sufficient income to purchase goods and they also live in underdeveloped areas in which there is usually a lack of sanitation, water, electricity, health services, employment opportunities and educational and recreational facilities (Triegaardt 2006; Nicholson 2015).

Mall (2011) reveals that adolescents who are deaf or hard of hearing are more vulnerable to becoming infected with HIV or AIDS than their peers whose hearing is not impaired, owing largely to the difficulties which they experience with communication. By contrast, adolescents who are able to communicate effectively are far more likely to be able to make informed sexual decisions. The greater vulnerability of deaf children and adolescents also stems from the fact that they are faced with a great many risk factors which result from being drawn into sexual activity early, having multiple sexual partners and even from experiencing sexual abuse, which they may not know how to report (Joffe and Bettega 2003 cited by Mall 2011).

Since 1994 the South African government has given high priority to concerns which pertain to disabilities. Its commitment to overcoming the profound social and economic injustices which are experienced by disabled people is evident in the range and the nature of the measures which have been introduced to achieve change and the importance which has been accorded to them. The range of measures includes legislation which gives equal rights to disabled people, the Integrated National Disability Strategy and the National Plan of Action for Children to convert the legislation into a framework for action, which is backed up by powerful political structures which have been designed to implement the strategies, systems for monitoring and evaluating progress, a provincial framework which is responsible for their implementation and the establishment of a statutory independent Human Rights Commission (Lansdown 2002: 8).

According to the Integrated National Disability Strategy White Paper (1997), the paradigm shift from the medical to the social model has come about largely through the development of strong organisations of disabled people (DPOs). A central tenet of the social model of disability is the principle of self-representation by people with disabilities through DPOs. One of the most important initiatives which has been undertaken by the DPOs over the past few years has been the development of a number of charters which express the demands and rights of people with disabilities in South Africa.

Problem Statement

Although South Africa has ratified international legal clauses as an expression of support for internationally acknowledged standards of human dignity and through the providing of inclusive access to services which are of equitable quality for all people and particularly for children with disabilities, these achievements for ensuring social justice are severely undermined by realities which make equitable access very difficult for disabled children. The lack of the specialised skills which are needed to train and teach disabled children and the lack of schools which are able to accommodate them are further aggravated by a lack of financial resources among most of the families which take care of them. The reports of investigations which have been conducted by reputable researchers have established that disabled children in these circumstances are particularly vulnerable to the effects of poverty and to becoming infected with HIV or AIDS and that, in most cases, they are likely to drop out of school if they do gain access to schooling. Although more than two decades have elapsed since the official demise of apartheid, it appears that this group of children remains trapped in a persistent cycle of vulnerability and poverty.

Aims and Objectives

The aim of this paper is to provide a succinct discussion and an investigation of the benefits which the support structures which exist at present in South Africa provide to children with disabilities and to their parents. This study will take the form of a review of the literature which documents how disabled children are enabled to improve their circumstances, particularly at school.

METHODOLOGY

This paper will endeavour to review the available relevant literature as a means of making an accurate assessment of the support structures which are available to children with disabilities and their parents, in order to alleviate their circumstances, to offer suggestions for improving their circumstances and to discuss the results of the policies and programmes which are being implemented at present. The literature which has been consulted includes United Nations documents, articles, news articles, government gazettes and books which are devoted to disabilities and children with disabilities, all of which have been assessed against the background of the experience of the researchers who compiled this paper.

OBSERVATIONS AND DISCUSSION

Benefits which are Available at Present from Support Structures for Children with Disabilities

This section will be devoted to a discussion of the problems which are encountered by children with disabilities, regardless of the support structures which are available.

Infrastructural Deficiencies

According to Manomano and Kang'ethe (2015: 247), the state of the infrastructure and equipment facilities which facilitate teaching and learning play a pivotal role in motivating learners and educators to achieve and to attain educational goals. Conversely, when there is a lack of adequate infrastructure, equipment and facilities, adverse consequences for teaching and learning will inevitably follow, because infrastructure and its various components, such as classrooms, ventilation, doors and books, create an enabling environment which fosters effective teaching and learning. It seems entirely plausible that either a lack of adequate funds or the poor administration of those funds which are allocated could account for the problems which are evident in the infrastructural deficiencies of certain schools.

Vosloo (2009) maintains that for learners with disabilities to function successfully in mainstream school settings it is very important to ensure the availability of special equipment, trained personnel to provide individual attention, suitable adaptations to the environment and devices to enable learners with disabilities to cope with the requirements of their schooling. Although the study which Vosloo (2009) conducted at a school in the Western Cape established that teachers were usually supportive, there were still hazards for children with disabilities, owing to a lack of information concerning meeting their special needs. As an example, children with brittle bone disease are likely to sustain fractures if particular care is not taken to ensure that they do not take part in contact sports or other activities which expose them to the risk of serious injury. In the case of the children with disabilities in the township of Orange Farm, a lack of transportation systems prevented them from attending schools, which was exacerbated by the conditions of grinding poverty in which most people live in this informal settlement (Ford-Shubrook 2007).

Inadequate Human Resources

Human resources constitute one of the most crucially important support structures for children with disabilities. Although caregivers, in the form of parents, guardians, teachers and trainers are some of the most vital human resources for children with disabilities, it has been reported that staff who are employed by the Department of Education are ignorant and unresponsive to the needs of their parents. In one of the studies which was conducted in Orange Farm, some of the participants revealed that when they visited the offices of the Department of Education to register their complaints concerning the failure of the department to secure places in the schools for their children with disabilities, they were told to tell the schools to find places for their children and they were also reminded that the officials were very busy. This finding demonstrates that the channels which are available to these parents can actually be very reluctant to offer the support which they need (Elphick 2015). Du Toit and Forlin (2009) explain that in many of the indigenous cultures in South Africa, parents do not regard it as their responsibility to provide education at home or to engage in any activities which augment what their children are learning at school. To make matters worse, they also do not perceive it to be their role to support or assist their children by preparing them in order to enable them to engage well with the various academic disciplines which are taught at school. In addition, high divorce rates, single-parent families, extended families and grandparent-headed households have also contributed to a lack of support for the educational progress of learners who are raised in these family structures. This state of affairs is often still further aggravated by the financial difficulties which characterise the lives of most of these families, which obliges them to devote all of their efforts to eking out a meagre living and precludes them from having either the time or the energy to support the educational endeavors of their children and to provide them with adequate nurturance, which, in turn, tends to result in the children engaging in deviant or problematic behaviour. A study which was conducted by Kropiwnicki (2014) in Orange Farm found that most of the learners with disabilities were not safe, as they were frequently subjected to the risk of losing their belongings or even being bullied by other learners. Some complained that occasionally learners were left unattended and that in one instance, according to the testimony of two students who had hearing impairments, they had attacked a student who was in a wheelchair (Kropiwnicki et al. 2014).

Psychosocial Support

Families with children who have disabilities are confronted with a veritable minefield of potential problems in the psychosocial domain, some of which are traumatic in nature and may take the form of everyday reminders of the disabilities of their children or difficulties which are experienced in adapting to the reality of their disabilities. The discovery of having a child with a disability can, in itself, be an extremely traumatic experience, which can be accompanied by denial and inner conflict on the part of parents, which may also affect the disabled children. The experience of difficulties which are caused by a lack of adequate facilities to cater for the needs of disabled people can serve to exclude their families socially (Snell and Rosen 1997). Although the aim of psychosocial support (PSS) is to promote the psychosocial well-being of all children, some children are more vulnerable than others and programmes which are implemented to support vulnerable children need to take this fact into consideration through mainstreaming disability and also through providing disability-specific or adapted interventions. Psychosocial support should also be mainstreamed into programmes which provide support to children with disabilities and their families (Gwezera et al. 2012: 8).

In a study which was conducted in the Western Cape, some of the learners who participated in it expressed the opinion that although they were disabled, they expected to be treated well and as being the equals of the other learners (Vosloo 2009). In a study of the support which is provided to fathers in order to enable them to learn how to care for their disabled children which was conducted in the United Kingdom, one of the principal findings was that two thirds of the fathers in the study admitted to experiencing emotional difficulties in their attempts to deal with knowing that their children were disabled, with some having experienced a considerable amount of emotional stress. Some of the reasons which were given for these feelings of emotional stress concerned the fears of the fathers with respect to the future and their anxieties concerning whether they would be able to meet the needs of their disabled children, how their children would cope with the perceptions of others and how they would be able to interact with others and form interpersonal relationships. Most of the fathers revealed that they experienced difficulty in receiving adequate support from their extended families and in receiving adequate professional psychosocial support (Gore 2010).

In a study of inclusive education for children with disabilities which was conducted in Botswana by Mukhopaday et al. (2012), it was established that children without disabilities were quite prepared to share information with those who had disabilities. It was found that they helped disabled children with their classroom learning and even with the navigating of their lives at school. The class teachers also depended on these children to help one other. It was expressed by the authors of this study that the spirit of humanity which they had observed being displayed in Botswana should be emulated and practiced in South Africa, in order to promote the ideals of inclusive education.

Legislative and Policy Frameworks Remain Poignantly Theoretical

South Africa is considered to be one of the first African countries to draft legislation for the benefit of people with disabilities, particularly in the domain of inclusive education. An excerpt from the White Paper on the Rights of Persons with Disabilities of 2016, which was adopted from the constitution, is provided below:

"Everyone is equal before the law and has the right to equal protection and benefit of the law. Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken" (Republic of South Africa 1996).

From the beginning of the new democratic dispensation the government has displayed a laudable commitment to human rights through enshrining them in the constitution. The statement above constitutes an emphatic rebuttal of the apartheid dispensation of the past with all of its segregationist features, which the new post-apartheid government is committed to eradicate. The new White Paper on the Rights of Persons with Disabilities of 2016 provides essential guidelines which both the government and non-government organisations need to follow. The first concerns the need for the country to remove barriers to access and participation, to which the former President Mandela referred as obstacles: It is only when those obstacles are removed that equal opportunities will be realised (Republic of South Africa 2016: 49). In addition, Article 27 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) asserts that the state must take all reasonable measures to ensure that the best interests of the child are prioritised, which was also articulated in the Children's Act 38 of 2005 (Republic of South Africa 2016: 61). According to the African Charter on the Rights and Welfare of the Child (ACRWC), children "should grow up in a family environment in an atmosphere of happiness, love and understanding" (UNICEF 2012: 9).

The right of people with disabilities to adequate healthcare has achieved international prominence, which is confirmed by Article 25 of the UNCRPD of 2006. However, a great deal needs to done in order to accord this right to those who are infected with HIV and AIDS and in the domain of preventing the spread of the pandemic (Rohleder 2016). The government of the Republic of South Africa has provided legislative support for disabled children through the

Bill of Rights which is contained in the Constitution of South Africa (Republic of South Africa 1996) and the Children's Act 38 of 2005 (Republic of South Africa 2005) and also by ratifying international treaties and conventions. In addition, the government has provided support through cash transfers to the caregivers of children for children under the age of 14 years, which has also improved the lives of children in many ways (Williams 2007).

However, against the backdrop of steadily-rising levels of unemployment and poverty, some of the gains which have been made appear to be being undermined or even negated, particularly with respect to the well-being of children. For example, statistics show that close to seventy percent of children with disabilities of school-going age are out of school, while of those who do attend school, most are still in special schools for learners with disabilities. This finding reveals that the implementation of the legal frameworks which have been formulated in the name of inclusivity is still lagging behind (Donohue and Bornman 2014). In addition, it has been found that in South parents are often reluctant to spend money on the education of disabled children. Some parents believe that it is feasible to pay tuition fees to send their disabled children to school, particularly in those instances in which they have other growing children who do not have disabilities who have a greater potential to generate income after leaving school than their disabled children.

Financial decisions which are based on shortages of income also serve to limit the opportunities of disabled children to exercise their right to education. Children with disabilities are not the only ones whose right to education is often withheld as a result of a lack of financial support, as even in the mainstream higher education system many students are obliged to drop out owing to having their access to higher education terminated by financial constraints. The frustration which has resulted from this phenomenon has found expression in the #FEES MUST FALL movement from 2015 to 2016, whose voice will inevitably become progressively louder, accompanied by increasing outbursts of violence, if nothing is done to alleviate the circumstances of these students. A study which was conducted in Gauteng found that parents complained about the difficulty of gaining access to education for their children who had disabilities such as cerebral palsy and autism. The waiting lists for the special schools are too long while ordinary schools often appear to be unprepared to accept children with disabilities, which places a significant number of children outside of the school system. All of these problems are also evident in the other provinces of South Africa (Walton 2014: 210).

Although the care dependency grant provides much-needed financial support to disabled children who are in difficult financial circumstances, some are denied access to the grant owing to the failure on the part of the relevant officials to admit that some children are sufficiently disabled to be eligible for the grant. In one particular case, the mother of a child who had difficulty breathing and speaking was refused the care dependency grant by officials who insisted that it would need to be proved that the grant would be needed until the child reached the age of 18 years or that he or she was already receiving treatment on a permanent basis (Khoza 2015). Despite the huge financial burden which social services entail for the government, there is a need to employ a holistic view to sustain and assist children with disabilities, whether they are permanently disabled or they are in need of treatment to relieve their conditions. In many cases, the outcomes of surgery and operations are not certain and, in some cases, result in other chronic problems, which becomes particularly burdensome for parents who are struggling to obtain adequate medical assistance for their children. It is the considered opinion of the authors of this research paper that both the relevant stakeholders and the government need to give immediate priority to alleviating the extremely adverse circumstances of parents who require extensive medical treatment for their disabled children.

Disabled People's Organisations

According to the Integrated National Disability Strategy White Paper (1997), Disabled People's International (DPI) is recognised by the United Nations as the international assembly of disabled people. In turn, DPI recognises Disabled People South Africa (DPSA) as the national assembly of disabled people in South Africa. DPSA is a national organisation of smaller community-based disabled people's organisations. Over the years, a number of parent organisations have also been founded. The Disabled Children Action Group (DICAG) has the largest membership, with affiliated community-based parent organisations throughout the country.

A number of national disability-specific DPOs, with international links, have also emerged over the years. These include:

- The Deaf Federation of South Africa (DEAFSA)
- The South African Blind Worker Organisation of South Africa (SABWO)
- The National Organisation of the Blind in South Africa (NOBSA)
- The South African Mental Health Federation
- The Quadriplegic Association of South Africa (QUASA)
- The Down Syndrome Forum of South Africa
- The South African Epilepsy League

It is also important that people with intellectual or severe mental disabilities should be able to speak for themselves through the mediation of advocates. The South African Federation for Mental Health has embarked on an advocacy programme in order to develop the concept of self-representation by people with severe mental or intellectual disabilities. The disabled people and parent organisations concentrate on advocacy and development work which is aimed at empowering people with disabilities. Very few of them receive any form of support from the government.

South African Federal Council on Disability

The South African Federal Council on Disability (SAFCD) is the national umbrella body for all national disability NGOs. It is the national forum under whose auspices all national welfare organisations and national organisations of disabled people and their parents come together to negotiate and to develop common visions for the equalisation of opportunities for people with disabilities. The national welfare councils concentrate on service delivery and are partially subsidised by the government.

The following service and welfare organisations are affiliated to the SAFCD:

- The Deaf Federation of South Africa (DEAFSA)
- The South African National Council for the Blind (SANCB)
- The National Council for the Physically Disabled (NCPD)
- The South African National Epilepsy League (SANEL)
- The South African Federation for Mental Health (SAFMH)
- The South African Foundation of Cheshire Homes
- The Occupational Therapy Association of South Africa (OTASA)
- The Cancer Association of South Africa (CANSA)
- The South African Council for the Aged

Organisations for disabled people and parents which are affiliated include:

- Disabled People South Africa (DPSA)
- Disabled Children Action Group (DICAG)
- The Down Syndrome Forum of South Africa
- The National Council of Quadriplegic Associations in South Africa (QUASA)

The SAFCD is the recognised structure which interacts with the government concerning matters which pertain to disabilities. At present the government and the SAFCD are investigating the feasibility of transforming the SAFCD into a statutory body. The paradigm shift away from the medical towards the social model implies a change in the way in which financial support is to be provided by the government, which requires the development work which is done by DPOs to be carefully evaluated against the work which is being done by those service organisations which are being funded by the government at present.

The Disabled Children Action Group (DICAG) estimates that in the rural areas ninety-eight percent of the mothers of children with disabilities are unemployed, semi-literate or functionally illiterate single women (Integrated National Disability Strategy White Paper 1997) and these social conditions are confirmed by Oosthuizen (2010). Deserted by husbands and lovers, often socially ostracised by their communities and banished into isolation by their extended families, they tend to withdraw into a world of their own. This finding suggests that there is a real need for a more situation-specific and a more context-specific approach towards providing social assistance, particularly to households in the rural communities in which there are children with disabilities, without neglecting those in the urban areas.

CONCLUSION

This study found that there are structures which are available to children with disabilities and which endeavour to make their lives less difficult. However, the work which these structures perform is severely undermined by a lack of adequate funding and infrastructure, which makes them ineffective, to large extent and results in their failing to provide the support which is needed by most disabled children. The situation as it stands at present and the underlying problems which prevent most disabled children from receiving adequate assistance have been discussed extensively in this paper, which has prompted the recommendations which are offered in the next section, in order to establish other platforms for discussion, debate and further research, in an attempt to increase and redirect efforts towards ensuring that support structures are responsive to the plight of children with disabilities.

RECOMMENDATIONS

In light of the points which have been covered in this paper, the following recommendations are made:

1. Infrastructure plays an undeniably pivotal role in advancing access to education in ensuring that the needs of children are met, both in South Africa and throughout the world. The lack of an adequate transportation system in a great many poor areas effectively denies children with disabilities access to education and other basic human rights. It is recommended that a multisectoral approach should be adopted in order to ensure that there are adequate road networks and that access to various social and economic opportunities is improved for disabled children and their families. A commitment of this nature would require the Department of Social Development to monitor progress towards achieving this goal very closely.
2. It is of crucial importance for the Department of Basic Education and the Department of Higher Education to ensure that access to education remains inclusive, particularly for those with disabilities. Programmes such as Speak Out and government offices, such as those of the Public Protector, need to give priority to the plight of disabled children, in order to ensure that they and their families receive equal and humane treatment which accords with the basic human rights which are enshrined in the constitution. In addition, the active involvement of parents remains a crucial means of ensuring that disabled children benefit from the services which they receive, such as education. Consequently, it is of great importance for both social workers and policy documents to ensure that the parents of disabled children are provided with parenting skills and knowledge to care for their children. Special support needs to be given to the teachers and the fellow learners of disabled children and their communities need to be educated through both the print and the electronic media, in order to sensitise them to the needs of these children and to protect them from stigmatisation and bullying.
3. It is also important to ease the burden of school fees for families with children with disabilities, in order to ensure that they are not tempted to discontinue their schooling or to resort to dropping out of school as a result of being unable to pay fees and any other associated costs. The Budget Portfolio Committee and other relevant Ministries need to ensure that special care is taken to lighten the financial burden of these families, as most of them live in circumstances which severely strain their meagre financial resources, apart from the pressures which are brought by the medical requirements and the other special needs of their disabled children.

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