

Discovering The Child's Disability: Challenges with Parenting and Implications for Social Work Practice in South Africa

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ABSTRACT This paper sought to investigate the consequences of discovering that children have disabilities and their implications for parenting. The study upon which the paper has been based took the form of a literature review. There is a great deal of evidence to suggest that parents tend to blame themselves upon discovering that a child of theirs has a disability. Some parents experience great difficulty in obtaining medical or educational information to assist them to deal with the disabilities of their children. In addition, the children themselves are often subjected to mistreatment as a result of their ignorance, particularly as a result of having little or no knowledge or understanding of sexuality. Disabled children are also often subjected to being excluded from inalienable human rights such as having access to an acceptable quality of education. In the light of the challenges which they face in these respects, it is recommended that there should be a concerted and a committed endeavour to maximise public awareness and education through the printed, audio and visual media, in order to bring an end to the stigma and the additional challenges, such as social exclusion, which often accompany disabilities for children, by promoting and monitoring inclusive systems for communities and all institutions which are dedicated to meeting the needs of children, including schools.

INTRODUCTION

A significant body of literature pertaining to previous studies of parenting and childhood disability indicates quite conclusively that childhood disability adversely affects the emotional and mental capacities of families to cope with disabilities and also their well-being (Erickson and Upshur 1989; Beck et al. 2004; Chimhenga and Musarurwa 2011; Gupta et al. 2012, cited by Muthukrishna and Ebrahim 2014). The discovery of the disability of a child is frequently accompanied by great risks for many parents. Significant findings from studies explain that great setbacks are experienced by parents and children when disabilities either go undiagnosed or are misdiagnosed (Brown 2015). A study which was conducted by an informal outreach program in the Eastern Cape, Free State and KwaZulu-Natal provinces established that deaf children are ignorant concerning subjects such as HIV and AIDS, sex education and rape. In instances in which they receive education in life skills, deaf children are often likely not to understand their teachers or the content of the subjects, as the information is not given in sign language and there is a shortage of deaf people working as trainers (Department of Social Development/Department of Women, Children and People with Disabilities/UNICEF 2012:8). A narrative study

of families with children who have disabilities found that most of the parents shared the traumas which are experienced by their disabled children during the course of mastering the task of parenting children with special needs. These traumas ranged from minor traumas to major ones, such as those which were experienced as a result of their children being teased by their peers, at one end of the continuum, to those resulting from recurring injuries, at the opposite end. Two types of shared traumas were identified as being dominant among parents, namely, the trauma experienced as a result of being initiated into the special needs of their children and that experienced as a result of everyday reminders of them. The discovery of the conditions from which their children suffer and the realisation of the special needs which they will entail for the rest of the lives of their children, in all probability long after the deaths of the parents, are very often the cause of great distress for the parents. An example of the everyday reminders which the parents of disabled children confront was provided by some of the parents, who explained that when they tried to take their children to social events, they often found that there were no ramps for wheelchairs (Snell and Rosen 1997). In addition, a study which was conducted in the province of the Western Cape in South Africa, which drew on the findings of many other studies, found

that parents often experience a great deal of difficulty and confusion in deciding which schools their children should attend, with some parents explaining that they lacked medical advice concerning the conditions of their children, in order to be able to ensure that they would be able to cope adequately with their adolescence and also with their studies (Vosloo 2009). As these researchers from their own experience concur, Gray (1995) maintains that parents often assume the blame for the disabilities of their children, while they try to cope with them, which constitutes maladaptive behaviour on their part, as doing so is severely detrimental to the development of their ability to cope with the conditions of their disabled children. A study which was conducted by Altieri and von Kluge (2009) found that for some parents, learning to cope with the disabilities of their children facilitated their own personal development in terms of acquiring patience, humility and compassion, through living with children with disabilities. However, the stigma which is associated with disabilities often continues to affect both the parents and also the children who have the disabilities, which is of particular concern in the light of the fact that the families of disabled children very often constitute their primary support system.

Problem Statement

The plight of children with disabilities has become a global concern, which has resulted in a steadily increasing awareness of the great need for support mechanisms for both the children themselves and for their parents. Despite the numerous policies and programs which have been introduced and implemented to bring relief to the lives of people who are adversely affected by the disabilities of children, it appears that these measures, to a very large extent, fail to take into account the actual challenges which are faced by parents with children who have disabilities, particularly in South Africa. Valid concerns which are difficult to ignore pertain to inequalities in terms of access to resources, the mistreatment and stigmatisation of children with disabilities and the lack of the awareness and the compassion which are needed to dispel the stigmatisation which occurs as a result of ignorance. It is hoped, by these researchers, that a paper of this nature will make a significant contribution towards raising awareness

sufficiently to encourage sincere and committed research into improving the lives of parents with children who have disabilities.

Aim and Objectives of this Paper

The aim of this paper is to obtain an understanding of the experiences of parents upon discovering that their children have disabilities and to determine what the practice of social work can do to facilitate and to promote the social functioning of families which are affected by the discovery of disabilities.

RESEARCH METHODOLOGY

As this paper takes the form of a literature review, the researchers consulted books and articles in journals and government gazettes which were devoted to the subject of parenting children with disabilities and drew on their own experience in the field of social work, in order to compile a meaningful paper.

DISCUSSION

Parents Tend to Blame Themselves for the Disabilities of Their Children

It is seldom easy for parents to adapt to the discovery that a child of theirs is disabled. Although, in many cases, parents respond to the crisis by blaming themselves, many of the principal causes of disabilities among children are related to poverty. It has been established that families in the lowest socio-economic groups have a two-and-a half times greater likelihood of bearing children with disabilities than those in more affluent groups, while other principal causes stem from illness, accidents, birth trauma and genetic disorders. It has also been established that children living in rural areas are at a significantly greater risk of being disabled at birth than children who are born in towns and cities. Another significant factor in South Africa is the *dop* system, which has its origins in the apartheid era, in which many of the people who worked on farms and lived in abject conditions were paid with wine for their labour. This system resulted in extremely high levels of alcohol abuse, which, in turn, has resulted in extremely high incidences of foetal alcohol syndrome (FAS) in South

Africa, particularly in the Western Cape, which is known to have the highest incidence of FAS in the country. As a consequence, many people who abuse alcohol and have children with disabilities are particularly likely to blame themselves and their lacking the will, the resolve or the ability to cease abusing alcohol will inevitably result in relationships within families which are affected in this way becoming increasingly dysfunctional, which has dire implications and consequences for both the families and for the disabled children, in particular (Lansdown 2002). Sifama (2004), Russel (2003:144) and Thwala et al. (2015: 207) explain that discovering that a child has a disability also tends to impose severe strain on the marital relationships of the parents, as the shock which often accompanies the discovery often introduces friction to the relationships, which can be characterised by parents experiencing spiritual crises or by one parent blaming the other for not providing the support which is needed by both the other parent and the disabled child.

Difficulties Encountered by Parents in Obtaining Adequate and Appropriate Medical or Educational Information

Adequate, appropriate and relevant knowledge is needed to enable parents, caregivers and even schoolteachers to care for children with disabilities. The Department of Social Development of South Africa has revealed that it is experiencing great difficulty finding willing foster parents to care for disabled children without parents. Some of the potential foster parents have indicated that the prospect of caring for disabled children is a frightening one for them, which is a disturbing finding, as between 800 and 1000 disabled children are in urgent need of caregivers or foster parents to take care of them (Meyer 2016). Although the department has indicated that it is willing to train people who may wish to act as foster parents to these children, it is of crucial importance that the training should be made freely available to everyone, as these children not only need parents, but also the understanding and support of the entire communities within which they live. As the general lack of knowledge is widespread and many people continue to labour under misconceptions and myths and to have uninformed attitudes concerning dis-

abilities, there is a great need for increased awareness of the realities of disabilities through education, in order to assist people who are affected by them. As an example, some of the participants in a study which was conducted in South Africa maintained that they experienced great difficulty making their way in clinics which have no ramps for wheelchairs or other facilities to ensure that they are able to move within and to have relatively easy access to the institutions which attend to their needs (Philpott and McLaren 2011).

Attitudes of Other Children Caused by Ignorance and the Sexuality of People With Disabilities

The siblings of many disabled children often tend to experience feelings of bitterness and resentment towards their parents or the sibling who has a disability. They may feel jealous, neglected or even rejected as they watch most of the energy, attention, money and psychological support of their parents flow to the child who has special needs (Gargiulo 2014: 112). The reaction and adjustment of siblings to a brother or sister with a disability may also vary according to their ages and their levels of development. The younger the sibling who is not disabled is, the more difficult it may be for him or her to understand the situation of the family and to interpret events realistically. Younger children may be confused about the nature of the disability, including its cause, and they may feel that they themselves are to blame or they may worry about "catching" the disability (Smith 2003). McKenzie and Swarts (2011) maintain that people with disabilities experience marginalisation, even with respect to sexuality. Misconceptions concerning children with disabilities tend to hold that they are either not sexual or that they should not be sexual, which has no basis in fact and serves to vilify and to negate the existence of people who have disabilities. As the cultures of modern societies tend to acknowledge that the lives of people are improved through the use of innovative technology and enlightened attitudes tend to be much more accepting of diversity among people than many previously-held ones, it is contended by these researchers that obtaining an understanding of the needs and experiences of children with disabilities would make a significant contribution

to providing the support of society to them and their parents and to enabling them to feel a sense of worth and dignity.

The Enduring Stigma Caused by Disabilities and Other Associated Challenges Encountered at School

Caring for a child who has a disability often entails coping with an enduring stigma and the challenges which are associated with it. The stigma arises mainly as a result of misconceptions and often results in the polarisation of communities and the marginalisation of disabled children, which tends to isolate them and to restrict their participation in activities in which they deserve to participate (Mitra et al. 2011). The former Special Olympics athlete, Greg Sylvester, has explained that there is a crucial need to remove the great stigma to which children with disabilities are subjected, which could be remedied not only by individual countries, but also by more responsive and humane approaches, at both the macro and the micro levels (Special Olympics athlete tells committee about stigma in Africa 2014). Kachaje et al. (2014) explain that there are still many great obstacles to be overcome in order to ensure that people with disabilities are permitted to enjoy inalienable human rights such as equal treatment and human dignity in African countries, despite the numbers of policies which have been formulated in order to rectify the problem and the research which has been conducted concerning the plight of the disabled. Fewster and Gurayah (2015: 31) explain that a lack of public awareness of the nature of disabilities, the inappropriate labeling of children who suffer from autism spectrum disorder as being disobedient and the lack of opportunities for schooling serve to exacerbate the degree to which autistic children and their parents tend to be excluded. Sarri (2015) maintains that people in many countries view autism as a source of disappointment, annoyance or shame. It is also, mistakenly, attributed to poor parenting or interpreted as being a manifestation of either a dangerous lack of self-control or of mental illness, all of which serve to increase the burden imposed by the stigma. Rule and Zuma (2011:15) maintain that people with disabilities in the province of KwaZulu-Natal are subjected to material deprivation, violations of their rights, a lack of access to education and an absence of places of safety for children and

teenagers. The inequalities and disparities experienced by disabled people also extend to the domain of housing, which, in turn, affects the degree of access which they have to clean piped water and electricity (Lehohla 2005, cited by Rule and Zuma 2011). Rule and Zuma (2011) go on to explain that government officials and other stakeholders lack sufficient knowledge of the needs and experiences of disabled people and the types of support which they require. The authors of this paper conclude that there is a pressing need for exhaustive investigations to be carried out in order to gain a comprehensive and accurate understanding of the experiences of children with disabilities and their parents, and the realities of their circumstances, in order to give meaning to the human rights which they ostensibly enjoy as citizens of South Africa in the post-apartheid era, but which are, all-too-frequently, effectively denied them.

CONCLUSION

This paper sought to investigate the challenges which are faced by parents with children who have disabilities. From the available literature it was found that in many cases, the parents of disabled children suffer from the effects of blaming themselves for the disabilities of their children, which frequently results in the discovery of disabilities and the taking care of the children being accompanied by great emotional strain and severe stress being imposed upon marital and family relationships. For some parents, the stigma and exclusion suffered by their children is further aggravated by the children either dropping out of school or discontinuing their tertiary studies. Apart from the effects of the stigma associated with being disabled, the sexual confusion which children who have disabilities often experience tends to make them vulnerable to abuse and unwise sexual decisions, which further emphasises the need for a significant amount of effort to be given to providing these children and their families with sufficient psycho-social and material support to enable these children to take their rightful places in society and to be protected from the risks to which their disabilities expose them.

RECOMMENDATIONS

This paper has compiled several concerns which have been raised by other writers with respect to the plight of parents with children

who have disabilities and endeavoured to offer some insights from these researchers themselves. In view of the enormity of the challenges with which these parents and their children are faced, these researchers, as social workers, respectfully offer the following recommendations:

1. Consideration needs to be given to including content in the curricula of the degree courses in social work which will equip social workers to be able to understand and to develop professional methods of assisting and promoting the interests and the needs of parents with children who have disabilities.
2. It is also of crucial importance that the White Paper on Families should make explicit provisions, in both the drafting of policy and in its implementation, for assisting social workers and parents with training for parents of children with disabilities, particularly with respect to overcoming the tendency to blame themselves and the stress and the stigma which they experience in their lives. This training should be extended to communities and to the country, as a whole.
3. There is a great need for task forces to make communities aware of the need to protect children with disabilities against sexual abuse, to educate these children concerning sexuality and to make communities and families aware that disabled children have the same rights as all other human beings.
4. As this paper took the form of a literature review, these researchers also suggest that broader empirical studies should be conducted among parents with children who have disabilities, in order to record and evaluate their experiences to determine how they may be adequately assisted.

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