Discovering the barriers that stop children with disabilities from being children:  
The impact of lack of access to mobility devices – a human rights perspective

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ABSTRACT

In most research projects there is a tendency not to consult young disabled children about their priorities and experiences. Their needs and aspirations are pre-empted through service providers. Furthermore, there is little research about how resilient young disabled children are in dealing with or overcoming the barriers in their daily lives due to inadequate provision of mobility devices. Therefore, this study undertook to explore and describe the perceptions and experiences of a sample of children with mobility impairments from disadvantaged backgrounds with regard to the impact of lack of access to mobility devices on their lives. From 1998–2000 in a qualitative study, a case study design was used as a method of inquiry to explore the experiences and perceptions of disabled children at a special school in a township in Cape Town in the Western Cape Province, South Africa with regard to the impact of inadequate provision of mobility devices on their lives. Analysis of the stories of disabled children revealed that without adequate mobility devices they were deprived of their right to development, education, play and social interaction as well as adequate health and rehabilitation services. The stories told by disabled children, their caregivers and therapists reflected the contradictory messages sent to disabled children about service delivery. Recommendations were related to the urgent need for transformation in the provision of mobility devices, based on the needs of disabled children.

Key words: disabled children, mobility devices, development, rights

Background to the study

The South African government as one of the signatories which ratified the Convention on the Rights of the Child adopted by the UN General Assembly in 1989, committed itself to the principle of establishing “first call for children”. This means that governments which have ratified the Convention on the Rights of the Child have made a promise to uphold the far-reaching principle that children had ‘first call’ on all resources and that they would always put the best interests of children first.

This is reaffirmed in the South African Constitution in Chapter 2, the Bill of Rights, Section 28 (1b) which states that every child has the right to basic nutrition, shelter, basic health care services and social services; and that a child’s best interests are of paramount importance in every matter concerning the child. This is widely considered to be the means through which South Africa undertook to fulfill its obligations in terms of the UN Convention on the Rights of the Child. The South African government has undergone transformation in education, health, welfare and other sectors so as to meet its vision of achieving a better quality of life for its citizens. Despite this constitutional right, disabled children do not enjoy the same privileges as their non-disabled counterparts. Disabled children still lack access to health care and rehabilitation services such as assistive devices, which are critical for their development and growth as well as for their participation in major life activities such as education.

Robinson and Sadan suggested that the quality of child health care services is dependent on the provision of adequate resources, good management of services and the competence of health care workers to deal with children. The challenge is for service providers to meet the needs of children and provide services in a manner that does not create dependency and devalued status.

Philpott4 indicated in her study that professionals often could not identify with poverty and discrimination. Yet, it is they who are responsible for the assessment of impairment, provision of mobility devices and care-dependency grants, and the articulation of the problems of disabled adults and children to the public at large.

There are civil society organisations like Disabled People South Africa (DPSA), Disabled Children Action Group (DICAG) and the South African Federal Council on Disability (SAFCD) which lobby and advocate for the rights of disabled people and children. There are also strategies that have been put in place to implement policies related to disabled people and children. However, these organisations do not implement policy nor do they develop budget lines for service delivery or decide on resource allocation for disability programmes and services. Philpott emphasised that it is essential for those affected by the problem to participate at all levels in addressing it. This will ensure that services are both appropriate and accountable to the consumer or users.

In most research projects there is a tendency not to consult young disabled children about their priorities and experiences. Their needs and aspirations are pre-empted through service providers. Furthermore, there is little research about how resilient young disabled children are in dealing with or overcoming the barriers in their daily lives due to inadequate provision of mobility devices. Priestley claimed that disabled people maintain that disability is a result of the failure of a structured social environment to adjust to the needs and aspirations of disabled citizens rather than from the inability of a disabled individual to adapt to demands of society. Therefore the nature of society in addressing or not addressing their needs is reflected in their experiences of disability.

Problem statement, research question, purpose and aims

In the period between 1998 and 2000 provincial budgets were cut in the Western Cape which led to delivery and the provision of assistive devices being stopped. As a result, the only public sector orthopaedic workshop in the Western Cape was closed. Backlogs occurred, leaving disabled children without the neces-
sary mobility devices for long periods of time. By the time the children received their mobility devices, these devices were too small or inappropriate. Furthermore, service providers failed to disseminate information about their resource constraints to the people affected and terminated essential services without notice. This left disabled children and their caregivers not only with limited resources, but also disempowered.

The question that was asked by the first author, as an occupational therapist at a school for physically disabled children in a township was: "What were the consequences of lack of access to mobility devices on the lives of disabled children from disadvantaged backgrounds?"

The aims of this study were:

- to explore and describe the perceptions of a sample of children with mobility impairments from disadvantaged backgrounds, with regard to their experience of the impact of lack of access to mobility devices on their lives and
- to identify the consequences of inadequate provision of mobility devices as perceived by disabled children.

**Literature review**

The United Nation's Convention on the Rights of the Child, Article 24.1 adopted in 1990, states that a child has the right to the highest attainable level of health, and disabled children should not be treated differently to their non-disabled counterparts. Health care should be seen as a precondition for disabled children to exercise their other rights. This is affirmed in The United Nation’s 22 Standard Rules on the Equalisation of Opportunities for Persons with Disabilities which states that it will be impossible to realise equal opportunities without the acknowledgement of certain preconditions. These preconditions are espoused in the Standard Rules in Chapter one, containing Rules 1 - 4 concerning awareness-raising, medical care, rehabilitation and support services. There is no accurate information on disability prevalence in South Africa. Census 2001 reports a prevalence of 5% of the nine million young children and also indicates that 2% of persons aged nought to nine and 3% of persons aged 10-19 are disabled. Furthermore, the Census suggests that half a million children in the country are in need of disability services. The majority of black disabled children from disadvantaged backgrounds are dependent on government or public sector services for assistive devices, but still lack access to mobility devices. In addition they bear a particular burden as their caregivers have a slim chance of acquiring assistive devices from the private sector as a majority of these are single parents who are mostly unemployed.

In order for disabled children to reach and maintain optimal health and function, they need a range of health services such as assistance with moving through all the developmental phases in their lives, access to basic and advanced curative care and to rehabilitative care when required. Werner states that for millions in their lives, access to basic and advanced curative care and to assistance with moving through all the developmental phases of medicine as it is not only about improved function or loss, but also about how to begin and sustain a different way of life.

In South Africa primary health care services are offered at three different levels: primary care level, secondary care level and tertiary care level. Watson highlighted the need to break the tradition of seeing rehabilitation as only a specialised service and to recognise that rehabilitation is part of all three levels of service provision. She continues to say that, in reality, some disabled people or their families require long-term or lifelong support and assistance. Watson concluded that development occurs within local communities and this is where the greatest need lies in South Africa. Therefore, rehabilitation extends beyond the boundaries of medicine as it is not only about improved function or loss, but also about how to begin and sustain a different way of life.

South Africa’s commitment to equalisation of opportunities was announced in the White Paper on An Integrated National Disability Strategy (INDS). The document represents a paradigm shift away from perceiving disability as a health and welfare issue that identifies disabled people as ill, different from their non-disabled counterparts and in need of care. Instead, it takes an integrated approach to addressing their broader social needs by defining disability as a development and human rights issue. The INDS shows that disabled persons have the same rights and obligations as able-bodied people. It is based on a social model of disability where equal opportunities are seen as a constitutional right of disabled people.

A study by Disability Action Research Team (DART) for the Health Systems Trust, suggested that the provision of support services, namely assistive devices and equipment, to disabled people is a precondition to equalisation of opportunities. Hurst asserted that all societies and communities should have basic socioeconomic rights i.e, the right to housing, health care, education and social security and that these rights should ensure the integration of citizens into civil society. The Community Agency for Social Enquiry (CASE) reported that, while Africans and Indians with disabilities tended not to have the required medical devices and equipment, Coloureds and Whites generally did have the necessary devices. A majority of black disabled children, who are dependent on government for assistive devices, do not have the required devices. Their participation in school and social activities is thus reduced, thereby limiting their potential to develop fully. If all people have the same rights, why are the services directed at the needs of disabled children inadequate? How equitable is the distribution of services?

**Methodology**

In this qualitative study a case study design was used as a method of inquiry to explore the experiences and perceptions of disabled children in a special school in an historically disadvantaged township in Cape Town in the Western Cape Province with regard to the impact of inadequate provision of mobility devices on their lives. The sample consisted of ten purposely selected physically disabled children from this school. The criteria for selection were that they had to have a wide range of mobility impairments; be users of the public health sector assistive device service between 1998 and 2000; be between eight and 18 years of age; and speak isiXhosa.

The disabled children were interviewed individually and/or in a focus group, being invited to tell their stories and use drawings to illustrate how they experienced lack of access to mobility devices in their lives. Interviews with the children were in isiXhosa, the children’s and researcher’s first language. Participant observations were also conducted by following the children to the classroom, playground, home and orthopaedic workshop. In addition, semi-structured interviews with the physiotherapist, two caregivers and two teachers at the school were done.

The research aims formed a framework for the analysis and interpretation of data. All transcribed data were analysed by the researcher using content analysis. In Holloway and Wheeler’s content analysis is referred to as the process of identifying, coding and categorising the primary patterns within the data. Through content
analysis, the codes emerged from the data inductively. Each code was then labelled and the researcher then categorised the codes, developed typologies and generated themes. Furthermore, the study was undertaken in isiXhosa, which is rich in symbolism expressed by the use of proverbs. In the African culture proverbs play an important role in telling the stories of the people’s daily lives. The meaning behind the proverbs explains the true experiences of people in their natural environments ie, the school in a township, a migrant labour hostel or shacks. Hence some of the findings related to the consequences experienced by disabled children are presented using proverbs to name the themes.

Lastly, the researcher ensured the rigour of the study by establishing trustworthiness through using the techniques of peer briefing, member checking, decision trial, triangulation, transferability, dependability and confirmability to ensure the accuracy of the findings.

For the purposes of this paper, I will discuss two major themes: Who am I without my mobility devices? and The chaos: “Umdudo wononkala” (The dance of the crabs). These were themes that emerged from the analysis of 10 life stories of disabled children to describe ways in which they experienced and perceived the consequences of inadequate provision of mobility devices in their daily lives. (See Table 1)

### Findings

**Who am I without my mobility devices?**

The findings in the first theme are represented by sub-themes emerging from the disabled children’s stories of how the opportunity to “grow” was taken away by not having the required mobility devices. The term “grow” is used broadly to explain achievement of the developmental tasks of childhood. It also describes how disabled children’s lives are affected globally. It became clear from the findings that a broad range of influences resulting directly from the unavailability of mobility devices, negatively impact on the findings that a broad range of influences resulting directly from the unavailability of mobility devices, negatively impact on the development of disabled children.

Major Theme | Sub-themes
---|---
Who am I without my mobility devices? | I am stopped from maturing and achieving my goals
| I watch the world pass me by
| I am excluded from participating in play
| I am unable to look after myself
| I am unable to make my contributions at home

| The Chaos: “Umdudo wononkala” (The dance of of crabs) | You give it to me and you take it away
| Children are dying
| “Akulahlwa mbeleko ngakufelwa.” (You do not lose hope of giving birth again, when you have had a miscarriage.)

| Table 1: Themes and sub-themes |

Both teachers interviewed voiced their concerns that the children’s education was hindered when they were admitted to hospital due to the complications of not having an appropriate mobility device ie, pressure sore treatment and contracture release. It became evident from the findings that disabled children did not necessarily follow an academic programme when they were admitted for these complications.

“Before he went to hospital his performance was good, but now that he is back things have completely changed. He is now weak and slow in understanding his classwork. I guess the stay in hospital is very long; it becomes too much for them to absorb everything when they came back.”

I watch the world pass me by

Persson17 asserted that disabled people have the same right as other people to an independent life and participation in society. The findings of this study revealed that children were denied this right as they were confined indoors as a consequence of inadequate mobility devices. The pain that was caused by this became apparent as the children described how they watched the world pass them by. This reinforced the stigma of disabled children being locked away. Furthermore, these children were not involved in social activities and thus not integrated into their communities. Children spoke about their desire to be a part of the outside world.
It was clear that when children were unable to perform self-care, disabled children of their sense of responsibility to themselves. It was also assumed that a disabled person does not have other roles to fulfil. The findings could be seen only in part. He goes on to say that it is assumed that someone who has a disability is not able to participate in the everyday lives of their peers. Findings must be seen to be important for disabled children to be accepted by their peers. Healthy development is the single most important task of childhood and play is an essential component. When play is disrupted, the consequences are far-reaching. Children who participated in this study all spoke of how their ability to play had been hampered by inadequate provision of mobility devices. Disabled children in the study regarded playing as an integral part of their lives. They had an urge to play in order to make sense of their world. It became apparent that inadequate mobility devices isolated disabled children from their peers and excluded them from participating in play. Because they were unable to participate actively, their peers treated them like outsiders. The findings showed that it was important for disabled children to be accepted by their peers.

"I watched my friends playing uNopentana (form of indigenous skipping using old pantyhose) sitting on the floor rug that my mother put outside for me. They talked and laughed together as if I was not there. I sometimes cried when my mother took me inside."

Persson7 confirmed that a child with a disability is first and foremost a child who has a right to experience stimulation, security and friendship as a basis for his or her development. Findings from this study demonstrated that because they were not able to move around, disabled children's sense of freedom, autonomy, exploration and spontaneity were diminished.

"I would ask my mother to call other children to come and play with me. They would not come because they want to play uAkikhalu (chasing game) outside and without my calipers I could not chase them. My mother would tell me that she could not force them to come."

One child noted that his peers find him a source of ridicule: "Other children laugh at my old boots because my toes are peeping out. Sometimes I go home and cry, but I know eventually I will get my new ones."

I am unable to look after myself. Coleridge8 stated that to be cast in the role of a patient means to be seen only in part. He goes on to say that it is assumed that a disabled person does not have other roles to fulfil. The findings revealed that inadequate provision of mobility devices robbed disabled children of their sense of responsibility to themselves. It was clear that when children were unable to perform self-care tasks, they were unable to achieve functional independence. This seemed to have a negative impact on the child's self-esteem.

"Sometimes my mother would leave early for char-work and I would be left with my sisters who are also going to school, and I have to wait upon them to help me put on my school uniform."

"When I come home from school my brother would put me on the bed and, while I take off my school uniform, he would make food for me."

It was found that without mobility devices at their disposal disabled children were unable to get up and perform self-maintenance tasks as they were dependent on their siblings to carry them on their backs around their homes. I am unable to make my contributions at home. When children were unable to make their contributions in their homes because of reduced mobility, they lost their roles as valuable family members.

"My younger sisters did not respect me anymore. For example, when I ask them to make a peanut butter sandwich after school, they would run and play outside knowing that I can't chase them. I am bound to the floor."

Mbigi and Maree9 claim that people gain recognition and status through making a contribution. Children in African families are integrated in family rituals by being given responsibilities. Disabled children have a role to play within their families. Children spoke of their desire to make their individual contributions in the form of errands and house chores within their homes, which was impossible because of their immobility.

"I could not go to the spaza to buy bread."

"I can't make tea for my mother."

The Chaos: “Umdudo woonankala” (The dance of the crabs)

The second theme symbolises the chaos and confusion which was based on a visualisation of what it would be like if crabs attempted to dance. Thus the stories told by disabled children, their caregivers and therapists reflected the contradictory messages sent to disabled children in times of need and desperation. For example, it was revealed that disabled children had the use of mobility devices at school, but not at home. Also, children expected to receive their devices at the anticipated/expected time. The waiting was for prolonged periods again and again, confusing them as to what they were entitled to and when it would come. It became apparent that, as a result of inadequate mobility devices, disabled children "lived in waiting". The children in this study did not have a sense of stability, and this created chaos in their everyday lives. They accepted whatever came their way, regardless of the condition or the sustainability of the mobility device with the hope of getting something better one day. The theme is played out in several sub-themes as illustrated and discussed below.

You give it to me and you take it away. The children were confused about what they were entitled to. The interviews with them revealed that the children's lives were put on hold indefinitely because mobility devices belonged to the school and they got their devices in bits and pieces.

"At school we have the mobility devices; we do all the things we want to do. After school we can't take them with us because they belong to the school. At home we have nothing; we must wait until the next day when we come to school."

"Just when I think at last I will get my calipers to do all the things I miss to do. On the day of fetching at the workshop the man will tell the physiotherapist that the measurements are missing."

This was confirmed by the physiotherapist:

"Sizwe waited for almost a year for his calipers, only to find out his measurements were lost (at) the workshop. He had to do fittings all over again. I can say he almost stayed for two years without his calipers, I had to borrow him one of the "vrot" (debilitated) wheelchairs."

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1. Coleridge, 19th-century English poet and philosopher.
Children are dying

"Extinguishing the life of any infant we are denying the world the contribution that infant can make by simply being alive."18

The consequences in the lives of disabled children brought about by inadequate provision of mobility devices were manifold and detrimental to their lives. It became apparent that most respondents were vulnerable and susceptible to health complications and developed secondary disabilities as a result. It came as a shocking realisation that children were dying because of inadequate mobility devices. Interviews with the teachers and the physiotherapist revealed that death at a young age was a reality. This was reflected by the recent deaths of two children, aged six and nine years, due to respiratory and pressure-sore complications.

"Ndimbikwe the young boy who had spinal muscular atrophy passed away last month. He was not able to sit properly in the buggie without his body brace. Therefore he struggled to breathe and he passed away because of that. The school was forced to bury him because the mother who is a bread-winner does not work."

"Do you remember Fezekile? She died too due to these complications brought on by not having mobility devices and her parents are poor and struggling."

Robinson and Sadan1 claimed that poor children in our country suffered and died from diseases that could easily have been prevented by improving basic health conditions. This experience was supported by one of the teachers.

"Andile has been in hospital for pressure sores since last year. We are worried of what is going to happen to him; he is not getting discharged."

The above is clearly stated in the Health Review by DART.12 They showed that assistive devices are an essential component of rehabilitation in that they provide a means of compensating for loss or limitation of function. In addition, they are a mechanism for the equalisation of opportunities for disabled people by enabling them to participate on equal terms with others in society. This loss or limitation of function, being hospitalised for pressure sores, could have been prevented if a child with spina bifida had been issued with basic mobility devices. Instead he was at home in bed with bladder infections which led to pressure sores and other complications. As a result he was unable to attend school for a year.

"Akulahlwa mbeleko ngakufelwa." (You do not lose hope of giving birth again, when you have had a miscarriage)

This is symbolic of perseverance and hope that things will improve. The findings showed that disabled children were battling to live without their devices. Disabled children and their caregivers were not asking for much, only for the necessary mobility devices to continue functional daily living. Children continued to believe that provision of assistive devices would improve, and that their mobility needs would be met adequately.

"The old ones are on top of the wardrobe. Maybe when the physiotherapist comes back she will take me to the workshop for new fittings. Maybe this time they will be quick."

"I am still hoping that when school reopens they will find money to buy the cushions for our chairs."

Philpott and Sait20 in their paper asserted that the government of South Africa had made a number of specific attempts to address the many difficulties facing children in the country. Children were promised a “better life”, and children’s needs had been prioritised in an effort to address poverty. They went on to say that whilst these initiatives were commendable, and a great deal had been achieved to date, the challenge remained to bridge the gap between the rhetoric of progressive policies and the reality faced by disabled children on a day-to-day basis.

Conclusions

The lessons learnt from the study were that mobility devices are key to the development of a physically disabled child and when there was lack of access to mobility devices for disabled children, the consequences were profound. Inadequate provision of mobility devices interfered with the development of disabled children which led to severe health complications, even death. Disabled children in the study were deprived of their basic right to education, to play and to social interaction. The consequences did not only have an impact at the level of the individual disabled child but also at a family level. When disabled children lack access to mobility devices at public health institutions, caregivers cannot afford the services of private agencies which sell mobility devices. They are dependent on the goodwill of the government to resolve the situation. In the absence of adequate mobility devices disabled children are a burden and dependent on others for their functional needs. The demand for services required for the development of disabled children is huge, but providing information on the consequences of the lack of access to mobility devices for disabled children will enable providers and parents to lobby for improved services delivery.

Recommendations

A number of recommendations directed at policy makers, disabled people’s organisations (DPOs) and service providers in health, social development and education arose out of the study.

Personalised experiences and needs of disabled children should be taken into account in the provision of assistive devices

The experience of disability is personal and unique to each child. The findings reflected that ignoring individual needs resulted in inappropriate mobility devices being issued to disabled children. The concept of cost-effectiveness in providing mobility devices for a large number of disabled children through buying in bulk needs to be rethought. In addition, accepting donations of consignments of mobility devices should not be done at the expense of the development of a disabled child, who is dependent on the appropriate mobility devices to grow. Therefore, the system of determining the need for mobility devices should change from broad categorisation to the capturing of the individual needs of disabled children.

Develop a needs-based measurement tool

Support services are needed to enable caregivers to access mobility devices for their disabled children. Categorisation of disability based on medical diagnosis alone is a barrier to accessing social assistance. Categorisation of severe, moderate, mild does not reflect the actual developmental needs of disabled children. Eligibility criteria need to be reviewed so as to consider criteria related to the needs of disabled children and thereby develop a needs measurement tool.

The needs of disabled children should be prioritised

Lack of access to mobility devices and backlogs have resulted in negative consequences for disabled children as some experienced health complications and even death. It is therefore imperative that the needs of disabled children be prioritised. The budget should be dedicated towards the relevant provision of mobility devices in order to avoid child mortality or regression in the development of disabled children.

An implementation strategy for provision of assistive devices is needed

The study illustrated that disabled children were already at risk for the inadequate provision of mobility devices. Creative implementation strategies for addressing the backlogs need to be developed in consultation with DPOs. Disabled children and
their caregivers are in the best position to articulate their needs, therefore consultation with the users is essential if solutions are to be found. The Department of Health must use existing ties with the Office on the Status of Persons with Disabilities in Presidency and the nine provincial offices based in the Premier’s offices, as well as the South African Federal Council on Disability (SAFCD) which is an umbrella body for DPOs and use the platform for consulting with government to call for improvement in assistive device service.

Awareness of service providers of socioeconomic and environmental context of disabled children

Service providers should be aware of the socioeconomic and environmental constraints on the caregivers and/or the disabled child. In order to relate to the socioeconomic barriers that disabled children and their caregivers face on a daily basis, service providers involved in rehabilitation should strive to work with disabled children and their caregivers in their communities. Service providers need to recognise the value of the role played by disabled people and caregivers of disabled children in articulating their needs. They should be called upon to build partnerships with DPOs like Disabled People South Africa (DPSA) and Disabled Children’s Action Group (DICAG) and other service providers.

Social action by DPOs needs to be more focused

The findings showed that caregivers were disempowered and they did not benefit maximally from addressing the needs of their disabled children through self-reliance and independence. Groups such as DICAG need to take the lead in strengthening and supporting caregivers to advocate and lobby as a collective for the adequate provision of mobility devices. Caregivers need to be informed of their children’s rights so that they can join hands in mass action with the broader disability movements in campaigns for mobility devices and services for disabled children.

Key existing stakeholders should lend support to ensure adequate provision of mobility devices

The South African Human Rights Commission (SAHRC) should monitor all national and international policies impacting on the lives of disabled children in South Africa.

- The Office on the Rights of the Child should make a concerted effort to recognise and integrate needs of disabled children in their programme planning and policy-making initiatives.

Hospital-based education of disabled children needs to be improved

The study showed that due to inadequate provision of mobility devices disabled children often spent a large part of their lives in hospitals, recuperating from complications. This resulted in their scholastic progress being jeopardised and the repeating of grades. The curriculum for the training of teachers needs to have a childhood disability module included. Teachers’ internship practicals should be done in the hospitals in which the majority of children are hospitalised. More posts should be created for hospital-based teachers, as a short-term strategy.

References


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