

ABSTRACT

This chapter outlines the particular vulnerabilities of disabled children and explores various factors that create and perpetuate these. The determinants of disability – both impairment and exclusion – are described. The limited prevalence rates that are available for childhood disability and chronic illness are presented. Key policies and legislation that affect children with disabilities are cited, particularly in relation to the health sector. The impact of these policies at service provision and community level is described, as there are persisting barriers that exclude children with disability from effective preventative, curative and rehabilitation health services. Finally, recommendations are made as to how these should be addressed.

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INTRODUCTION

The particular vulnerabilities of children with disability are created and perpetuated by a number of factors. This vulnerability is determined not only by levels of impairment, but also by levels of exclusion and poverty. Despite key achievements in terms of the legal framework protecting the rights of disabled people, many children with disability still do not have access to the services that they require.

This chapter explores several existing guidelines and policies of the Department of Health (DoH) in relation to disabled children. It describes several policies and initiatives which aim specifically to improve accessibility of service and to promote the inclusion of children with disability. These include the Rehabilitation Policy¹ and advocacy around the Children's Act.

DISCRIMINATION AND DISABILITY

During the pre-1994 era, people with disabilities were closely aligned to the struggle for liberation, and the protection of human rights for all. Since that time, great strides have been made towards racial integration, and all discriminatory laws have been repealed. However, a number of recent publications²⁻⁵ indicate that disabled children do not have much to celebrate, as they continue to be excluded from access to a number of key social services, including health services.

“Major steps have been taken since 1994 to ensure that people with disabilities will not continue to be subjected to the discrimination, inequities and exclusion of the past. An enormous task remains, however, in transforming the institutions, attitudes, practices, buildings, facilities and environments that continue to deny people with disabilities their rights to dignity, equality and freedom.”⁵

As the country celebrates its 12th year of democracy, the challenge is to continue the process of transformation already begun in the health (and other) sectors, so that equal rights and opportunities for the most vulnerable groups, including children with disabilities is achieved.

DISABILITY IS A PRIORITY IN THEORY BUT NOT IN PRACTICE

That disability is a priority human rights issue is clearly articulated in policy guidelines such as the Integrated National Disability Strategy⁶ and in policies of the DoH – such as Free Health Care for Disabled Persons.⁷ However, to a great extent this priority is not reflected at the programmatic level. One reason is that there is competition for limited resources in the health sector. The needs of people with life-threatening conditions such as HIV, or those who are likely to ‘get better’ as a result of treatment, are given greater priority than people with disabilities. The tendency leans to that of ‘cure or care’ i.e. focus is placed on those who can be cured, failing which they need to be cared for. This leaves little room for those with chronic conditions and / or permanent disabilities who wish to live independent lives in the community. The pressure of service delivery in general and the focus on curative services for other diseases and prevention, treatment and care for people living with HIV makes it difficult to prioritise the needs of children with disabilities. An article reviewing the Health Sector Strategic framework⁸ indicated that with regard to mental health and rehabilitation:

“Physically and mentally disabled people have unique service needs. When budgets were growing some improvements were made, matching stated commitments. But, as budget cuts started to bite, advances in these services were one of the first casualties and this needs to be revisited... Service models need to be changed to more effective and cost-effective approaches.”

The lack of human resources is a major constraint at managerial and service delivery levels. The DoH faces an ongoing challenge not only to recruit rehabilitation personnel, but also to retain them.² The shortage of rehabilitation personnel means that rehabilitation often becomes a ‘forgotten part’ of Primary Health Care. Despite this, the compulsory community service programme has resulted in providing access to rehabilitation services in some rural areas which did not previously provide such services. In some instances, therapists have chosen to remain beyond their one year of compulsory service. Additionally, in some provinces, acknowledgement of the value of community service



therapists has resulted in the creation of new permanent posts. However, a limitation of this strategy is a lack of continuity of rehabilitation services, because the tenure of community service therapists is only for one year.

By its very nature, disability is a cross-cutting issue. The lack of coordination and communication among programmes, within government departments and between government and civil society (NGOs and Disabled People's Organisations {DPOs}) remains a critical factor undermining the prioritisation of disability needs. The lack of coordinated strategies means that service provision focusing on children, continues to be fragmented and thus available resources have limited impact.^{9,10}

Another critical factor that hinders implementation of policy is lack of information in regard to the prevalence of childhood disability, the needs of disabled children, as well the resources available.^{11,12}

LIMITED UNDERSTANDING OF WHAT INCLUSION MEANS

It is often assumed that inclusion means 'treating all children the same.' The problem with this assumption becomes evident when one realises that disabled children have an unequal start in life, and therefore equality cannot be achieved without certain provisions being made to ensure that all children can participate equally.

"Inclusion does not mean that disabled children should just slot into an unchanging society. This denies both disability and difference. It is about disabled children having their needs met and their rights protected in an adapting society. Most importantly, disabled people (both adults and children), should be involved in shaping an inclusive society."¹³

DIFFERENT DIMENSIONS OF DISABILITY

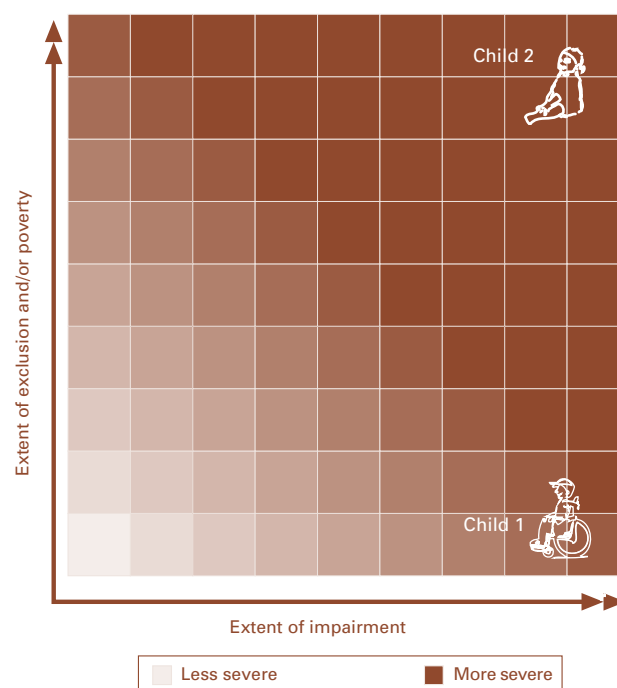
There has been a great deal of discussion regarding different approaches to disability which underpin service delivery. Within the health sector, the approach to disability is predominantly a medical one, focusing on the impairment or limitations of the individual,

with little consideration given to the circumstances which create and perpetuate these limitations. The current definition being used by the DoH (2005)¹⁴ is as follows:

"Disability means a moderate to severe limitation in a person's ability to function or ability to perform daily life activities as a result of a physical, sensory, communication, intellectual or mental impairment."

From a social model of disability, the view is that the greatest difficulties faced by a person with impairment are those barriers and limitations that are created by the way that society is organised, which exclude them from participating. However, in practical terms, disability is not determined only by the extent of the impairment, but is a function of both impairment and the level of exclusion being experienced. The determinants of disability are illustrated in Figure 1 below.

FIGURE 1:
Determinants of disability: impairment and exclusion



Source: Philpott, 2006.

It may be possible to have a high level of impairment, but a low level of exclusion, or a relatively small impairment with a high level of exclusion. For example (as illustrated by child 1 in Figure 1), a child may be paraplegic (high level of impairment) but with the necessary assistive devices and accessible environment, may continue her education, socialisation and other

activities. To the extent that she is able to participate in this way, the disability is minimal. Another child with the same impairment (child 2 in Figure 1), but in a context of poverty, even with an assistive device, would have much greater difficulty obtaining access to transport and to an accessible school. The child may never be able to attend school, and the extent of her exclusion (and disability) is high.

PREVALENCE OF CHILDREN WITH DISABILITY AND CHRONIC ILLNESS

A major challenge in identifying the number of children with disability and chronic illness is the lack of age, gender and cause-specific prevalence data on children with chronic diseases and impairments in South Africa.¹⁵ It is important that the age range of the population sample being studied is identified because impairments are age-dependent and the prevalence is difficult to interpret if age-specific rates are not given in relation to impairment types.¹⁶

It is not easy, particularly in developing and low-income countries, to obtain good estimates of the prevalence of disability, because chronic illnesses and diseases may go undiagnosed and resultant impairments unrecognised. Therefore, in such countries, population-based studies are essential to measure the prevalence of childhood impairment. According to three childhood disability prevalence population-based two-phased surveys conducted in South Africa between 1992 and 2002¹⁵ the overall prevalence rates, for all categories of developmental disability, varied from 1.6 to 6.0%. This variation might have been due to poor methodologies that did not meet the criteria for the two-phase surveys.

The only national disability survey was population-based, but was not a two-phase prevalence survey. It was commissioned by the national DoH and conducted by the Community Agency for Social Enquiry (CASE) in 1999.¹⁷ It described reported moderate to severe disability. It should be noted that it is not possible to use the CASE prevalence rates in combination with the StatsSA Census data of 2001 because different age groupings were used.

According to the CASE study, the overall crude rate for children under-18 years of age was 3.3%. The age-specific rates for children by age-category were:

Years	%
◆ 1-5	1.6
◆ 6-10	3.2
◆ 11-15	4.5
◆ 16-20	4.1

In terms of impairment-specific surveys, the studies on hearing loss in SA have been school or hospital-based rather than population-based.¹⁸⁻²⁰ The overall crude prevalence rates for first year entry (Grade 1) school children were 6% for mild hearing impairment and 0.2% for bilateral sensorineural deafness, while 74% of the children had both normal ears and normal hearing. The prevalence of overall ear disorders was 96.1 per 1 000 children. Improved treatment of otitis media, which is common in pre-school age children, could reduce the sequelae of the disorder, which have serious effects on hearing and impairs educational achievement in school children. It is important that health services be developed for this target group, which is presently poorly serviced in regard to the management of deafness and ear disease.²¹

There are no accurate population-based data for childhood blindness in SA.²²

DISABLED CHILDREN AND DEVELOPMENTS IN LEGISLATION AND POLICY

An important piece of legislation affecting adults and children with disabilities is the Promotion of Equality and Prevention of Unfair Discrimination Act.²³ This Act identifies ways in which discrimination is manifest in South African society, and deals with the prevention, prohibition and elimination of unfair discrimination, hate speech and harassment. It prohibits discrimination on the ground of disability, and in doing so addresses issues around environmental accessibility as well as reasonable accommodation in the workplace. According to this Act, neither the state nor any person may unfairly discriminate against any person on the grounds of disability, including:



- ◆ Denying or removing from any person who has a disability any supporting or enabling facility necessary for their functioning in society;
- ◆ Contravening the Code of Practice or regulations of the South African Bureau of Standards that govern environmental accessibility; and
- ◆ Failing to eliminate obstacles that unfairly limit or restrict those with disabilities from enjoying equal opportunities, or failing to take steps to reasonably accommodate their needs.

As a result of this Act, it is anticipated that there will be more respect for the human rights and dignity of persons with disabilities, and people who find themselves discriminated against can take the issue to court. This Act will also help to improve access to services by persons with disabilities – such as free health care, social security, employment and economic opportunities.

Despite these achievements, a recent review of legislative provision for children identified the gap that exists for children with disability.²⁴ However, there are a range of guidelines and policies that relate to children with disabilities, including the Integrated National Disability Strategy⁶ and Education White Paper 6.²⁵ Within the health sector, the priority given to disabled persons is reflected in one of the goals contained in the White Paper for the Transformation of the Health System in South Africa,²⁶ which is:

“to enable people with disabilities to become less dependent and reach their potential for achieving a socially and economically productive life”.

It is envisaged that this will be achieved with improvement of access to health services and early diagnosis and referral of persons with disabilities.

The National Rehabilitation Policy,¹ the Assistive Devices Policy,²⁷ and the policy guidelines on Free Health Care for Disabled People at Hospital Level,⁷ all aim at improving access to services for disabled adults and children. However, although these policies guide service planning and implementation, they do not place any obligation on government to budget for or to ensure provision of services to disabled children. As a result, services are discretionary and subject to competing priorities.

The Rehabilitation Policy¹ entitled Rehabilitation for All, adopts as one of its key strategies, Community Based Rehabilitation (CBR) the principles of which are applicable at all levels of service delivery. The policy defines CBR as follows:

“CBR is strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education, vocational and social services.”

This definition indicates that CBR is not just about providing community rehabilitation services, it is also about the continual improvement in the quality of life and social integration of all people with disabilities. A description of CBR is contained in the norms and standards of the PHC package,²⁸ where the philosophy of CBR is stated as being the concept of shared governance viz. the active participation of disabled people and their families in identifying needs and resources, as well as planning, implementation monitoring and evaluation.

The debate between CBR as a philosophy / strategy and CBR as a service has had a major impact on service conceptualisation and development in the health sector. Currently, SA has no comprehensive strategy for CBR, and different strategies are in use in different provinces:

- ◆ In Mpumalanga and some districts of KwaZulu-Natal, programmes have been established in which disabled people are given basic orientation and work as CBR consultants. The primary focus of their work is peer counselling, information dissemination and referral. In both of these provinces, this is being done through a partnership between Disabled People South Africa (DPSA) and the provincial Departments of Health, however, in Mpumalanga this is being done on a much larger scale than in KwaZulu-Natal.
- ◆ Another approach is where CBR is being implemented through mid-level workers who are employed by the DoH or NGOs. A review undertaken in 2005, indicated that there are close to 180 Community Rehabilitation Workers / Facilitators deployed in 6 provinces: Gauteng,

Limpopo, Mpumalanga, North West, KwaZulu-Natal and Free State.²⁹ The Community Rehabilitation Facilitators undergo an intensive 2-year training programme, which combines elements of community development and various therapies.

One of the most significant pieces of legislation which is being finalised at present is the Children's Act.³⁰ The Disability Task Team, representing the Disabled Children's Action Group (DICAG), and other member organisations of the SA Federation on Disability, has been part of the broader civil society Children's Bill Working Group. The Task Team has been advocating for the inclusion of children with disability or chronic illness in all aspects of the Bill. Key activities of the Disability Task Team during 2005/2006 have been:

- ◆ Compilation of submissions on the Children's Act in relation to children with disability or chronic illness, and engaging with the disability sector on the basis of these submissions; and
- ◆ Interaction with policy makers through constituency visits, meetings with Members of Parliament and members of the Portfolio Committee on Social Development.

In addition to strengthening disability sector networks and dialogue, this wide range of advocacy strategies has contributed to advances in the rights of children with disabilities as evidenced by amendments reflected in the Children's Act.³⁰ The disability-specific clauses (Box 1) represent major advances in recognising the rights of children with disability or chronic illness, guaranteeing they have access to all services provided by the Act. The general principles section of the Act recognises that to have equal access to those services, disabled children may require special support. It not only prohibits discrimination against disabled children, but places on government the obligation to provide an enabling environment for them. Disabled children have the right to be treated equally, to have access to justice and to be offered protection by the courts. They also have the right to participate fully in decisions that affect them.

These provisions mean that when planning and budgeting for services, all spheres of government departments have to take into account the needs of children with disabilities. The onus will be on departments to show that they have taken effective measures to address special needs of disabled children.

RESPONSES

POLICY

As described earlier in this chapter, the DoH has several policies that impact on services to disabled children.^{1,27}

There is currently no general policy on prevention of disability, as the DoH is moving away from a generic policy on prevention, towards a set of impairment-specific policies.^a For example, the DoH strategic plan (2006-2009) has identified birth defects as a priority. It aims to reduce morbidity and mortality due to genetic disorders or birth defects and improve birth defects surveillance. It is planned that, by 2006/07, 50% of districts should have at least one genetically trained health care provider and 15% of districts should be implementing the new standardised birth defects data collection tool.

The government's Free Health Care (FHC) policy for disabled people at hospital level is an indication of the political commitment to ensuring improved accessibility to services by disabled people. But on a practical level, discretionary funding means that provision of services does not always take place. Among the key limitations of the policy-level response by the health sector to provision of services for disabled children are:

- ◆ Lack of monitoring mechanisms. There are no mechanisms in place to monitor the extent of accessibility to services. For example, it is not known how many clinics or hospitals are physically accessible, how many disabled children have been immunised, or have benefited from nutrition programmes. Given that disabled children have been excluded from most of the services, it is important to disaggregate data on disabled children within information systems, so that the number of disabled children benefiting from different services can be tracked.^b

If there are no clear mechanisms to monitor the access to services for particularly vulnerable children, patterns of discrimination and exclusion are likely to be perpetuated.

- ◆ Lack of focus on community level services. A recent review of disability research conducted on children

a Personal communication M. Tshivhase, Directorate: Chronic Diseases, Disabilities and Geriatrics, national DoH, 2006.

b This is closely linked with the determinants of disability.



from 1994-2005³¹ revealed a lack of development of community level services, including CBR. Of over 350 studies that were reviewed, the research by Behr³² was one of the very few to evaluate the impact of outreach services on disabled children. Given that SA has adopted PHC as a principal

strategy for health care delivery since 1994, it is a concern that more studies have not been carried out to assess the impact of community outreach services – a component of PHC – on children with disabilities.

Box 1:

Key clauses in the Children's Act relating to disability

Principles

6. (2) All proceedings, actions or decisions in a matter concerning a child must:
- (d) protect the child from unfair discrimination on any ground, including on the grounds of the health status or disability of the child or a family member of the child;
 - (f) recognise a child's disability and create an enabling environment to respond to the special needs that the child has.

Best interest of the child standard

7. (1) Whenever a provision of this Act requires the best interest of the child standard to be applied, the following factors must be taken into consideration where relevant:
- (i) any disability that a child may have;
 - (j) any chronic illness that a child may have;

Child participation

10. Every child that is of an age, maturity and stage of development to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.

Information on health care

13. (2) Information provided to children in terms of this subsection must be relevant and must be in a format accessible to children, giving due consideration to the needs of disabled children.

Children with disability or chronic illness

11. (1) In any matter concerning a child with a disability due consideration must be given to
- (a) providing the child with parental care, family care or special care as and when appropriate;
 - (b) making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have;
 - (c) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and
 - (d) providing the child and the child's care-giver with the necessary support services.
- (2) In any matter concerning a child with chronic illness consideration must be given to
- (a) providing the child with parental care, family care or special care as and when appropriate;
 - (b) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and
 - (c) providing the child with the necessary support services.
- (3) A child with a disability or chronic illness has the right not to be subjected to medical, social, cultural or religious practices that are detrimental to his or her health, well-being or dignity.

SERVICE PROVISION

Although a range of services on the PHC continuum are being provided to disabled children, the focus of health services tends to be on the medical condition of the child, and not on the child as a whole. For example, the DoH Goals, Objectives and Indicators³³ for the period 2001-2005 included the goal of improving the quality of life of people with disabilities. Although the objective was to increase accessibility of health services to people with disabilities, the indicator was narrowly focused on the percentage of people with disabilities in need of assistive devices, who have received these devices (per province).

There exist a number of key barriers that limit children with disabilities from accessing and / or benefiting from services of DoH. These include:

- ◆ lack of information about available services on the part of caregivers and service providers;
- ◆ lack of access to transport;
- ◆ negative attitudes on the part of service providers and caregivers themselves; and
- ◆ fragmentation of services.^{3,11,12}

Box 2:

“Thandi is a five year old girl with cerebral palsy. Her mother has passed away, and she is being cared for by her grandmother. Since she was a baby, Thandi was taken by her grandmother to the nearest clinic for medication to control her epilepsy. Thandi’s grandmother is now complaining that Thandi is too heavy – and she can no longer carry the child on her back. She needs a wheelchair or buggy to transport Thandi.

But as she goes to the clinic, they do not care about how she (the grandmother) is carrying her, and whether this is a good position or not. The nurses just treat her epilepsy, but they don’t do any referrals. They don’t tell her that the child should be handled like this or like that... they don’t do that. They have not supported the child to get into a pre-school or crèche... A child like this could easily learn to feed herself, if she doesn’t have contractures. But if the granny continues to carry her in the wrong way, it will make everything worse. Maybe she will never go to school...”

Source: Personal communication, from Gloria Mnchunu, Community Rehabilitation Facilitator, Pietermaritzburg, June 2006.

Despite the many challenges, there have been some specific initiatives by the DoH focusing on the removal of barriers to access to information, particularly for disabled young people. This has included a brochure on prevention of hearing impairment. In addition, there has been the production of health information video material for deaf children, and translating of information on HIV, AIDS and TB into Braille, as part of Khomanani.^{c,34}

COMMUNITY LEVEL RESPONSES

A number of NGOs and DPOs have been set up to address the gaps in service provision for children with disabilities. These include impairment specific organisations (such as Cerebral Palsy Association, Epilepsy South Africa), parent support groups, and charity-orientated groups which focus on donations of specific assistive devices or services (e.g. Rotary, which donates wheelchairs). While the support provided by these organisations is critically important, their services are not comprehensive or sustainable due to constant difficulties in accessing funding from donors.

KEY CHALLENGES

The challenges facing the health sector include the following:

DEVELOPING A HOLISTIC APPROACH TO DISABLED CHILDREN

Currently within the health sector, there is a tendency to focus on the medical needs of the disabled child, and not on their life as a whole (e.g. improving their independence, and providing opportunities to play). It is important for personnel within the health sector to develop a holistic understanding of the determinants of childhood disability, which takes into account both the impairment and the levels of exclusion. This would enable them to acknowledge the broad-ranging risk factors for disability, and to work more collaboratively in prevention and early intervention programmes.

Further, the challenge is more than improving access to rehabilitation services and to appropriate assistive devices, it requires ensuring that children with

c Khomanani is the government’s main communication campaign on HIV, AIDS and TB.



disabilities and their families have access to all services of the health sector, including prevention and early intervention.

TRANSLATING POLICIES INTO PRACTICE

Currently, policies within the health sector aim to improve access to services by persons with disabilities.^{1,7,27} However, the challenge remains to develop specific programmes and budgeted services to ensure that existing barriers to access (including negative attitudes, ignorance about disability, physically inaccessible built environments) are identified and minimized. Ultimately, it involves transforming the institutions, attitudes, practices, buildings and facilities of the DoH, so that the constitutional right of children with disabilities to health care services is protected.

INFORMATION ABOUT DISABILITY AND USE OF EXISTING RESOURCES

Research has shown that there still exists a great deal of ignorance on the part of personnel in the health sector about the need for and type of support for disabled children and their families and caregivers.^{3,11,12,35} This includes a lack of awareness of resources available for disabled children, and procedures for referral to these services where necessary. This is compounded by the difficulties that health personnel face in providing long-term psycho-social and other support to disabled children and their families, when there are so many short-term medical needs which are pressing.

Relative to many other countries in the SADC region, SA is well resourced. A key challenge however, is how to use available resources in a way that allows children with disabilities access to a freely available and comprehensive basic package of health services.

RECOMMENDATIONS

POLICY

There is a need to ensure the inclusion of children with disabilities in all aspects of service provision in the health sector, not as an 'add on' or specialist programme. Disabled children need to be considered in the planning of services, as an integral part of services that reach all children in the community. While there is a commitment to improving access to comprehensive

services for disabled adults and children within health policies, a great deal more needs to be done in terms of removal of the (physical, attitudinal and information) barriers that currently limit access of children with disabilities and their families or caregivers to these services.

PLANNING AND RESOURCE ALLOCATION FOR COMMUNITY LEVEL SERVICES

There needs to be a focus on the development of community level services for children with disability, both to improve access and to ensure that they are appropriate. A clear strategy needs to be in place for the development of CBR nationally – both in terms of translating policies into actual programmes with budgetary allocations. In addition, it is essential that there are mechanisms in place for monitoring of these services.

FORMAL SERVICE PROVISION

A health facility is often the first place at which a parent is informed, or there is confirmation of, a child's disability. The manner in which this information is communicated to the parents has a long-term impact on the parent's own attitudes and their relationship with the child. It is therefore essential that health care professionals are given an orientation to disability, and positive attitudes towards adults and children with disabilities are promoted.³⁵ There needs to be training for all nurse and clinic staff on disability awareness, with specific focus on:

- ◆ Causes of impairment and disability;
- ◆ Early identification (of risk factors and conditions that could result in impairment) and intervention;
- ◆ Available resources and mechanisms for referral; and
- ◆ Communication skills.

There needs to be a multisectoral approach to addressing the needs of disabled children and closer collaboration between sectors (e.g. housing and health) as well as between government and NGO service providers. Each child must be viewed holistically – not just as a recipient of health services.

COMMUNITY BASED RESPONSES

The need to involve disability organisations in addressing disability issues is clearly reflected at policy level.^{1,6,28} However, in recognising the critical role played by NGOs, Community Based Organisations (CBOs) and DPOs, the DoH needs to support and build capacity within the sector. This needs to be accompanied by clear mechanisms of accountability and effective management of available resources. For example, where there are groups of parents or caregivers meeting in a community, the clinic staff could support them by:

- ◆ Offering a venue in which to meet;
- ◆ Meeting with the parents / caregivers to offer advice and answer questions on nutrition or health-related issues; and / or
- ◆ Referring other newly disabled children and their parents / caregivers to join a support group.

The focus needs to be on development of partnerships and recognition of the wide range of resources that each group brings. All stakeholders must work together – families, children and service providers – to protect the rights of disabled children and to promote their well-being.

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