Wheelchairs - A Human Rights Issue or a Mere Mobility Device? Personal Reflections of an Occupational Therapist

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ABSTRACT

People with disabilities, such as those with mobility impairments are particularly vulnerable to the abuse of many of their human rights. There seems to be little difference whether they access services through the public or private health care system. Drawing on the author's many years of experience as the project coordinator of a wheelchair donor programme in the province of KwaZulu Natal (KZN) in South Africa (S.A.), this article seeks to explore some of these issues with the use of illustrative case studies of clients accessing wheelchairs both through the public health and the private sector.

Key words: wheelchair provision, human rights, public and private health care system

Introduction

"*Bestowing rights is not enough: rights holders must be able to access those rights*".[1]

S.A. has an internationally acclaimed constitution which encompasses a very comprehensive Bill of Rights[2]. The South African government is a signatory of the UN Convention on the Rights of Persons with Disabilities, as well as the optional protocol.[3] There are also good policies in place that ensure quality of life for example the National Rehabilitation Policy[4]. Yet access by people with mobility problems to the rights enshrined in many of these documents appears to be a problem.

The South African Human Rights Commission has identified groups that are more vulnerable to abuses of human rights, which include disabled women and disabled people who are poor, and those resident in rural areas.[5]

Rehabilitation, and therefore by implication wheelchair provision in KwaZulu Natal (KZN) is confronted by problems which may be the same as those experienced in similar poorly resourced provinces of S.A. Considering that it is estimated that close on 20 000 individuals (outlined in the statistical information below) in KZN may be in need of wheelchairs at any one time, it touches on several human rights issues as contained in the S.A. Constitution, Bill of Rights[2] such as human dignity (section 10), privacy (section 14), freedom of association (section 18), freedom of movement and residence (section 21),), health (section 27) and education (section 29), as well as the UN Convention on the Rights of Persons with Disabilities[3], such as accessibility (article 9), living independently in the community (article 19), Personal mobility (article 20), health (article 25), education (article 24) , habilitation and rehabilitation (article 26), work and employment (article 27), adequate standard of living and social protection (article 28).

This article will explore the ethical dilemmas that arise from the limited access, limited resources and inappropriate provision of wheelchairs, which cause harm to the client.

Context

The following information places potential wheelchair users in the province of KZN into a contextual, statistical perspective.

Using figures drawn from the 2001 national census[6], an estimated 21% of the total population of S.A. is resident in KZN, with the prevalence of disability being 5% (which is similar to the prevalence nationally). 47% of the population live below the poverty line compared to 45% nationally. These people all depend on the public health system.

5,8 million people resident in KZN are between the ages of 15 and 65, and of these only 1, 6 million are employed. In comparison, only 17, 9% of disabled men and 12, 9% of disabled females are employed. (The number of people with mobility impairments in this group is unknown). These are the potential number of people, and their families, who may have access to medical aid schemes. There are no figures to substantiate this, as this information is not readily available outside of the place of employment, or from individual medical aid schemes themselves.

There are a number of hospitals and clinics, both fixed and mobile, within each of the 11 districts of KZN. The clinics are run by both the local authorities and the Department of Health of KZN. *Figure 1* shows a district map of KZN and *Table I* gives a breakdown of the hospitals in each area, as well as the number of residents, and an estimated number of mobility impaired people, using figures based on Cornielje's estimate that the crude prevalence rates in S.A. of mobility impairment resulting in the inability to walk is 0,2%[7]. This translates to 18 852 people (0,2% of 9 426 017people[6]) resident in KZN potentially needing wheelchairs.

Figure 1: Municipal district map of KwaZulu Natal [8] – districts correspond with health districts

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*Table 1: Hospitals in each area, number of residents, and estimated number of mobility impaired people[6,9] **

District	Population	Potential mobility impaired (0.2%)	Public hospitals	Private hospitals *
Amajuba	468 038	936	3	1
eThekwini (metropole)	3 090 119	6 180	13	15
Ilembe	560 390	1 120	4	0
Sisonke	298 395	596	6	1
Ugu	704 030	1 408	5	2
uMgungundlovu	927 845	1 855	9	6
Umkhanyakude	573 342	1 146	5	0
Umzinyathi	456 451	912	4	2
Uthungulu	885 963	1 771	6	2
Uthukela	656 985	1 313	3	2
Zululand	804 450	1 608	7	2

(These figures have been deduced from the websites of the large private hospital groups, as well as those known to the author – they cannot be seen as being complete. There does not seem to be an easily accessible way of obtaining these figures, as for example only one health district in KZN has figures for private health care available on their link on the KZN Department of Health's website.[9])*

The rehabilitation departments of many of the 65 public hospitals within the present KZN health department are staffed by Community Service Officers (CSOs), occupational therapists (OT) and/or physiotherapists. Thus staffing has implications for the general sustainability of wheelchair provision in the region. A limited number of senior staff is available, with some of the health districts having only one or maybe two senior therapists.

Only one of the private hospitals in KZN has a dedicated rehabilitation unit, at other private hospitals, rehabilitation services may be offered by private practitioners. Many practitioners in both the private and public sector are not equipped or skilled to provide wheelchair assessments.

From the above it appears that there is an uneven distribution of health care resources throughout the province and by implication, also access to the provision of the correct wheelchair for the user.

Wheelchairs as essential mobility devices

Bengt Engstrom is considered to be the father of seating and is quoted by Scheffler as saying that a wheelchair can be described as a body orthosis on wheels[10]. An orthosis, to function correctly, has to meet the following criteria:

- it is usually custom made,
- it cannot be freely used between people,
- it influences the position of the body by maintaining alignment, providing symmetry and preventing injury.

The wheelchair therefore should prevent secondary complications by supporting weak muscles, providing postural support and preventing pressure ulcers. It enhances function by improving movement. The provision of the correct type and size of wheelchair will prevent further disability, whilst at the same time addressing the rights of the individuals as mentioned above.

Case stories:

Case stories are used to illustrate the need, implementation of policy or lack thereof, the violation of rights with the implications for the individual concerned and, where possible, remediation/rehabilitation and its significance for quality of life. (Names have been changed to protect the privacy of the people concerned)

Case story 1:

Ntombi is a 16 year old girl who had been given a 20 inch (50cm) wheelchair 4 years prior to assessment by the author. At the time she was assessed, she needed a 12 inch (30cm) wheelchair. In the four years that she used this large chair, she was not able to propel herself and she had developed a large number of preventable deformities, which included bilateral dropped feet, a severe scoliosis and a thoracic kyphosis. She had become an object of pity and ridicule in the rural community where she lived, and was not able to go to school.

The above demonstrates how several of her human rights were violated. These include a disregard for her right to human dignity (Section 10) and freedom of association (section 18), as she had to depend on others to get her where she wanted to go, which in turn depended on their willingness to take her. Other violations were related to freedom of movement and choice of residence (section 21), the important basic needs (section 27), access to which was limited, as well as inability to access the educational system (section 29 and article 24). This case illustrates that the provision of an inappropriate wheelchair can in fact lead to a violation of at least 5 basic human rights.

Intervention included the provision of a more appropriate wheelchair, taking her severe limitations into account. This enhanced her access to her rights: for example she was now able to propel the wheelchair herself, thus she was given freedom of movement and was able to access the shops to get basic necessities. She was also able to collect her disability pension without having to pay someone to push her to the pay point, which in turn gave her back some of her dignity. She was given the correct information to help her access other rights for example the right to access to the educational system.

Intervention also included the training of the rehabilitation staff at the local hospital, volunteers from the community and the client herself in the importance of the use of the correct wheelchair so that other people within that community in a similar position could be helped to similarly access their rights.

Case story 2:

Jacob has a spinal cord injury resulting in quadriplegia and is currently resident in a long term care facility, where he is living in a communal type ward housing about 30 residents. His only personal space is the bed and a small bedside locker, and curtains around the bed to provide minimal privacy. He had been injured while on duty, but was not able to return home or to work because a number of factors, including the fact that his home was not accessible to the motorised wheelchair provided for him during rehabilitation. He has been resident in the facility for about 18 months and is now so institutionalised that he and his family do not believe he could cope at home.

Several of his rights were violated, including the right to privacy (section 14), freedom of association, as he now had to associate only with the people that were resident in this facility and their visitors, and his own visitors (section 18), and freedom of movement and residence (section 21) as he now had to comply with the rules of the institution, as well as the structural limitations of the actual facility.

Intervention included the education of the client, his family and the staff at the facility about the client's abilities, as well as recommendations about the provision and use of the correct type of wheelchair to allow him more mobility and therefore access to his rights, such as to refuse treatment.

The client chose not to follow up on any of the suggestions, and therefore no further action was taken, as this would be a further violation of his rights.

Case story 3:

Sally is a woman in her late 50s, with post polio syndrome, who had her application for a motorised wheelchair turned down by her medical aid because, according to the doctor's report, she was able to walk.

A visit to the client's home by the author and a physiotherapist (at the request of the medical aid) illustrated the fact that she needed

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a motorised chair, as she had been using one for the last seven years. Although she was able to "walk" it was only for about 2 metres, as her breathing was severely compromised, she needed to sit for at least 30 minutes following this activity in order to participate in any other activity. She was also using a nebuliser regularly to aid her breathing. As a result of these problems she was confined to one room in her flat.

The rights that were violated in her case include that of accessibility (article 9), living independently and being included in the community (article 19), personal mobility (Article 20), health (article 25), adequate standard of living and social protection (article 28).

Intervention ensured that she was no longer confined to one room in her flat and was able to access services with minimal assistance; she was able to participate in all the activities she was engaged in before the need for a wheelchair, which included volunteer work in the broader community.

Case story 4:

Fred is a 40 year old moderately mentally retarded man, who has been resident in a long stay residential facility since being abandoned in infancy. He has spina bifida, and a large hydrocephalic head. He attends the OT programme, and is pushed around the grounds in a large wheelchair, as he is not able to propel it himself.

He was later provided with the correct size and type of wheelchair and was very excited to receive his first personal wheelchair. He demonstrated to everyone he came into contact with that he was now able to propel himself, declaring that it made him very happy to be able to push his own chair. The provision of the correct wheelchair allowed him access to number of his rights, including the right to being included in the community of the hospital (article 19) as well as personal mobility (article 20). This led to a significant enhancement of his quality of life.

Discussion

Considering the case studies above it is clear that several factors impact on and determine the provision and appropriate use of wheelchairs. These merit further consideration and discussion which will be done under a number of headings for ease of reference. These range from providers to structures for and of people with disabilities to record keeping. Reference will be made to the identification of problems as well as some suggestions for addressing these.

The provision of wheelchairs by donor organisations

Firstly, many of the wheelchairs provided by donor organisations are not of the correct size or type, and many are provided from cheap overseas imports. Donors often think in terms of the volume of chairs needed and how much they can get for their money, rather than the needs of the end user[11].

Secondly, it is often the number of people in a newspaper picture, or mentioned on the radio, rather than the correct chair for the user that is the motivating factor in the provision of the chairs by donors.[11]

Thirdly, the durability of the chair in the context in which it is used is seldom, if ever, considered.[11]

Fourthly, maintenance of the chairs also becomes a problem e.g. if a container of wheelchairs is brought in from the UK, often the footrests get lost or were not packed with the original consignment.[12] Local spares do not fit these chairs and importing the missing component often costs more than purchasing a brand new locally produced chair, due to the exchange rate, the import duties payable and the freight charges.

Finally there is also the ethical dilemma faced by therapists as to whether or not to accept these chairs, bearing in mind that this might be the only wheelchair the client might be able to obtain at that time.[13]

All the above problems can be addressed by the provision of training for the local therapists, and non-governmental, faith based organisations of people with disabilities and other relevant bodies about alternatives. Donors should be made more aware of the problems they create by this practice, and helped to make better use of their funding through the provision of the correct wheelchair.

This problem is not unique to KZN. The Western Cape has provided a guideline to aid donors in making decisions[14], similar measures should be considered in KZN, taking the unique circumstances in this province into consideration.

Provision of wheelchairs within the KZN Department of Health

Statistics for the provision of wheelchairs by the Department of Health in KZN[15], for the 2007/ 2008 financial year report that 1 437 wheelchairs were provided during this time. A further approximately 1000 were donated to recipients through the local Grant Making Non Profit Organisation the author is employed by on a part time basis, and donations received via other organisations such as faith based organisations, the King of the Zulus or politicians e.g. at local International Days of Disabled Persons events and similar types of occasions, local service clubs and large corporate businesses. Thus about 3 000 people with mobility impairments needing wheelchairs through the public health services in KZN would have accessed them. (These figures indicate that the KZN government was only able to fund less than half of the wheelchairs provided in the province over the financial year 2007/2008). This number would include those that needed replacement chairs. Comparing these numbers to the number of people who potentially have mobility problems severe enough to make it difficult for them to walk, leaves a large number of people without access to a wheelchair.

The hospital budgets are stretched with the high number of people with HIV and AIDS related conditions needing treatment. There is also the increased number of people who are on antiretroviral medication and therefore live with permanent disabilities for example the sequelae of TB spine, TB meningitis, and strokes, all which may result in mobility impairments[13].

Access to reliable statistics would aid in drawing up realistic budgets. "Ring fencing" the budget (in other words a budget which can only be spent on the provision and repair of wheelchairs) could also ensure the money does not get used for other more urgent health needs. The organisations outside of the government can then assist in providing more specialised seating requirements that would be too expensive for the government budget to cover.

The private health care system:

No figures are available for those accessing wheelchairs through private health care, as people obtain these through a large variety of sources, including self funding. Many medical aids often do not have a dedicated amount for the provision of assistive devices and the funds often come from the savings component of the person's medical aid. This means that many people are not able to access wheelchairs at all, due to the other costs of their disability[16]. There seems to be no uniform policy guiding medical aid schemes in this regard, such as prescribed minimum benefits with regard to mobility devices and specifically wheelchairs and cushions.

Reliable statistics would also assist medical aids in making informed decisions about the provision of assistive devices, including wheelchairs. It would also be of great benefit if the decision makers in the medical aids were more aware of available equipment and the durability. There is very little evidence based information to inform decision makers about equipment – more research needs to be done. Discussions are underway about encouraging research at an undergraduate level at the University of KZN (UKZN) in the O.T. Department to get some base line data.

A doctor may also provide the person with a prescription for an incorrect type or size wheelchair due to a lack of understanding about the implications of this, for example the author had to persuade a client with severe bilateral circumferential burns over his lower limbs that he did not need the elevating footrests the doctor had insisted he be given to prevent flexion contractures at his knees, as he was already developing severe extension contractures because of these footrests.

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In the same way orthotists may also provide an incorrect type or size of wheelchair, so that, for example, when a person gets admitted to the local private rehabilitation unit with this incorrect wheelchair, they cannot be supplied with the correct equipment, as the medical aid or other funder has already been paid[17]. This problem also occurs with the newly disabled person who is injured on duty and falls under the Compensation for Occupational Injury and Disease Act and the person whose treatment is funded by the Road Accident Fund.

Medical Aid schemes are also often not paying suppliers for the correct types of wheelchairs or totally refuse to pay for wheelchairs or cushions based on the recommendations of an untrained or uninformed person, who does not understand or appreciate the functional difficulties of people living with mobility impairment who do not have access to the correct wheelchair[16].

Clients may be supplied with the incorrect equipment through suppliers, either through ignorance, or through the unethical conduct of providing a cheap chair and billing for a more expensive one[16].

Added to this, is the funding practice of medical aids concerning certain mobility aids, for example, if a person has had a unilateral lower limb below knee amputation; they are able to access a significantly higher amount of funding for a prosthesis than if they choose (or are advised) to use a wheelchair for whatever reason[16]. This is also part of the pricing for assistive devices that is given by the Department of Labour as part of the Compensation for Occupational Injury and Disease Act (COIDA)[18].

Addressing prescription and provision of the correct type and size of wheelchair needs to be done on an ongoing basis. This is being addressed by a Continued Professional Development (CPD) programme at the UKZN, Department of OT. The programme will be expanded in the future to ensure that more people within the private health care system will be reached.

The organisations for and of people with disabilities

The brunt of the problem is usually passed on to organisations for and of people with disabilities, who need to access donor funds to provide wheelchairs. They are often very poorly resourced both in terms of staff and equipment, and, where organisations are in receipt of subsidies, these are low. There also seems to be little networking with the department of health in certain districts, and addressing the issues at this level might enable these organisations to make better use of their resources and not duplicate services[19].

Many of the problems can be solved by more efficient networking of the staff employed at grass roots level, as currently much of the existing networking seems to be done at management level.

Personnel and social networks:

Poor staff resources mean that services are rendered to people with mobility impairment by staff that might be under trained in the provision of wheelchairs.

When CSOs are confronted by the issues of practice, it can become very overwhelming[6]. The overwhelming odds at which many CSOs have to run a service, often with little or no support from management at the hospital or district level is a concern. Protocols differ in the various hospitals and districts, with no uniform protocol adopted. Many of the posts for rehabilitation coordinators in the various districts are vacant, and rehabilitation is a low priority in these areas.

Should a CSO provide a good wheelchair service in conjunction with the local community, including people with disabilities, there is no guarantee that this service will continue in the following year, if and when a new CSO arrives.

The presence of community rehabilitation facilitators or other mid level workers in a community varies from district to district, with no consistent protocols in place for the provision of wheelchairs.

Social workers in the non profit organisations do not seem to stay long before they get more lucrative jobs elsewhere, leaving under trained and inexperienced staff or volunteers to provide services to people with disabilities[19]. Many do not even understand the disabilities they are dealing with, for example, requests for wheelchairs are made for a person whose disability is described as *"can't walk"* or "*disabled"*.

Faith based groups may identify people who are in need of wheelchairs, as do many other people working in communities, for example, councillors from the local authorities, crisis centres at local South African Police Services (SAPS) offices. Yet, few if any of these organisations or groups has access to anyone who has any knowledge of disability or of the wide variety of wheelchairs available and the importance of providing the correct equipment.

Many of these problems can be addressed by the establishment of effective networks in districts, as has been shown in some of the districts with a functioning rehabilitation forum which includes all the relevant stakeholders.

Training can also aid all the relevant staff to enable them to offer a more effective service. Training is being offered by the OT Department of the UKZN to identified groups and people in the community on an ongoing basis as part of the CPD programme. Not all the people that attend the workshops are therapists, as discussed earlier, as much of the service in the communities is offered by other relevant people, including people with disabilities.

Post graduate training at present is focussed on improving and building on clinical observations with regard to seating, the basic principles of correct seating, and exposure to a variety of wheelchairs, with some basic guidelines on how to assess the equipment, the user and the environment in which the user functions. Both formal and informal discussions, with all relevant stakeholders (wheelchair users, wheelchair providers, wheelchair manufacturers) on available equipment, advantages and disadvantages of these and other factors to consider, form the basis of the training programmes, which then are tailored to meet the need at that time. Feedback from participants at workshops, wheelchair users and other relevant people help build up a reservoir of knowledge and identify potential research topics.

Access to other government services:

Another important issue compounding the problem is that many people identified who need a wheelchair, have no identity document, making it almost impossible for them to access any services provided. They are often not able to get to the local Department of Home Affairs, as they are not mobile, they have no income and therefore they cannot pay anyone to transport them there and the terrain where they reside is particularly inaccessible to the person with mobility impairment.

This issue can be addressed very effectively at the time of national or local elections, as the various political parties are very willing to ensure that people access identity documents to enable them to vote. This has worked well in a number of areas, where the Department of Home Affairs has visited outlying areas to register people to obtain the necessary documentation. This in turn has a double benefit, as people are also then able to access other services such as grants.

A "ring fenced" budget, as previously discussed can help to ensure that essential equipment, like the appropriate wheelchair, is provided to people who need it.

A wheelchair policy by the Department of Health for KZN is at present being drawn up, which should aid the provision of necessary wheelchairs to the people with mobility impairment.

Statistics:

Before concluding, it is important to note that the absence of reliable statistics in both the public and private sectors hampers planning for the provision of mobility devices – specifically wheelchairs, as there is minimal data to work with. This situation is in direct violation of the convention Article 31 of the UN Convention on the Rights of Persons with Disabilities[3], which promotes statistics and data collection. It is therefore very important that appropriate statistics be gathered and research be encouraged to ensure that evidence supports our practice. The Rehabilitation programme of

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Department of Health in KZN is at present in the process of getting uniform statistical data gathering tools in place, and the author has offered them access to her data base (in the form of a spread sheet) of the approximately 10 000 wheelchair users who have accessed donations over the last 120 years.

Conclusion

The article uses four case studies to illustrate how inappropriate allocation of wheelchairs could have a major impact on quality of life, and how such allocation does in fact violate human rights as enshrined in the constitution and Patient's Rights Charter[20]. The author is of the opinion that the appropriate size and type of wheelchair for each individual is as much a human right as the right to freedom, dignity, health care and mobility. It is evident that issues are multi layered and complex, ranging from seriously limited statistics available and accessible, providers of wheelchair who are poorly informed and equipped, to users themselves and their care providers. It would seem that the "system" with which wheelchair provision takes place is seriously flawed, a situation exacerbated by practitioners, however willing, who seem not to have the necessary knowledge and skill to ensure correct provision, follow up and replacement.

The social model of disability involves removing barriers preventing people with disabilities from exercising their rights to participate in society[21]. This can be addressed through firstly ensuring reliable statistics are available, which will aid in ensuring that adequate budgets are available to access the wheelchairs. Lobbying for "ring fenced" budgets in the public sector, and dedicated allocations within medical aid schemes will then be easier. Secondly addressing training of all people involved with accessing wheelchairs for users – including therapists, social workers, people with disabilities (the users and the people that run the various groups of people with disabilities, who might not be wheelchair users themselves), volunteers in various organisations, as well as donors such as service groups. Training at undergraduate level will need to be more specific to the identified needs in the provision of wheelchairs.

It is our duty to ensure that people with mobility impairment can make informed decisions about their wheelchairs and can access the correct size and type of wheelchairs, to empower and enable them to access their rights.

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