

PRODUCTIVITY COMMISSION REPORT

COMMENTS ON CHAPTER 5 - ASSESSING CARE AND SUPPORT NEEDS

Dr Neil Kirby
Disabilities Research Unit
University of Adelaide

The following comments on the sections of Chapter 5 of the Productivity Commission Report are made by Dr Neil Kirby, Director of the Disabilities Research Unit (DRU) at the University of Adelaide and are based on the development and research work of the DRU team over the years that they have been developing D-START (Disability – Support, Training and Resource Tool) in collaboration with the South Australian Government Department for Families and Communities.

Each of the sections of Chapter 5 is commented on, with particular reference to the work that the team has conducted on D-START. Our direct comments and recommendations concerning points made in the report are written in bold to make it easier to identify what we would add or change in the report.

Briefly, the D-START assessment system is designed to assess the support needs of people with different types, levels and combinations of disabilities. It conceptualises disability as an interaction between the individual and their environment, and accordingly, it also assesses opportunities and risks associated with the individual's environment for developing and maintaining independent living.

KEY POINTS

Individual and carer focussed funding – **need to also assess the environment**

We agree with an assessment process focused on the individual and their informal carers, **but would add in this first section a reference to the need to also assess the environment in which both the individual and the carer function.** The availability of support services varies from one environment to another and individuals can have more opportunities or be more at risk in some environments than others.

Assessment for individualised funding – **also to assess short term support packages**

We also agree with the need to use the assessment to formulate a person's individualised funding, taking into account natural supports **but would add that there is a need in some cases to consider a short-term funding package (to deal with behaviour, skill training or other possible short-term issues) as well as long-term support-needs funding.**

Reassessment of support needs – **need for computerisation to facilitate this**

The need to reassess people's support needs is essential **and we would argue that this would best be accomplished using a computer based system that can automatically program in dates for reassessment.**

Need for a “toolbox” of assessments – **need to have a flexible assessment system**

No single assessment can cover all support needs at the present time. **The difficulty in using different assessments is integrating them so that there is minimum duplication of data collection and efficient data transfer between assessments. There is a need for a flexible assessment system that can be adapted to cover the major support needs domains in a brief or more comprehensive way for different assessment purposes.**

Need for funding to develop assessments – **there should be continuing development**

There is no computerised comprehensive support needs assessment system at the present time, and accordingly, **there is a need for funding to be made available for the development, maintenance and continual updating of such a system.** The need to ensure that a computerised system of this kind is maintained so that it operates without “bugs” and is continually updated to represent best practice will require an ongoing dedicated assessment team. An attempt to fund just the development of an assessment system without ongoing maintenance and revisions, on the basis of feedback from users, will result in a less than optimal system with the possibility of accumulating user problems over time that would eventually require a major revision or new assessment system development at considerable cost.

Effective assessment use requires trained staff – **and ongoing training**

We agree that the effective use of an assessment system requires trained staff. We would add that **training must also be available to new staff hired after the original training, and additional revision training should be provided on a regular basis for existing staff, based on feedback from assessments that they complete.** These provisions are important given the relatively high turnover in staff in disability services and the tendency for existing assessors to begin to use their own criteria for assessment if they are not periodically reminded of the appropriate criteria.

The use of a “benchmark” range of assessed needs– **need to continue to update and provide evidence of best practice to assessors**

To ensure optimal outcomes in terms of independence for people with disabilities and reduced costs for government, there is a need to ensure that assessors of support needs and those implementing support to increase independence and reduce long-term costs are kept aware of best practice as it evolves over time. Such **information and periodic updates concerning bench marks and best practice need to be made available to assessors and service providers on an ongoing basis rather than as information that would be available only after a major evaluation of the assessment.**

An assessment tool would need to be continually monitored and refined – **assessment improvements would best be achieved by a permanent dedicated team receiving continual feedback from users and from the research literature on best practice.**

5.1 INTRODUCTION

The introduction states that an appropriate assessment tool needs to provide resource allocations that are not “too generous or too tough” using a process that must be “fair, rigorous and safeguard against exaggerated claims of support needs”. **We would add that it also needs to be transparent so that it is clear how support resources are allocated and for what purposes.**

The desirable features of assessment reliability and validity are obvious, **but what also needs to be noted is the scale of the research that will be required over time to determine these characteristics of an assessment system for different types, levels and combinations of disabilities in different environmental conditions.**

Most measures of support needs have been designed primarily to assess one particular type of disability, such as intellectual or psychiatric, and while reliability and validity may be established for that particular group, this does not mean that the measure will have similar reliability and validity for people with other types of disabilities, or even for that particular type of disability if it is combined with other secondary disabilities. Little or no research has been carried out on the reliability and validity of measures of the environment, as these have only recently been developed and most support needs and adaptive behaviour measures either do not have them or only have a few such items.

The question as to whether a single tool should be used or a tool box, relates to the relative complexity of a person’s support needs. There are obvious advantages in having a single tool in which the relative needs across different domains can be compared. A major problem with most assessments of support needs or adaptive behaviour is that their size and scope makes them appropriate for certain purposes but not others. Thus, some measures are brief and suitable for assessing eligibility for a service and / or for an overall measure of funding but are not sufficiently detailed for use in the program planning associated with the service or that funding. Alternatively, an instrument may be sufficiently comprehensive for program planning but be considered by users as unnecessarily complex and time consuming for assessing eligibility or an overall funding level. The main problem here is that the two types of forms may differ so much that they do not relate easily to each other, so that the assessment of eligibility or funding does not relate in any obvious way to the assessment of the service program that is required. It would therefore be useful to have a flexible assessment tool that can be adapted to different purposes.

The issue of “when, over the course of an individual’s life, assessment should take place” raises the issue of early intervention and continued intervention with support at various stages of an individual’s life. Support needs assessments at or just before particular developmental changes and transitions such as from school to work, from family accommodation to individual accommodation or from work to retirement would serve to avoid difficulties that might otherwise occur and require even greater support to resolve.

Whether carers should have their own assessment is a very good question but if so, **the information obtained from the carer assessment needs to be integrated with the support needs of the person they are caring for.** Checking for fairness and sustainability requires a system that allows comparison of an individual’s support

with other individuals having similar disabilities and contextual circumstances but **it also requires the capacity to monitor the support provided to an individual over time to assess the extent to which the support is increasing independence and quality of life and / or reducing costs.** A danger with support assessment systems is that they may allocate support on the assumption that it should be used to maintain the person at that level for life rather than be used for skill development and / or behaviour intervention that would increase the person's independence and quality of life and reduce the costs of the support they require.

Ensuring that “the tools are applied rigorously, including safeguards and processes for adapting and refining them over time” will require ongoing research into the reliability and validity of the assessment instruments **for different types, levels and combinations of disabilities in different contextual circumstances.** It will also require checking in individual case studies to ensure that the assessment instruments address the unique needs of individuals and do not just provide a “one size fits most” approach to assessment. While independent research evaluators should be used to check on these issues, there is also a need for the assessment developers to have the continuing opportunity to obtain feedback on the assessment and to work collaboratively with users to continually refine the instrument to ensure it achieves the outcomes of increased independence and quality of life for people with disabilities and /or reduced costs of support. A “start, stop, start again’ approach to the development of assessment instruments is likely to lead to significant periods of time during which the instrument may be considered by users to be increasingly ineffective or inefficient, and changes eventually made by those other than the original developers may be limited in scope.

5.2 WHAT IS BEING ASSESSED? – NEEDS, WANTS AND ASPIRATIONS

Distinguishing between needs, wants and aspirations is important in any assessment of support needs **but we would argue that all three should be assessed in order to understand the individual in relation to the support they require.** While need should be the primary focus of support, wants and aspirations are less easily distinguished as reported by people with disabilities. We have encountered case studies in which a person with a disability has wanted or aspired to have a girlfriend but needs training in social skills because of their difficulties in relating to other people. Another case study involved a person who had been in trouble with the law because of aggression and had been assessed as having difficulties with anger management, who nevertheless expressed an aspiration to belong to a gun club! Examples such as these show how important it would be for those developing a support needs program plan to take account of needs, wants and aspirations in assisting and, in particular, motivating a person to become more independent.

Most measures of support needs attempt to assess a wide range of aspects of a person's life and some use the ICF framework in order to structure their support needs domains. The ICF cannot itself be used as an assessment tool but it does provide a very comprehensive list of activities associated with independent living. A comprehensive list of activities is required as a basis for consideration of individual needs, wants and aspirations.

5.3 WHAT IS THE PURPOSE OF THE ASSESSMENT PROCESS?

Determining whether an individual would receive individualised supports

In the section on “determining whether an individual would receive individualised supports” it is stated that a “short upfront module would establish whether an individual would receive NDIS – funded, individualised supports”. **We would add that that these two types of assessments should be interrelated so that there is minimum duplication of assessment data.**

Determining the service offering

In the section on “determining the service offering”, the importance of allowing a person to “fulfil a range of functions, such as participate in their community” implies the need to comprehensively assess support needs for the individual within the context of the environment in which they live. The need for person-centred assessments that “take account of people’s unique circumstances” means that an essential part of the evaluation of any assessment system must be its capacity to identify individual needs.

Also indicated in this section is “having regard to fluctuating needs and anticipating changes that can be expected to occur”. This has been a major omission of many support needs and adaptive behaviour measures, **and we would add that in our view this is a major reason for “gaming” and exaggerating support needs.** In one of our research studies, we were asked when the next assessment would be, and when asked why this was important, the assessor stated that if it was going to be in a year’s time, she would need to increase the support levels because she knew that this person was deteriorating and that in six months, their support needs would be greater than they were at the time she was completing the assessment. Accordingly, **there is a need to not only assess whether a person’s support needs are stable, increasing, decreasing or fluctuating, but also to indicate when another assessment should be carried out.**

Determining what reasonably and willingly could be provided by unpaid carers and the community

The section on unpaid carers highlights the importance of considering their support needs. **We would also add here the needs of other family members including siblings of the person with a disability.** The provision of supports that might be relatively inexpensive, such as respite or behaviour management advice, could enable considerable savings in the cost of full time care that might otherwise be provided by a government agency. The statement that “most carers wish to continue to provide care for as long as they feel able to do so” **implies a need to consider whether the carer’s needs are increasing or fluctuating as part of program planning.** Providing the person with a disability who is receiving informal care with skill training, behaviour management, and/or short-term experiences in alternative residential care, could all facilitate their eventual transition when the informal carer is no longer able to provide support. This would avoid the tendency to put off such planning until a crisis occurs in which, for example, the informal carer requires extensive medical care, and the person with a disability has to be placed in an unsatisfactory residential situation because that is all that is available at the time.

An issue with respect to informal care that also needs to be addressed is the situation in which the person with a disability has informal care duties of their own for a family member, such as their own children.

Determining an individual's budget

In the section on determining an individual's budget, it is stated that "it will be important for the scheme to monitor patterns in assessments to test whether these reveal any unwarranted cost pressures (for example, arising from defects in the assessment tool or permissive use of the instruments)". **There is a need for assessment instruments to include checks for incorrect or inappropriate use, including gaming. There is also a need for assessments to be checked against outcomes to ensure that allocated support needs have achieved the independence and quality of life outcomes intended.**

Determining suitability for self-directed funding

A support needs assessment system could be used to identify individuals who might be suitable for self funding. **However, what also needs to be pointed out in this section is that those suitable for self funding may not remain in that situation, so that they may need to return to agency support; for example, due to an accident or a suddenly deteriorating medical condition.** It might also be the case for people with psychiatric disabilities, that they are capable of self funding for relatively long periods of time but with relatively regular, though infrequent, occasions where they would also need agency care.

Associated with the issue of self funding, is the issue of self assessment. It might be considered useful for someone with a disability, for example, a professional person in a wheel chair, to be able to fill in their own assessment of their support needs and submit that to an appropriate funding committee. **An important consideration here is the need to make sure that the assessment is not seen as just an assessment of deficits but rather provides a balanced picture of both the capacities of the individual as well as their needs.** While this is obviously also important in a third party assessment to ensure that the report of a person being assessed contains what they can do and aspire to do as well as what they need, this would be particularly important if self assessors are not to feel that the assessment is demeaning.

Another issue that should be mentioned under this heading is the involvement of informal carers in self funding for an individual. Thus parents of an individual with a disability may be quite capable of "family" rather than "self" funding, with again appropriate monitoring to ensure that the family situation remains stable and able to maintain control of their own funding.

Providing a referral to other schemes

In this section, there is mention of the need for assessments to be portable across the system. **An important point that needs to be made here is that this is likely to be much more easily accomplished if the assessment system is computerised.** This would allow virtually instant transmission of all relevant information about a person

from one agency to another. A paper and pencil system is vulnerable to substantial delays in obtaining relevant information and thus leaving a person without support (e.g. a suitable residential placement), for some period of time. It is also vulnerable to key information being lost or misplaced and thus being unavailable, so that certain assessments have to be repeated and / or programs are implemented that have already been tried and failed, or previous successful programs are not re-implemented because there is no current knowledge of them. Computerised information collected by an assessment system can also ensure that information relevant to the dates associated with assessment, programs and counselling are included. This can be achieved by the computer being programmed to prevent the assessor from proceeding without filling in the required information.

An additional critical issue that needs to be referred to here is the need for security of information. This is particularly important with electronic information from a computerised system, which could inadvertently be made available to more people than intended.

Providing data for program planning and cost management

Two important points can be made concerning the information in this section. The first is that assessments should be used not just for eligibility and funding a particular level of support but also for devising programs and interventions aimed at increasing the independence and quality of life of people with disabilities and also for ensuring that these outcomes are achieved in the most cost effective way. There is a real danger that assessments of support needs will be used as a means of placing people permanently on a particular level of funding for support in the same way that people were allocated to different types of institutions based on measures of adaptive behaviour.

The second point involves the need for a computerised system to provide individual data on allocated support needs, programs implemented and outcomes achieved for particular costs. The effectiveness of outcomes for the costs involved might be measured in terms of the degree of independence (and associated quality of life) achieved or in how well a deteriorating disability condition and its effects on the person's quality of life are managed.

5.4 DESIRABLE FEATURES OF THE ASSESSMENT TOOLS

Good reliability and validity are essential for any assessment tool, but **a number of points can be made in relation to the information in this section. First, validity ultimately must be considered in terms of the extent to which it is both effective and efficient. Effectiveness must be considered in terms of the extent to which the assessment can be used for funding support and associated program planning that lead to greater independence and quality of life for people with disabilities. Efficiency needs to be considered in terms of the relative costs compared to other similar systems.**

A second consideration involves the need to establish reliability and validity for different types, levels and combinations of disabilities since many support needs assessments have been designed for one particular disability group such as

intellectual or psychiatric. The fact that an assessment is found to be reliable and valid for that group does not mean it will necessarily be equally reliable and valid for other disability groups. One complicating factor is that as many as half of people with a disability have one or more other disabilities so there is a need to consider reliability and validity for those having different numbers and types of other disabilities associated with that primary disability.

A second complicating factor is that disability is now commonly considered, although not as yet commonly assessed, as an interaction between the person and their environment. Thus, the reliability and validity of an assessment instrument needs to consider not only different types, levels and combinations of disabilities but their interactions with different personal environments. It can be readily appreciated that collecting reliability and validity data of these kinds would require a considerable amount of data collection and could involve changes to the assessment instrument in order to improve its reliability and validity for different disability and environmental conditions.

A third consideration involves the need to consider the validity of any assessment in terms of its capacity to identify individual needs in the context of the person's environment, the combination of which may be unique to an individual.

An important requirement for assessment mentioned in this section is the capacity of an assessment tool to detect change in a person over time. **We would add here that it is not just changes in the person that need to be assessed but changes in the person's environment that may affect that person's support needs.**

In terms of an instrument's capacity to detect change, we would emphasise the need to include qualitative questions that can capture unique changes, not all of which could be included in a check list.

We also believe that there is a need to distinguish between sensitivity to change in support needs, which may be associated with changes in the person's disability (e.g. a deteriorating medical condition) **or environment** (e.g. moving from informal home based support to residential care because the person's mother is aging and no longer able to provide the needed support), **and changes that are due to intervention programs** (e.g. skill training, behaviour management, counselling or advocacy). Sensitivity to changes that are due to program interventions is important in order to evaluate what is being achieved in the short and long term for the cost of the program. For example, a program to teach people with severe intellectual disabilities to dress themselves may require many months of intensive training by experts in behaviour management and cost many thousands of dollars, but if successful, the savings in support that would otherwise have to be provided to dress them over the following forty years or more would constitute a major reduction in the cost of government support to disability.

Another aspect of the detection of change that we believe is important concerns changes in the associated individual program plan. Thus, it is unlikely that all initial program plans will achieve their goals without the need for changes in the program.

A final requirement on validity and reliability which quotes our own work (Guscia et al 2006a) involves “susceptibility to manipulation, completion time, assessor training requirements and ease of administration more broadly”. **We would like to stress the importance of the assessment instrument being “user friendly” since this will make it more likely that users will not only fill in the data more accurately but also motivate them to use more of its features.** Users need to be considered as not just those who fill in the assessment form, whether a paper or computerised version, but also those who have to read the reports in order to make eligibility, program planning and funding decisions.

A final point that is made in this section is the need for the instrument to be nationally consistent. **While we would not advocate funding the development of only one instrument at this early stage, given how recent measures of support needs are, we would point out the need for any computerised system to be designed so that it can be readily incorporated into state and national services. A critical issue that needs to be commented on with respect to the national collection and storage of assessment information, and particularly computerised assessments, is the security of the information.**

Rigour

Much of the information considered in this section comes from research on D-START (Harries, 2008; Guscia, et al 2006a). The main issue considered in this section is “gaming”, i.e. exaggerating support needs by assessors to gain more funds. We have already discussed some of the reasons for gaming. **An important point to repeat here is that in the instance of gaming that is reported from our work, one plausible reason for this concerns how long it is likely to be before the next assessment. The assessor in our example stated that the particular person she was assessing had a deteriorating medical condition, and would therefore require additional support in the not too distant future. Thus, if the next assessment was not going to occur until a year’s time, she would have to increase her estimates of the present support needs for the person in order to help ensure that they would be sufficient over the next 12 months.** This tendency can be reduced by providing the capacity to indicate changing support needs, and a date that can be set for a reassessment.

On page 5.13, line 2 and following, it is stated that: “It has been suggested that the use of objective functional measures are potentially less susceptible to manipulation and therefore may be more appropriately suitable to funding purposes”. **We would argue that functional skills should not be used by themselves for funding purposes but in a complementary way with measures of support needs. The problem with using functional skills for funding is that there is not a one to one correspondence between functional deficits and support needs.** This is the main reason for the recent development of support needs assessments, when there have been for over 60 years a range of functional skills scales that have been progressively improved on the basis of research. Because support needs scales are so recent and have relatively little evaluative research associated with them, they cannot at the moment match the reliability and validity of measures of functional skills. **The lack of one to one correspondence means that funding based on functional skills may be too little or too much for the required support services for an individual. An**

important problem for measures of functional skills is that most have no assessment of the environment in which the person with a disability is living. This can have important implications for funding the same support needs in different environments, e.g. the city versus the country. It also means that there is no close relationship between funding and the actual programs or services that are designed on the basis of measures of support needs so it is difficult to evaluate the effectiveness of interventions on the basis of costs.

Applicable

Under this heading, the point is made that a suitable assessment system must be applicable to a wide range of types, levels and combinations of disabilities. We have already pointed out that a problem with many assessment systems is that they are designed primarily for one particular disability. **We would add that given disability is now considered as an interaction between the individual and their environment, there is a need to also consider the above conditions in relation to different environments.** Very few measures of functional skills or support needs have adequate measures of the environment, in spite of the comprehensive classification of different kinds of environments that has been made available by the ICF.

The point is also made in this section that an assessment “does not unfairly discriminate against people from the indigenous or ethnic communities”. In our research (Guscia et al, 2006), we were surprised to find that of 20 current and commonly used support needs or adaptive behaviour measures, half did not have a single item that considered the environment and of those that did, very few included an item on community attitudes.

Practicality

In this section it is pointed out that in the case of the “NDIS, a tool will be used for both screening prospective users and for determining an individual’s package of supports and the budget associated with meeting those reports”. It is anticipated that a “quick and easy to administer” tool might be preferred for the first task and a longer and more complex tool suggesting either “a hierarchical tool or multiple tools”. **We would argue that a hierarchical tool is preferable because of its greater comparability between the shorter and longer assessments.**

Public domain

The issue of whether the assessment tool should be in the public domain raises difficult questions concerning intellectual property and any possible commercial value of an assessment tool produced by a research and development team. **This is not such an issue for simple paper and pencil assessments and simple funding formulae such as averaging scores to determine a funding level, but the more comprehensive the system, the more it is computerised and the more sophisticated the algorithm for determining a funding level, the more important the issue of intellectual property becomes.**

It would seem reasonable, given the extensive intellectual property involved in a complex assessment system, that it should be available at a cost to the user that compensates those producing it and allows for continuing research to be funded for its improvement.

Efficiency

As already indicated in previous sections, the problem for an efficient support needs assessment tool is how to collect all relevant information without wasting time collecting information that is not important. **We believe that the best solution to this problem is a hierarchical system that can direct questioning only to issues relevant to support needs.**

Nationally consistent

A major problem with respect to national consistency is that there is no existing support needs assessment tool that has demonstrated the required reliability, validity and user acceptance for people with different types, levels and combinations of disabilities in different environmental contexts. **Most existing instruments have been designed primarily for one particular type of disability and hence would not be appropriate nationally for services dealing with people who have other types of disabilities. There are also very few such instruments that have an adequate assessment of the context in which support needs are required and hence might be suited nationally only to some environments.**

Accordingly, it would seem that, as recommended, a ‘tool box’ consisting of a range of suitable tools would be advantageous, allowing each to be developed, used and evaluated in terms of its scope and limits with respect to nationally funded support services.

5.5 THE CURRENT SUITE OF ASSESSMENT TOOLS

Mentioned in this section is the fact that there has been relatively little investment within Australia in the development and refinement of support needs assessment tools. D-START is mentioned as one of the tools that has received investment, in this case by the South Australian Government. As indicated in the introduction to these comments, D-START has been designed to provide comprehensive support needs assessments available for different types, level and combinations of disabilities in different environmental contexts. We have also mentioned research carried out on D-START that has supported the reliability and validity of the instrument.

5.6 A SINGLE TOOL OR “TOOLBOX”

In this section, the question of having a single tool or a “toolbox” is posed. We would agree with the report that in spite of believing that our own assessment system, D-START, is capable of providing a comprehensive assessment of most support needs and that this will improve with future developments, **it would be rash at this stage of limited development of support needs assessment to try to rely on one assessment system only. Much will be learnt from the use of different assessment systems in different states and services providing that they all cover the same basic needs**

and result in broadly equitable funding. Research will reveal which assessments provide the most reliable, valid, cost effective, and user friendly system for evaluating and funding support needs in order to achieve the best outcomes in terms of individual independence and quality of life.

5.7 WHO SHOULD CONDUCT ASSESSMENTS?

How accurate is self-assessment?

Does self –assessment deliver greater user involvement and partnership?

The main question considered in this section is that of self assessment, and while self assessment sounds like a good idea and one that would enhance a sense of dignity and independence in the person with a disability who is assessing their own support needs, a number of research reports are cited from the UK indicating that there is a need for caution in proceeding with self assessment, and in particular, that there is already evidence to suggest systematic distortions in self assessment depending on the type of disability and demographic characteristics. It is stated, in our view correctly, that self assessment remains largely untested.

We would make the following additional comments. Since self assessment would have benefits in terms of dignity and independence for the person with a disability who is assessing their own needs, and since it would save some of the time and expense of professional assessors, it is a way of assessment that should be investigated. **The accuracy of self assessment might be enhanced by using a computerised system that guides and checks information entered into the assessment. However, a computerised system of this kind would only be practical if it was very user friendly and could be easily accessed, e.g. in a web based system.**

We would argue that because of the cautions in existing research reports, self assessment should initially be carried out with professional assistance. This might proceed by starting with individuals with disabilities who would seem most likely to be able to accurately assess their own support needs, e.g. the professional person in a wheel chair. Research of this kind would be directed to identifying criteria for self assessment. **Even for those types of individuals who might qualify for self assessment, we believe that it will still be necessary for a committee of some kind to check and approve the suitability of the support needs indicated.** It might be found that with self assessments, certain biases for different disabilities have to be taken into account.

Another important caution in self assessment is that the capacity to self assess might change; for example, a new or deteriorating medical condition might reduce the person's capacity to self assess accurately. This capacity might also fluctuate in a person who has a psychiatric condition with which they cope very well most of the time but need periodic stays in a closed clinic situation. Thus, self assessment might need to be accompanied by regular monitoring and with on-call support from a professional who is skilled in providing this kind of support.

The same issues occur not just with self assessment but also with self-administered funding where on-call support and occasional intervention might be needed, perhaps

with this intervention eventually having to become permanent in some cases where there is a deteriorating disability condition.

The same issues might also apply to family assessment and family administered funding. There might be families, e.g. with well educated professional parents, who are quite capable of not only providing an accurate assessment of the support needs of their son or daughter but also of administering that funding as competently as a disability professional. Nevertheless, **on call support or information, periodic intervention and eventual permanent intervention might all be needed if and when the family is, for whatever reason, unable to cope temporarily (e.g. due to divorce) or permanently (e.g. due to increasing ill health as a result of ageing).**

Keeping the person with the disability front and centre

The argument that the person with a disability should be actively involved in their assessment and particularly in identifying and articulating outcomes they wish to achieve, can be supported with a number of additional points. **First, it is important to distinguish between what the person says they want to achieve and what a family member or informal carer might say the person wants to achieve.** This is an instance in which it might be important to interview the person and family member or informal carer separately. **A second point is that involvement of the person is particularly important in motivating them to achieve any goals that are set as part of program planning or intervention.** Goals are much more likely to be achieved if they are important personally to the individual concerned and if the person feels ownership of the goals. Hence the importance of distinguishing between what the person with a disability says they want and what a family member or informal carer might be prepared to support. This also applies to the strategies and services used to achieve those goals. If the person or the family member or informal carer disapproves of the program or feels that they have not been sufficiently involved in its design, either or both might find reasons for not cooperating with what, from a professional point of view, is a well-designed and appropriately resourced program or intervention.

It is also important to ensure that assessments contain feedback from the person with a disability about the current support services that they receive. Information about the person with a disability's degree of satisfaction with their services could have important implications for the retention of particular services that are very important for their independence and quality of life, and for the modification and/or substitution of services that they feel are not contributing to their quality of life.

Also important in this process is the training of the professional person or persons involved in these decisions. Careful consideration needs to be given to the person's wishes and there may need to be some creative thinking in working out how they can be achieved. At a conference in the US attended by one of the D-START team the example was given of a person with a moderate intellectual disability who, when asked what he wanted to do, answered that he wanted to be an airline pilot. A person untrained in this area of expertise might reasonably conclude that this is a completely unrealistic goal and that therefore some other appropriate goal should be chosen by the family or the professional person or the person involved. However, the speaker in this example said that instead of doing this, the professional person involved went on to ask what it was about being an airline pilot that the

individual in question liked. He replied that it was because he really liked planes. When it was suggested that he might be trained as a cleaner in an airport where he would be able to see planes come and go all the time, he enthusiastically agreed. This example nicely illustrates how it may be possible for an appropriately trained professional to involve a person with a disability in achieving outcomes that they might not have originally considered or thought possible, but which could contribute very significantly to their quality of life.

Maintaining professional integrity

In this section it is argued that for objectivity and fairness, the assessment should be carried out by a suitably trained professional who is independent of the person being assessed. This is to reduce what is referred to as “sympathetic bracket creep”. While professional independence is obviously very important, it also important that those providing the relevant support needs information know the person very well and this is very likely in many cases to involve some sympathy for the person and their condition. **It is therefore important that the actual assessment process be as objective as possible, with checks on accuracy and a final support level and funding that is determined by a predetermined weighting of relevant information based on expert opinion.**

5.8 WHEN SHOULD ASSESSMENTS OCCUR?

In this section, reference is made to reassessments that might occur at particular developmental levels and life stage changes. The implication here is that an assessment instrument should ideally be a whole of life instrument so that it would be suitable for a person’s developmental stage and so that assessments could be scheduled for particular life stages. **An important point that we would make here is that early intervention with the most appropriate support might assist in a lower need for support at later stages in the person’s life thus increasing their overall independence and lowering the cost of providing long term support. Another important point is that to be most effective, assessing the need for support should occur prior to the developmental life stage so the person can be prepared and assisted through the transition rather than wait, as is often the case, until a transition crisis occurs, after which much more support may be required and for a longer period of time.**

Shifting the emphasis towards wellness

In this section the point is made that a “major criticism of the current system is that it is not forward looking” and that it “fails to systematically explore ‘what might be’”. **We would add to this that a major danger of support needs assessment systems is that they may end up having the same problems that afflicted the use of adaptive behaviour scales and which caused the change in the concept of disability from one which focuses on deficits (as measured by adaptive and maladaptive behaviour scales) to one of support to access the community.** Adaptive behaviour scales were originally designed to identify areas of adaptive behaviour that would benefit from training and / or areas of maladaptive behaviour that could benefit from behaviour management. In this respect they were seen as more practically useful than intelligence tests where the implication was that relatively little could be done to

improve a person's intelligence. However, adaptive behaviour scales came to be criticised for classifying people in terms of their relative lack of adaptive behaviours and presence of maladaptive behaviours and using these measures to place people in various grades of institutions, with the implication that lack of adaptive behaviours or the presence of maladaptive behaviours were more or less permanent and would prevent a person from being able to engage in independent behaviours in the community. The risk with measures of support needs is that they may also come to be considered as indicating only the level of support that is needed to maintain the person in their present situation rather than as a means to make them more independent. Thus, instead of using adaptive behaviours to assign people to different levels of institutions, measures of support needs may come to be used to establish a life-long level of support to keep them where they are. **It is therefore important for support needs assessments to provide information that can be used for service interventions such as training or behaviour management that can, in collaboration with the person with a disability, increase their independence and quality of life.**

The issue of a transition model mentioned in this section raises the question of possible discontinuities between services that provide support for an individual at different stages over time, e.g. during rehabilitation from a head injury by a more medically oriented team in a hospital, to support provided by social workers when the person is transferred to the community. If the assessment systems and associated individual program plans in these cases are quite different, then gains made at one stage of the process may be lost at the next because training, behaviour management or a particular service is not continued or progressively modified to maintain what it has achieved. It may also be that in such cases, services earlier in the process receive little or no feedback about their usefulness from subsequent services that take over but have quite different assessment systems that do not allow ready transfer of their progress reports to the earlier service in a form that they can understand or that is relevant to their service. When one of the D-START team members asked a rehabilitation professional in the UK about what they knew concerning the progress of patients after they had left a head injury rehabilitation program lasting six months, the answer was that they had no idea. Once the person left their head injury related service and was transferred to community care, they had no further contact with the person, nor did they receive any information about their progress and whether what they had achieved in their program had been maintained, progressed even further or lost. An important element in any disability support system is that it should be possible to track a person's level of independence and need for support over time and services in consistent terms. **A computerised system would facilitate the transfer of such information from one agency to another so that a person's progress over time could be assessed in an agency and feedback given by it to an earlier agency on the effectiveness of its programs and interventions.** The same kind of issue, of course, occurs in other developmental sequences such as in education where there can be a lack of feedback from high schools to primary schools and from universities to high schools.

5.9 SHOULD CARERS HAVE THEIR OWN ASSESSMENT?

The issue of a separate carer assessment can be considered in two ways; firstly, whether there should be a separate type of assessment for a carer, and secondly,

whether the carer should be assessed without the person they are caring for being present. **We would argue that it would be preferable to incorporate carer support issues into the contextual factors of the assessment of the person with a disability.** A completely separate carer assessment form runs the risk of indentifying carer support needs that may be present but not directly relevant to the support needs of the person with a disability. Thus, a mother might benefit from support for a medical condition or to deal with the behaviour of another child but this support may not necessarily have any benefits for the person with a disability. While a separate assessment could be useful to provide a more detailed account of how the informal carer could be assisted in order to benefit the person with a disability that they are caring for, there is also a danger of finding that almost everyone would benefit from some kind of support.

With respect to whether the person with a disability should be present when the carer's need for support is considered, there are advantages and disadvantages. The disadvantages have been noted in this section, particularly, the carer not being prepared to say some things in front of the person with a disability. However, in some cases, there may be advantages in resolving different viewpoints about support needs and in gaining commitment to goals and strategies from both parties. It is also possible to do both in some cases, so that some issues that arise when both are present might be dealt with later with each separately or both might be seen separately first and then together to discuss differences and obtain agreement about the best way to proceed. **We believe that professionals should be trained to start by privately offering separate assessments and then negotiate with appropriate sensitivity for whichever option or combination of options they believe will work best. They should also be trained to be able to discontinue a combined assessment, again with appropriate sensitivity, if they consider that continuation with both parties present would not be in their best interests. This particular issue highlights the need for appropriate training of those conducting assessments.**

5.10 HOW ASSESSMENT MIGHT WORK IN PRACTICE

This section sets out a rational procedure for organising, conducting and agreeing on a support needs assessment package. It is noted that the rollout of the public information campaign prior to the commencement of the scheme will take place over five years. **We agree with this time line and would add that the same order of time would be required for the development and evaluation of an accurate, reliable, valid, user friendly and appropriately comprehensive support needs assessment system with associated reports, support and funding levels, and individual program plans for different types, levels and combinations of disabilities in different contextual situations.**

As far as the procedure goes, it sets out a very logical process with appropriate options for the resolution of disagreements over the assessment and associated support and funding packages. **We would add that this process might need to be flexible to suit the wide range of people and their carers, particularly those with different levels of abilities, and / or from different cultural backgrounds and / or in different contextual circumstances.** Thus, for example, more emphasis may need to be placed on some parts of the process for some people. **The procedure also might**

need to proceed at different speeds depending on the relative urgency of providing support and the associated risks of delaying intervention.

5.11 DILIGENT USE OF THE ASSESSMENT TOOL

The need expressed in this section for an assessment that in use is neither too generous nor too harsh and does not tend to one of these extremes over time **highlights the need for an assessment that is as objective as possible and where there are built in safeguards against gaming and inaccuracy Built in checking would not, however, avoid the need for periodic independent evaluations of the supports and funding allocated against agreed bench marks and in comparison to those applied by other agencies.**

5.12 THE TRANSITION TO A FULLY-FLEDGED ASSESSMENT TOOLBOX

We agree with the point made in this section that is quoted from Madden et al that “an exact answer to the wrong question is inferior to an approximate answer to the right question” and that it is better to start by “identifying and evaluating nominated tools against criteria” and that existing tools that met most or enough of those criteria should be used while a better tool or tools are being developed. **We agree that the Government “should not delay in the implementation of the NDIS in the absence of ‘perfect’ tools”, but would add that the Government should also not delay in funding the development of new tools or existing tools that have the potential to provide the kind of reliable, valid, user friendly and appropriately comprehensive assessment that is needed to achieve the outcomes of greater independence and quality of life in the most cost effective way.** Much of what has been discussed in this chapter of the report has highlighted the extensive and long term research from dedicated teams of assessment developers and evaluators that will be needed to achieve the assessment instruments required. These will not result from simple modifications to existing instruments (in Australia or overseas) or to the development of new instruments that have face validity but not the extensive testing with the wide range of disabilities and environments that need to be assessed and funded by the NDIS. Waiting for someone to develop such an instrument without providing funding for it is likely to mean that this development will occur, if at all, over too long a period of time and with inadequacies that will compromise its usefulness. Waiting for overseas researchers to develop such an instrument, even if it was to occur relatively quickly, could result in an instrument that is not applicable to the needs of the NDIS or useful to Australian disability services. The Government will, accordingly, need to commit itself to provide considerable funding over a number of years for more than one research team to develop or further develop a suitable instrument. **We would not recommend that the Government itself try to put together a team of researchers but instead invite experienced research teams who have worked collaboratively with disability services over a long period to apply for such funds.**

It should be pointed out that any research team will need to have access to people with a wide range of different types, levels and combinations of disabilities in different environmental contexts and with agencies that provide current services. Cold calling of such professionals and agencies on an “as needs” basis is likely to result in limited

access to less than the required numbers and types of people with disabilities, in long delays in obtaining such access and the unexpected termination of access due to the agency being busy with other issues that it sees as more immediately important.

RECOMMENDATIONS

We would agree with all the draft recommendations **but would add the above point concerning the need for the Government to provide funding over a number of years to achieve an assessment system or systems suited to the requirements of the NDIS in Australia. We would also argue that such funding should not necessarily be restricted to one team, providing that teams are given a set of basic guidelines for what is required in terms of an assessment system. More than one approach may be needed to finally produce an optimal system.**

Finally, we believe that it will be necessary for some funding to continue indefinitely in order to ensure that any assessment system, particularly if it is computerised, continues to operate effectively (including corrections, improvements and updates to accommodate new technologies such as Ipads). Accordingly, some consideration should be given to long term sources of funding to sustain such continuing development and research. One particular possibility would be to ask such teams to eventually consider at least partial funding from the commercialisation of such systems, which might be sold or licensed by users nationally and overseas.