APPENDIX 7

DATA

[Note: definitions and terminology have also been discussed in Appendices 5 & 6]

1. The issue of data collection, and the generally poor, incomplete, and incompatible nature of such data as are available on the numbers of people with disabilities has been referred to in the Committee's report on the accommodation needs of people with disabilities.[1] However, the issue of data collection and use is one of major importance, and the Committee believes that not enough progress has been made in obtaining suitable standardised information on the extent of possible service need. The Committee has made recommendations concerning much needed improvement in this area.[2]

2. Data Collections

Australian Bureau of Statistics (ABS)

2.1 The 'ABS Survey', while covering the national population, utilises definitions which are sometimes difficult to translate into either need or ability.[3] There is also the additional problem of whether the census is an underestimate of disability (because individuals may not wish to identify themselves) or an overestimate (because of reduced stigma resulting from changing community attitudes or awareness of available services). Because of terminology used by ABS (for example, 'mentally' handicapped) it is difficult to determine distinctions between people with intellectual and psychiatric disabilities.

2.2 According to the 1988 ABS Survey out of an Australian population of 16,338,600 a total of 2,543,000 persons (or 15.6 per cent) was classified as 'disabled', with the majority (84 per cent) of these being considered as 'handicapped' – 2,124,100 persons, or 13 per cent of the total population.

2.3 Within the definition 'handicapped' (that is, the category most likely to be meant when discussing a level of disability likely to require some form of assistance), severely handicapped persons totalled 657,000 (4 per cent of the total population), moderately handicapped were 3.4 per cent (550,000 persons), mildly handicapped 613,000 persons (3.8 per cent) and the level of

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[1] *Accommodation for People With Disabilities*, 1990, Paragraphs 1.9-1.16.

[2] See Recommendations for Chapter 1, Recommendations 1-5.

[3] ABS, *Disabled and Aged Persons, Australia 1988*, 1989, hereafter cited *ABS Survey*.

handicap was not determined for 302,800 persons (1.9 per cent).[4] Definitions of 'severe', 'moderate', and 'mild' were based on individuals' perceived/identified need for help from another person to perform one or more of a group of selected tasks in the areas of self-care, mobility and verbal communication.[5] Those who did need such help were classified as having a severe handicap; those who did not need help but had difficulty in performing one or more of the tasks were considered to have a moderate handicap; and those who needed no help, and did not have difficulty with any of the tasks, but used an aid to perform one or more of them or had difficulty in walking 200 metres or up and down stairs, were seen to have a mild handicap.

2.4 Those who were in the category of 'severity not determined', (302,800, or 1.9 per cent of the total population) were considered to have a 'schooling or employment limitation only', or were aged less than 5 years.[6]

2.5 As noted in the ABS report, personal assessment is the basis both for identification of disability/handicap and the level of this.[7] While the percentage of the population with a handicap was reported to have increased from 8.6 per cent in 1981 to 13 per cent in 1988, this is attributable to a number of factors, including an increase in the aged population and possible less stigma attached to reporting 'disability' or 'handicap'.[8]

3. Working Age Population

3.1 According to the ABS survey, the number of handicapped persons between 15-59 in 1988 was 923,500 (between 15-34 years, 289,900, and between 35-59 years, 633,600). Of these 226,200 were severely disabled, 251,600 moderately disabled and 259,400 mildly disabled.[9] These figures obviously do not include persons of working age 60-64 years.

3.2 What is noticeable however, is the extremely high number of persons in the older age groups (35-59) in each category, severe (153,900), moderate (189,900) and mild (175,800).[10] This is particularly important in that the emphasis in new employment programs appears to be on younger age groups, particularly persons just leaving school. Those persons needing help (i.e. those with a severe disability but not receiving help) were also noticeable for much

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[4] *ABS Survey*, p. 1.

[5] *ibid.*, pp. 1 and 39.

[6] *ibid.*, p. 1.

[7] *ibid.*, p. 2.

[8] *ibid.*

[9] *ibid.*, p. 42.

[10] *ibid.*, p. 2.

the same reason – 36 per cent of those 30-44 years, and 29.5 per cent of those aged 45-59 years indicated that they had unmet needs for assistance; 32.4 per cent of women (in all groups) reported unmet need, as against 24 per cent of men.[11]

4. Commonwealth Departments

4.1 The major difficulties with departmental data collection in the past have been both the fairly loose definition of disability used by some departments and the fact that there appeared to be little co-ordination of either definition or of data collection. The absence of detailed and standardised information on the numbers of people with different types and levels of disability presumably reflects community attitudes towards people with disabilities and the role of governments and organisations in providing services.

4.2 As is noted in Chapter 3, the perception of the community towards people with disabilities has varied over time and appears to have influenced the extent and type of data collections in funding departments. The earlier emphasis on needing to care for people with disabilities and/or institutionalisation may have been the basis for the limited evaluation and accountability required of traditional sheltered workshops. There appears to have been limited concern with the identification of numbers and needs, and with the development of a range of services and types of support to meet widely differing needs. Much of the individual development and support was carried out by specialist organisations which catered for particular disability types and in a number of instances provided a life package of services, including education and employment, in a segregated setting. These organisations maintained data collections but these were not linked with other collections; hence, there was limited sharing of information and this reflects the somewhat isolated nature of earlier service provision.

4.3 Individual organisations themselves expressed to the Committee their concern at the quality of their own data collections.

4.4 A major organisation, such as ACROD, acknowledged that the lack of detailed information was factor a which must necessarily qualify their position on issues:

> I am ashamed that our Association does not have its own database and when we get it we intend to keep it updated every year through our membership so we will never again be in such an embarrassing position. We are giving views and making statements that are not well based.[12]

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[11] *ibid.*, p. 5.

[12] *Transcript of Evidence*, p. 1456 (ACROD).

4.5 The Endeavour Foundation (Queensland) believed that it was extremely difficult to determine numbers of people with different types of disabilities (as opposed to people just in funded services).

> . . . the databases are appalling. Even the Department of Community Services and Health can only make rough predictions about how many people may wind up being served by the *Disability Services Act*. One of the figures is 93,000. The Australian Bureau of Statistics picks up something like 2.1 million people who are disabled. There is a great difficulty in defining who is disabled. I would not for one moment say that somebody with an IQ of 60 is necessarily automatically a person in our services or someone else's. The simple answer is that nobody really knows. But I would say that currently there is a dreadful amount of underservicing going on.[13]

4.6 In the past there was limited pressure by departments on service providers to demonstrate or to prove outcomes, and apparently little evaluation of services.[14] If expectations were low and outcomes expected to be limited, the data requirements were minimal, static rather than active.

4.7 While the Department of Health, Housing and Community Services (previously the Department of Community Services and Health) has established a regular collection of information via a census process, this material (collected in 1986 and 1991) relates only to services funded by the Department. It cannot identify areas of unmet need in the community, and this fact reflects the Department's basic orientation – that it does not have as its major objective the provision of services to meet all existing or future need, that is, there is no entitlement to services.[15] Thus, while the Department did acknowledge that there was unmet need[16], this was not in the context of the Department being able to meet all needs even in the future. Service development, particularly transition of sheltered workshops, has tended to progress with limited regard to extent of need in the wider community. Most emphasis has been placed on quality, and on the effect of service types on those people who have managed to obtain access to the system.

4.8 Early in its evidence to the Committee the Department emphasised that it would not be the case that 'fewer people will be getting improved

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[13] *Transcript of Evidence*, p. 4256 (Endeavour Foundation).

[14] See, for example, Chapter 6, Paragraphs 6.152-6.177.

[15] See above, Paragraphs 1.21 and 5.177. See *Transcript of Evidence*, p. 1579 (DHH&CS).

[16] *Transcript of Evidence*, p. 5943 (DHH&CS).

services',[17] believing that more people would be able to utilise funds as others went into open employment and no longer required support.[18] Thus, while conceding that 'there is never going to be enough for the program if we achieve all that we do want to achieve',[19] Departmental representatives believed that there would be sufficient funds to provide reasonable growth.[20] The implication was clear that there would not be an inequitable allocation of resources.

4.9 Another area of growth in service use has come from the development of the CRS as a decentralised service provider, increasingly working to achieve employment-related outcomes.[21] The CRS, for example, has provided services to a range of users, and will be increasingly involved in the development of services for people with psychiatric disabilities,[22] a group not well-catered for in many other services because of fluctuating work patterns, lack of incentive, difficulty in relating to other people, sometimes low self-esteem, and unpredictable behaviour.

4.10 The issue of non-entitlement not only raises questions about access and about equitable distribution of resources. It must also raise questions about the extent to which substantial numbers of people with disabilities gain access to broader community options in less formal or structured ways and the role of both individual carers and organisations in the provision of such support as is needed. An additional concern must also be the degree to which other disadvantaging factors affect access, but are not identified because needs-based planning is only rudimentary and because these factors are often not taken into account as fully as they might need to be.

4.11 This matter has been considered by the Committee, which has recommended that a number of factors should be considered in planning and providing services in order to meet these needs. (See Recommendations in Chapter 2.)

4.12 Similar concerns may also be expressed about the extent to which the programs of other Departments are able to do more than meet the needs of a relatively small number of people with disabilities. Again, it is often difficult to identify the extent of need and the ways in which programs can meet needs

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[17] *Transcript of Evidence*, p. 1562 (DHH&CS).

[18] *ibid.*

[19] *ibid.*, pp. 1562-3.

[20] *ibid.*, p. 1563.

[21] Nonetheless, a percentage of CRS service users achieve non-vocational outcomes. See above, Chapter 1, Paragraph 1.13, Footnote 7.

[22] See above Chapter 5, Paragraph 5.29, 5.156-5.160.

because of limited information collected and also because of the different definitions or categories used.

4.13 Public Service Commission (PSC)

4.14 As is noted in the body of this report (see especially Chapter 3) the PSC has responsibility for monitoring the employment of people with disabilities in the Australian Public Service (APS). DEET provides information on people with disabilities who utilise the Selective Placements Program[23] and on IDAP. The Department of Finance maintains data on persons who have identified as having a disability, through the Continuous Record of Personnel (CRP). As noted in Chapter 3, these data are likely to be a underestimate on the Departmental EEO surveys. In evidence to the Committee, the PSC identified data collection as a problem and noted that a senior staff member from the ABS had been seconded to advise on changes.[24] Improved data collection has been a priority in changes recommended as a result of the report by a working party (including the PSC) on the employment of people with disabilities in the APS.[25]

4.15 DEET

4.16 Definitions of disability can also differ between Departments, making it difficult to determine exactly which groups of people are being referred to and whether programs are able to meet a range of needs depending on type and level of disability. The Department of Employment, Education and Training previously utilised somewhat broad definitions, primarily because it sought to make general distinctions between groups of disadvantaged people seeking to access labour market programs. Disabled job seekers were therefore labelled 'those who because of a physical and/or mental impairment resulting in loss or reduction of functional capacity are likely to encounter difficulty in obtaining or maintaining work and who are assessed by the Commonwealth Employment Service as work-ready with assistance'.[26] It is not clear if these guidelines would have included or excluded people with psychiatric disability or other disabilities which are less easy to measure, and in fact the statistics available on labour market programs could not be disaggregated to provide information on types or levels of disability.[27] Jobstart did include 'mental' disability but this may refer only to intellectual as opposed to psychiatric disability, and in any event reflects the terminology of the ABS which has

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[23] *Transcript of Evidence*, p. 5769.

[24] *Transcript of Evidence*, p. 5789 (*ibid.*).

[25] See Chapter 3, Paragraphs 3.104 and especially 3.108.

[26] Submission No. 205, p. 11 (Minister for Higher Education and Employment Services).

[27] However, see below, Paragraph 4.21.

elsewhere been noted as utilising definitions/terms that do not reflect current thinking.[28]

4.17 In addition, the purpose of categorising people with disabilities for DEET programs was essentially to determine the extent to which programs could meet a broad range of needs among a 'population' which was seen as generally disadvantaged. Because of this, it was possible for people to be placed in categories such as 'Aboriginal' or 'long-term unemployed', rather than 'disabled', so that the number of participants in different categories in programs was never very precise. The extent to which the needs of people with disabilities (as opposed to the needs of people in disadvantaged categories) could be met by specialist or generic programs was therefore difficult to determine.

4.18 This rather general definition of 'disability' or 'disabled' differed from the Department of Social Security's broad criteria for receipt of the Invalid Pension which included both medical and a number of socio-economic factors. In effect this meant that the three Departments which were most closely involved in the funding of services for, and the provision of income support to, people with disabilities used different assessments to determine their target population.

4.19 Recent changes, particularly those occurring through the interdepartmental Disability Task Force, have meant that some of these problems have been addressed. The major achievement – at least, as expected in the long term – is greater co-ordination and co-operation between a number of Departments; and a greater use of terminology and classification which reflects similar thinking and relates to much the same target group.[29] The changes in Social Security definitions and assessment will have a flow-through effect – for example, the impairment tables now in use in assessing eligibility for the Disability Support Pension by the Department of Social Security are the basis of the Department of Industrial Relations' determination of those people eligible for a proposed supported wages scheme.[30] This does not mean that such data as are collected will genuinely reflect people's needs and their capacity for paid employment, but it does mean that there is a greater chance of uniformity in departmental consideration of groups requiring particular types of services.

4.20 DEET has advised the Committee that with the advent of the Disability Reform Program the Department adapted the WHO definitions (of 1980)[31] and established a new system for coding people with disabilities who register

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[28] See Chapter 4, Paragraph 4.7, Footnote 9.

[29] However, see Chapter 1 Recommendations.

[30] This Scheme is discussed in Chapter 7.

[31] See Appendix 6.

with the CES. The coding system is also being used by DSS and DHH&CS, and is an attachment to this Appendix. The Community Strategies Branch of the Department, which administers the Skillshare program, has also developed a scale which can be used to assess needs and the extent to which the program is likely to be able to assist individuals. The scale runs from 0-6, with the following classifications of level of need:

0. no disability evident –

the individual can perform the activity or maintain the behaviour unaided, on their own and without difficulty;

1. difficulty in performance –

a difficulty is evident, but the individual can perform the activity and maintain the behaviour unaided;

2. aided performance –

aids or appliance necessary, or some modification of existing equipment required. The individual can only perform the activity with a physical aids appliance;

3. assisted performance –

the individual can perform the activity or maintain the behaviour (whether by aids or appliances) only with some assistance from others;

4. dependent performance –

complete dependence on the presence of another person. The individual can perform the activity or maintain the behaviour only when someone is with them for most of the time:

5. augmented inability –

activity or behaviour impossible to achieve other than with the continual assistance of another person; and

6. apparent inability –

activity or behaviour impossible to achieve or maintain even with ongoing assistance.[32]

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[32] DEET, letter to Committee, 21 January 1992, pp. 4-5.

The Department has advised that:

> Generally speaking, SkillShare projects, with assistance from Disability Access Support Units, would be expected to provide services and activities to people with disabilities up to and including Level 3 in the above table.[33]

Again, this suggests that people with more severe disabilities would be guided to other programs in DEET[34] or in other departments.

4.21 DEET is also planning a 'comprehensive evaluation strategy for the Disability Reform Program'.

The strategy proposes:

> an analysis of available data from the information systems of the three Departments and a series of surveys of interested parties, including people with disabilities, employers, service providers and staff administering the program. The object of this evaluation is to examine and make recommendations on the effectiveness and efficiency of the program.[35]

4.22 The Department also advised that its Post Placement Monitoring System:

> collects outcome data for all clients who participate in labour market programs including people with disabilities. ("People with disabilities" are analysed as a group, not by reference to disability type.) In future, once further enhancements of the Department's computer system are completed, it will be possible to monitor outcomes by individual disability type however it is not intended to do this as a matter of course. This information is collected only once, three months after their program placement is completed. Data are analysed on a quarterly basis.[36]

4.23 The Department noted that evaluation of the Disability Reform Program would include surveys of the clients of the three relevant Departments (DEET, DSS. DHH&CS). DEET's focus would include:

> . . . an analysis of the outcomes for DEET clients with a disability before and after the introduction of the DRP. It is anticipated that this may include some longitudinal follow up that will track

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[33] *ibid.*

[34] For example, 'Paid Work Experience for People with Disabilities', see above Chapter 5, Paragraph 5.69.

[35] DEET letter to Committee, 21 January 1992.

[36] *ibid.*

a person's job changes over a longer period of time to indicate increases/decreases in job status.[37]

5. Use of Data

5.1 It could be argued that, insofar as there is insufficient funding for full service provision, the absence of a range of information blurs the issues. Logically, there is limited purpose in collecting information which cannot be put to practical use, and the previous emphasis on submissions rather than a needs-based planning was part of this approach. However, as a question of social justice, the incompleteness of information even as regards numbers and types of people with a disability, may mean that the most vulnerable and those with the fewest personal resources can be further excluded from participation through limited access.

5.2 The DHH&CS has indicated clearly that an active strategy for people with disabilities and a belief that positive outcomes can be achieved, must mean a different and, indeed, more positive approach to service development, to evaluation and to the collection of information. Recent developments – a census of services in 1991, the development of a more extensive collection of data which links in with other information including information from other Departments, the evaluation of new service types, and moves towards greater accountability of the new services – indicate that the Departmental approach has changed. While the lack of information required from new services in particular, has been seen by the Department as indicating 'flexibility', it could also be seen as indicating uncertainty about the type of information that should be provided and about accountability and the need for firm controls. There were signs by the end of 1991 that a more rigorous control of 'new' services would be established.

6. Needs-Based Planning

6.1 The (then) Department of Community Services and Health stated in May 1989 that needs-based planning was a possibility;[38] however, at that time the Department was operating primarily in terms of the information obtained from the 1986 census of funded services, and it is unclear exactly how much the Department was either aware of the increase in need for services or was able to accommodate a substantial growth in demand.

6.2 ACROD representatives noted in evidence given in May 1989 that funding needed to keep pace with the numbers of people with disabilities, and that 'in many ways the problem is that disability itself is a growth industry'. While a certain percentage of increase in the numbers of people with disabilities can be attributed to an ageing population, there is also an increase in the

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[37] *ibid.*

[38] *Transcript of Evidence*, p. 1525; see also p. 1529 (DHH&CS).

numbers of younger people who are either born with, or later acquire, disabilities.

> . . . 1,000 young people, mostly male around 23 to 28, each year are severely injured in road accidents, et cetera in New South Wales, and out of those 300 have a need for ongoing support. A lot of these people, even 15 years ago, were not surviving. High technology; low weight babies; increasing professionalisation of our sector meaning more wages; having a whole lot of new services that never existed before – it is a growth industry. It needs a lot of money to ensure that the same number of people relatively are getting a service.[39]

6.3 A number of other organisations also pointed out the growth in numbers of people with disabilities of particular types,[40] and in general referred to a broader group including people who were not getting services.

> It is of great concern to us that in the debate over how quickly a service can move to a given service model, that we are not dealing at all adequately with the numbers of people that are coming out of school that are requiring services. While it is perfectly okay in abstract to say, 'Okay; we have a place of 100 people and a budget X, let us shuffle figures around it in order for something to happen for those 100 people'. That is good. The problem is: What do you do about the 20 and 30 and 40 – the numbers that are growing? Not enough attempts are being made to deal with that.[41]

> . . . even though many members find a lot of things wrong with the segregated sheltered workshop model, there is a strong recognition that those models are likely to exist for a long time, particularly for the people who are currently within them. We believe that where very strong efforts are required it is for the people whose needs are not being addressed adequately at the moment; that is, people who are not even in sheltered workshops; people who have not yet gained entry to any sort of employment option. It is our experience that a large number of those people these days are bypassing the sheltered workshop system and going straight into other employment options, which is very good to see.[42]

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[39] *Transcript of Evidence*, p. 1462 (ACROD Limited).

[40] *Transcript of Evidence*, p. 4107 (Headway).

[41] *Transcript of Evidence*, pp. 1330-31 (National Council on Intellectual Disability).

[42] *Transcript of Evidence*, p. 1174 (Professor T.R. Parmenter).

6.4 One researcher, not directly involved in service provision, also emphasised the problems that were being created, in part by the transition process, where very limited numbers of people could be accepted into existing services.

> The situation we have at the moment, because of the static nature of the programs and the lack of growth of the traditional models – the activity therapy centres and the sheltered workshop industry – during this transition period when we are trying to effect a change, is that overall we have not seen a growth in services and yet there are more and more children coming out of special schools and knocking on the doors of the traditional models, and they will increasingly knock on the doors of the new models. I cannot give you the data off the top of my head but I can use terms like, 'There are significant numbers who are being denied any form of service at the moment'.[43]

6.5 While the school to work transition programs are important and the Commonwealth has acknowledged the importance of providing places for school leavers (with the majority of the 4,000 new places arising from the 1990-91 budget being for school leavers)[44] neither the then Department of Community Services and Health or DEET had reliable statistics on the number of people with disabilities leaving schools each year.[45] Without an accurate forecast of the need for services for this group there is likely to be a continual build up of unmet need; unless those currently using services move into open employment and require little support, a substantial increase in funding is likely to be the only means of providing sufficient places.

6.6 This situation was referred to by a number of organisations, especially in the context of what were seen as 'high cost' services for a few with lower cost services, especially sheltered workshops, being seen by some organisations as providing at least some form of service for a greater number of people.[46]

7. Evaluation

(See also Paragraphs 4.20-4.22 above.)

7.1 Information, particularly evaluations of innovative services, is also required in report form on a more systematic basis. While it is acknowledged that it is too early to provide a definitive statement on the cost-effectiveness and success rate of a number of new service types, a consideration of many of the problems faced by sheltered workshops indicates that a number of these may have been averted by earlier intervention, and the development of more

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[43] *ibid.*

[44] *Transcript of Evidence*, p. 4749 (DHH&CS).

[45] *Transcript of Evidence*, p. 4750 (DHH&CS).

[46] See especially Chapter 5, paragraphs 5.159-5.161.

effective management, as well as more suitable levels of funding. It is possible that the problems of new services which were referred to by many service providers, could have been overcome by more careful assessment and stringent evaluation and data collection.

7.2 As noted above, the amount of information available on new services is somewhat limited, with data being held by the individual organisation rather than centrally by the Department of Health, Housing and Community Services. While different evaluations have now been carried out, the first of these was on a somewhat impressionistic basis.[47] This type of evaluation/survey does have some benefit, but it is important not only to evaluate *all* services systematically, but to do so in an awareness of the number of people who may also require a similar service. Until this is done, emphasis will continue to be placed by the Department on those who have managed to get a place, rather than on (a) the numbers who need the service and (b) the reasons why some people have access and a substantial number do not.[48]

7.3 At the time of the finalisation of this report, early in 1992, the Department of Health, Housing and Community Services had funded two evaluations of new services.[49]

7.4 The first evaluation (done by Roy Morgan) has as its major objective the evaluation of the new employment service types. The project brief states that the project team would 'develop, design, conduct, analyse and report on the "new models" of Employment Services'. However, in May 1991 when the project was advertised, the Department itself did not have access to key information, although it was expected to be available from the 1991 census by July/August 1991. Nonetheless, by the end of 1991 much needed data was still not available from the 1991 census. The project brief also noted (at Paragraph 3.5) that 'the collection and analysis of data beyond the scope of the Census is necessary to answer these questions for which Census data is not sufficient'.

7.5 The second project, also due to report in 1992, had the following aim:

To examine the employment environment for people with disabilities utilising employment services funded under Section 10 of the *Disability Services Act* including:

- individually supported jobs

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[48] Chapter 5, Paragraphs 5.187-5.191.

[49] Recommendations, Chapter 6, Nos. 12-13.

[50] See also Chapter 5, Paragraph 5.193, and associated recommendations. See in particular Paragraphs 5.219-5.245.

- enclaves
- work crews
- individual placements in open employment.

7.6 This study will evaluate the attitudes of employees, employers and co-workers in supported employment and open employment. It also will gather data on the employment environment, which is seen as incorporating the following factors:

- attitudes of employers, employees, and unions towards employment of people with disabilities
- suitability of work structures (including job design and physical layout)
- effect of economic environment (e.g. impact of last on/first off principle)
- awards and conditions
- support from employers, work colleagues, unions and family
- size and type of business
- technology change
- industry sector
- ongoing support from the DSP
- perceptions of productivity
- attitudes of people with disabilities towards the work environment.

7.7 Evaluation also needs to be carried out on the (relative) long-term success of funded new services. While there may be a number of different opinions as to the effectiveness of particular approaches, these opinions need to be based on studies as well as on impressions; in instances, Departmental officials appear to have based their evaluation of the success of options on information which, while entirely valid, also needs to be measured more systematically. 'Their families believe they are happier, and they are smiling, so that is an example'.[50] Others are less optimistic:

> I think some of the ideologies have given birth to an optimistic view of what we can do with disabled people. We have to keep in mind the concept that ideologies are

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51. *Transcript of Evidence*, p. 1572 (DHH&CS).

> speculations and are not fact, as it were; they are goals that we may be moving towards.[51]

7.8 The same witness stated a belief that longer term evaluation was necessary:

> The study that we are currently completing for the Association of Rehabilitation Facilities – whilst . . . data are not fully available yet and are not fully analysed – is throwing up information which I believe the Government could use very profitably in refining and extending the current new services. I will give you an example. One of the serious misgivings I have as a researcher is that there is a fairly naive belief in some of the CETP programs that, once you have placed a young person with a mild level of disability, that person is probably then set on the road for a successful vocational career.[52]

7.9 While a number of individuals may have been seen to successfully integrate into society, it is also likely that others may re-emerge, possibly to be classified under a somewhat different heading, but not perhaps as an 'employment problem'.

7.10 The correlation between evaluation and funding was stated clearly by representatives of ACROD.[53]

> The difficulties are that we are looking for clarity, rationale and scientific data so that not only do the outcomes work, not only are they effective, but also they are affordable. There is this general reluctance to dismantle the infrastructure and perhaps throw out the baby with the bath water, without the proving process having gone on.[54]

8. Conclusion

8.1 In terms of both general data collection for needs-based planning and for the evaluation of services, the main issues must be access to services and equity in the distribution of funds. The Department of Health, Housing and Community Services appears to have proceeded to implement the *Disability Services Act* with a limited awareness of the numbers and needs of people already in some form of service. Yet, statistics would indicate that people

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52. *Transcript of Evidence*, p. 1165 (Professor T.R. Parmenter).

53. *Transcript of Evidence*, pp. 1167-68 (Professor T.R. Parmenter).

54. While referring to accommodation, the comment is equally applicable to employment services.

55. *Transcript of Evidence*, p. 1470 (ACROD Limited).

receiving a service funded by the Federal government represent only a small percentage of people with disabilities. While it is essential for the government to recognise the needs of those people in funded services, and in effect to compensate many of them for previous poor service, it is also necessary to extend services as widely as possible.

8.2 This concern has been expressed by service providers and by consumers alike. Again, while extensive data collection have not been available to individual or even to national organisations, their own waiting lists and awareness of unmet need has provided them with the knowledge that service provision could not meet existing needs, and that the transition process (while commendable in itself) might mean a limitation of services. The needs of people with disabilities and their families were therefore met by the families themselves; information by Departmental officials that services were meeting needs more effectively must be countered by the individual experiences of many people who spoke to the Committee, that however good new services were, there were not enough of them. With the gradual decrease in places available in sheltered workshops, and with a possibility of people moving through and out of employment into other areas of need, the gap between funding and needs has become obvious. This is so even without taking into consideration the funding required to provide appropriate services for people who may never be in employment, and those whose needs include a mixture of services, including work, leisure, education etc.

8.3 This is not to deny the achievements of the *Disability Services Act* thus far; the legislation has achieved a considerable turn around in service provision and has contributed to a change in service and community attitudes. However, although there have been considerable achievements, there is still a substantial number of people with disabilities whose access to community resources is still limited – through a series of factors over which they have limited, if any, control.

8.4 It is for these reasons that the Committee has made its recommendations both as regards to data collection Chapters 1 and 2 and on the ongoing evaluation (including auditing) of all services (Chapters 5 and 6).

ATTACHMENT

DISABILITY CODES FOR USE BY DEET, DSS AND DHH&CS

MEDICAL CONDITIONS	CODE
Amputation (of any kind) including:	A
Amputation of arm at/above elbow	
Amputation of arm below elbow	
Amputation of fingers	
Amputation of foot	
Amputation of leg at/above knee	
Amputation of leg below knee	
Amputation of thumb	
Musculo-Skeletal & Connective Tissue including:	C
Ankylosing spondylitis	
Bursitis	
Curvature of the spine (not congenital)	
Diseases of the connective tissue (e.g. sceleroderma)	
Fractures and their residual effects	
Gout	
Intervertebral disc disorder	
Other back disorders (e.g. sciatica, backache)	
Juvenile rheumatoid arthritis (Still's disease)	
Osteoarthritis	
Other joint disorders	
Rheumatoid arthritis (not juvenile)	
Scheuermann's disease	
Soft tissue inflammation (e.g. tendonitis, capsulitis)	
Tennis/golfer's elbow	
Spondylosis	
Synovitis and tenosynovitis (including overuse syndrome)	

Nervous system G
including:

Carpal tunnel syndrome
Epilepsy
Motor neurone disease
Multiple sclerosis
Motor neurone disease
Multiple sclerosis
Nerve root and plexus lesion (e.g. brachial plexus)
Paraplegia
Poliomyelitis
Other diseases of the sensory nerves
Quadriplegia
Other degenerative diseases of the nervous system

Sense organs B
including:

Blindness or low vision
Other visual impairment
Hearing loss or impairment
Stuttering
Tinnitus
Voice disorder (e.g. hoarseness, nasality)
Other speech or voice disorders

Congenital anomalies P
including:

Cerebral palsy
Congenital defects of circulatory system
Congenital defects of heart
Congenital deformity/absence of lower and/or upper limb
partial or complete
Spina bifida

Respiratory system D
including:

Asbestosis
Asthma
Bronchiectasis
Chronic bronchitis
Emphysema
Fibrosis
Silicosis
Other diseases of respiratory system

Circulatory system E
including:

Angina pectoris
Chronic ischaemia
Chronic pulmonary heart disease
Myocardial infarction (heart attack)
Other disorders of the blood vessels and circulatory system

Intellectual/learning H
including:

Developmental disability or mental retardation
Learning disability

Psychological/psychiatric I
including:

Alcohol dependence
Anorexia nervosa
Bulimia
Drug dependence
Manic depressive
Neurotic disorders (e.g. anxiety, phobia, neurosis)
Non-psychotic depression (e.g. reactive depression)
Occupational stress
Personality disorders
Post-traumatic stress
Schizophrenia

Acquired brain impairment S
including:
Cerebral haeumorrhage/stroke
Degenerative conditions (e.g. Alzheimer's disease)
Infection of brain (e.g. meningitis, encephalitis)
Traumatic brain injury

Cancer/tumour including: Brain tumour (benign, malignant) Hodgkin's disease Leukaemia Skin cancers Tumour – benign Tumour – malignant (not lung, not brain) Tumour of respiratory system (e.g. cancer) Tumour of spinal cord	T
Endocrine and immune system including: Diabetes Disorders of immune mechanism (e.g. AIDS, HIV) Obesity Pituitary dysfunction (e.g. gigantism, dwarfism)	L
Skin disorders and burns including: Burns and their effects Eczema Psoriasis Other disorders of skin	M
Gastro intestinal or kidney and other disorders of stomach, liver, gallbladder, bowel including: Hepatitis, peptic ulcer	F
Chronic fatigue syndrome/post viral syndrome myalgic encephalomyalitis (ME)	V