

TERMINOLOGY

1. 'Disability'

1.1 Emphasis was placed in many submissions on the very idea of disability, quite apart from the issue of different types and levels of disability. Much of the emphasis was directed to the negative overtones of the word 'disability'. The Committee recognises the importance of avoiding stereotypes and of concentrating on the positive – on independence and on abilities, contribution made, by people with disabilities (and their families and carers) to society in a range of ways. Consequently, it wishes to underline the achievements of people, to 'focus on ability'.

1.2 To do so requires a shift in attitude, including among those responsible for collecting data, in order to more effectively plan service development and operations. The Committee has recommended improved data collection methodologies to achieve this end. While clearly it is necessary to establish a benchmark against which to measure need, it is equally necessary to demonstrate that 'need' is not a sign of inferiority or dependence or attributable to an individual's unwillingness to participate in society. The data collections which exist at present tend towards broad categories based on perceived lack of ability (ABS) or more usefully categories which at least indicate percentages of those who have obtained employment (DSS, DHH&CS). Even within the latter there are sub-groups of level of disability which may not accurately reflect eventual outcomes rather than current status. Further, they do not give clear indication of the type of assistance required to obtain employment.

2. Definitions – Types and Levels of 'Disability'

2.1 Disability is a general term encompassing a range of types and levels of ability measured against standard or normal behaviour and capacities. Any consideration of the positive – of the skills and abilities of people with disabilities – does not in itself mean a denial of the substantial difficulties which are faced by individuals, carers, etc. These problems must be identified in order to concentrate on abilities and the 'focus on ability' approach cannot operate without continually addressing the range of needs which individuals experience. The important factor is to move away from connecting disability with lack of ability to participate in life, and a consequent denial or limitation of access to the rights and responsibilities of society in general.

2.2 The distinction between 'disability' and 'handicap' is clearly made by Disabled Peoples' International:

Disability is a functional limitation within the individual caused by physical, intellectual, emotional or sensory impairments. Handicap is a loss or limitation of opportunity to take part in the life of the community on an equal level with others due to physical and social barriers. (Sub 168, p.1)

- 2.3 These definitions are effectively the same as those used by the Australian Bureau of Statistics and by Departments such as Health, Housing and Community Services, and are based on the World Health Organisation definitions.
- 2.4 In effect, a person with a disability may not be handicapped, but to some extent this will depend on the individual's ability to overcome certain effects of disability. In many instances this may not be possible, either because the disability *does* have a considerable effect on the capacity to participate fully in everyday activities and this is acknowledged, or because others are influenced by the disability. As is noted in Chapter 3, the influence of society, including employers, can be considerable and can continue to limit access to employment opportunities.
- 2.5 The absence of definitions in the DSA is seen as a flaw by some but this viewpoint is not shared by others. One of the reasons for not including definitions in legislation is the belief that definitions have limited individuals for too long by focussing only on the disability as a handicap and assuming restricted outcomes. Again, while definitions are necessary in the collection of data, it is equally necessary to use the data as a starting point; broad assumptions about capabilities of groups of people may be valid but the nuances of capacity will be considerable.

Another reason for not using definitions in legislation is that a definition useful for one purpose may not be valid for another purpose.

- 2.6 In accordance with current practice, the Committee has used the words 'disabled' and 'disability' rather than 'handicap', 'handicapped' or 'impaired'. It is accepted that precise terms are useful and necessary in medical descriptions, but it is also believed that such precision is not necessary or desirable in considering the needs and options of people with disabilities. What *is* required is an awareness of different outcomes and the possibility of more beneficial outcomes for a number of people than were once considered possible.
- 2.7 That is not to deny the importance of ensuring that a wide range of options exists for people so as to help overcome the handicapping factors resulting from their disabilities. A number of submissions have expressed concern that definitions (and outcomes) which are appropriate for one group or category may result in others not effectively being catered for. The Committee is aware of the different needs of different groups (see especially Chapter 5) and has

made a number of recommendations advocating programs and projects directed to meeting such distinct requirements.

3. **Types of Disability**

- 3.1 There are four major types of 'disability' – physical, intellectual, sensory and psychiatric – and within these a range of levels of ability depending both on the major areas affected and the extent of injury or illness.

4. **Levels of Disability**

- 4.1 Many people with multiple disabilities, while severely limited in some areas, may also be capable of substantial achievements, relatively speaking; nonetheless, they have often been seen as incapable of attaining a quality lifestyle. Others with more than one disability may have been placed in one category (e.g. intellectual disability) and little attention paid to the effect of other disabilities and the degree to which these may limit or enhance opportunities for the development. It is clear, however, that terms such as 'profound', 'severe', 'moderate' and 'mild' while useful to some degree (but only when clearly defined) should also be used carefully. Too often, classifications can be used to avoid individual assessment.
- 4.2 The needs of the individuals or of groups vary also according to the age at which the disability occurs and the extent to which it requires an adjustment of established lifestyle/expectations. The individual who has received an extensive education and established his or herself in a professional field may have fewer problems of adjustment if a disability manifests itself, but this will depend on the nature of the disability which may not remain steady in effect. The intellectual abilities of a person with severe cerebral palsy may be considerable but may receive limited encouragement or be considerably more difficult to express because of speech and movement problems. Disabilities which occur over a period of time may allow for adjustment and decreasing expectations, whereas those occurring suddenly may have a more severe effect. In short, the type and even the levels of disability, may have different consequences for individuals which data collections by themselves may not easily identify.
- 4.3 An additional factor which may also be difficult to measure is the fluctuating or variable effect of some types of disability and associated capacity to cope.
- 4.3.1 At least three factors should be identified here. The first is the need, certainly recognised by a number of Departments and service providers, to provide additional support to people when jobs may change in content. A variation of this may also be the need to accept that, depending on disability and previous experience, continuous and/or full-time employment or occupation, may not be a viable option for a number of people including those previously able to work full time.

- 4.3.2 The second factor is variable work performance which again cannot always be demonstrated in data, but which has a greater likelihood of being taken into consideration formally if allowance is made for such a category. Evidence was given in particular of the problem of establishing consistent work patterns for some people with psychiatric disabilities and some of those with various head injuries, because of fluctuating moods and difficulty in controlling behaviour.
- 4.3.3 A third factor is degenerative disease; disabilities in this category, such as MS/motor neurone disease, diverge from what may be perceived as a 'norm' for employment purposes, and need to be more carefully measured. A mild disability may well become severe, and employment options may decrease rather than remain steady or improve.
- 4.4 Insofar as data collections and employment options of people with disabilities are based on an expectation of stability and linear 'improvement', they will not best serve the interests of the community in general, or of people with disabilities and carers/families.
- 4.5 The characteristics of some disability groups are outlined in Chapter 5, Paragraphs 5.22 – 5.36. These characteristics are related to the need for different types of employment and other services in order to emphasise the need for employment options to meet a range of needs. The identification of characteristics of disability is not intended to emphasise limitations but rather the opposite – to ensure that services can provide what is required.