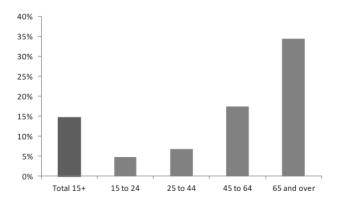


Disability in BC

According to Statistics Canada's Canadian Survey on Disability (CSD) for 2012, 546,760 people, or 14.8 percent of British Columbians aged 15 and older, reported being limited in their daily activities because of a disability.

The prevalence of disability increases with age. The prevalence of disability for youth (15 to 24) was 4.8 percent, increasing to 17.5 percent for those aged 45 to 65. The prevalence among seniors (65+) was 34.5 percent. Women (14.9%) have a higher prevalence of disability than men (12.5%). Women had higher prevalence than men regardless of age. The prevalence of disability among women age 15+ was 16 percent compared to 13.5 percent for men.

Prevalence of Disability by Age (%) British Columbia (2012)



The 10 disability types captured within the CSD are seeing, hearing, mobility, flexibility, dexterity, pain, learning, developmental, mental/psychological, and memory. Persons were identified as having a disability if they had difficulty performing tasks as a result of a long-term condition or health-related problem and experienced a limitation in their daily activities.

Of those reporting a disability, the most commonly reported disabilities were pain (69.5 percent), flexibility (49.6 percent) and mobility (48.6 percent). British Columbians reported different types of disability depending on their age. Those aged 15 to 24 with a disability most commonly reported learning disabilities (49.2%) and mental/psychological disabilities

Type of Disability of Those Reporting a Disability (%)

British Columbia (2012)

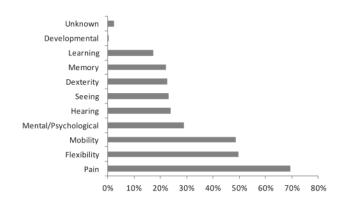
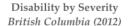
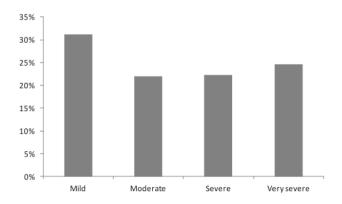


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(47.4 percent). Among those aged 24 to 44, the most common types of disability were pain (72 percent) and mental health (47 percent). For those age 45 and over, the most commonly reported disabilities were pain and flexibility.

A severity score, which was developed for the survey, takes into account the number of disability types, the intensity of difficulties and the frequency of activity limitations. Using this score, persons with disabilities were classified into four severity levels: mild, moderate, severe and very severe. In 2012, 24.6 percent of persons with disabilities were classified as very severe; 22.2 percent severe; 22 percent moderate; and 31.2 percent mild. Severity varied by age with 44.3 percent of youth reporting a severe or very severe disability. This rises to about 47 percent for those aged 45 and over. Almost 43 percent of those aged 24 to 44 reported a severe or very severe disability.





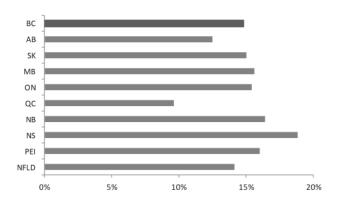
Inter-jurisdictional Comparison

In 2012, British Columbia had the fourth lowest prevalence of disability at 14.8 percent, above the national average of 13.7 percent. Only Newfoundland and Labrador (14.1 percent), Alberta (12.5 percent) and Quebec (9.6 percent) had a lower prevalence of disability. The highest prevalence of disability was in Nova Scotia (18.8 percent).

New Brunswick, Quebec and Ontario had the largest proportion of persons indicating a disability reporting a severe or very severe disability (over 50 percent). The lowest proportion of respondents indicating a severe/very severe disability was in Prince Edward Island (40 percent) followed by Alberta and

Saskatchewan (tied at 42.4 percent). In comparison, the proportion of persons indicating a disability that responded having a severe or very severe disability was 46.8 percent in BC.

Prevalence of Disability by Province (%) (2012)



Words of Caution

The Canadian Survey on Disability (CSD) is a different survey from the previous Participation and Activities Limitation Surveys (PALS) and therefore the results from the CSD cannot be compared to the results from the PALS. Under PALS, a person could be considered as a person with a disability if they had an impairment or condition that made it difficult to accomplishment certain tasks. Under the CSD, these difficulties or impairments must interfere with their daily activities for the individual to be considered to have a disability.

Those with sensory and physical disabilities were impacted the most by this change, as PALS identified these disabilities solely on the basis of an indication of some difficulty, not limiting daily activities. Another difference is in how severity is determined. M any of those classified as having a mild or moderate disability under the PALS definition will not be classified as a person with a disability under the CSD. At the same time, it appears that the definition of very severe has been changed. For example, there was a decline in the number of persons with disabilities classified as having a mild disability between 2006 (PALS) and 2012 (CSD), while about 55,000 more people were classified as having a very severe disability, an increase of 69 percent.

Disability in BC December 2013

					Age		
		15+	15-64	15-24	25-44	45-64	65+
Canada*	Persons with Disabilities	3,775,910	2,338,240	195,720	598,680	1,543,840	1,437,670
	Population	27,516,200	23,187,350	4,462,850	9,159,860	9,564,640	4,328,850
	Prevalence	13.7	10.1	4.4	6.5	16.1	33.2
Newfoundland and	Persons with Disabilities	59,300	40,060	3,090	9,720	27,250	19,240
Labrador	Population	420,970	350,100	61,070	126,290	162,730	70,880
	Prevalence	14.1	11.4	5.1	7.7	16.7	27.1
Prince Edward Island	Persons with Disabilities	18,840	11,500	870	2,850	7,780	7,340
	Population	117,440	97,620	20,160	34,220	43,250	19,830
	Prevalence	16.0	11.8	4.3	8.3	18.0	37.0
Nova Scotia	Persons with Disabilities	143,760	89,410	6,990	20,920	61,500	54,350
	Population	765,100	628,310	120,430	223,880	284,000	136,790
	Prevalence	18.8	14.2	5.8	9.3	21.7	39.7
New Brunswick	Persons with Disabilities	99,450	61,650	3,600	14,890	43,160	37,800
	Population	606,820	499,670	90,990	181,130	227,550	107,150
	Prevalence	16.4	12.3	4.0	8.2	19.0	35.3
Quebec	Persons with Disabilities	616,740	361,250	29,850	89,650	241,750	255,490
	Population	6,436,930	5,355,580	975,150	2,081,850	2,298,590	1,081,350
	Prevalence	9.6	6.7	3.1	4.3	10.5	23.6
Ontario	Persons with Disabilities	1,651,620	1,035,090	87,700	277,390	670,000	616,530
	Population	10,727,900	9,065,910	1,782,160	3,600,580	3,683,180	1,661,990
	Prevalence	15.4	11.4	4.9	7.7	18.2	37.1
Manitoba	Persons with Disabilities	145,270	87,120	6,770	22,900	57,450	58,150
	Population	929,650	782,650	163,470	301,540	317,640	147,010
	Prevalence	15.6	11.1	4.1	7.6	18.1	39.6
Saskatchewan	Persons with Disabilities	116,640	68,790	5,570	16,290	46,930	47,850
	Population	779,150	649,350	136,230	248,890	264,230	129,800
	Prevalence	15.0	10.6	4.1	6.5	17.8	36.9
Alberta	Persons with Disabilities	369,190	242,540	22,710	62,280	157,550	126,650
	Population	2,945,140	2,590,550	503,510	1,125,350	961,690	354,600
	Prevalence	12.5	9.4	4.5	5.5	16.4	35.7
British Columbia	Persons with Disabilities	546,760	334,800	28,190	80,160	226,450	211,960
	Population	3,703,010	3,089,450	591,710	1,203,340	1,294,400	613,560
	Prevalence	14.8	10.8	4.8	6.7	17.5	34.5

*Includes Territories

Data source: Statistics Canada, Canadian Survey on Disability (2012).

CONTACT INFORMATION

Research Branch

Ministry of Social Development and Social Innovation

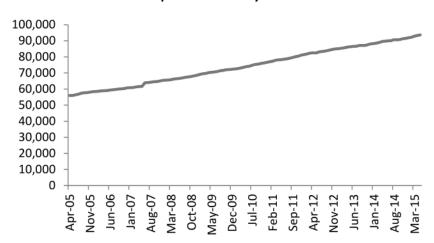
WHO WE ARE

The Research Branch provides highend analytics and modeling services involving advanced reporting, predictive and statistical modeling, forecasting and development of in-house analytical tools.

Disability in BC December 2013

Persons with Disabilities Caseload 2014/15 Monthly Averages

Persons with Disabilities Caseload April 2005 to May 2015

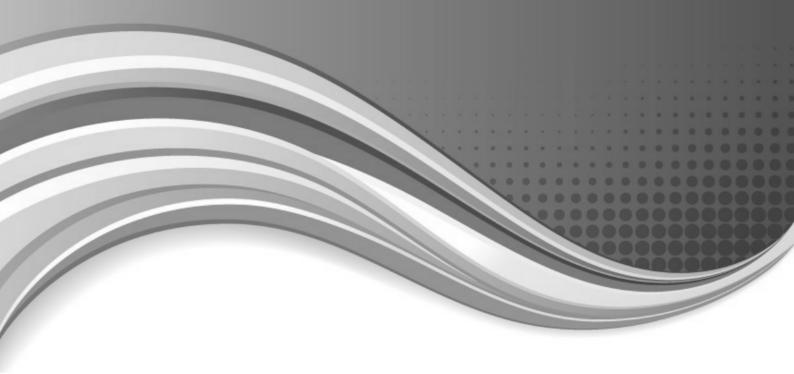


Caseload Dynamics	Cases	% of PWD
Flows in		
Starting Cases ¹	791	
New ²	243	
Cyclers ³	548	
Transfers into PWD from:		
Expected-to-Work	10	
Expected-to-Work Medical Condition	78	
No Employment Obligations	405	
Persons with Persistent Multiple Barriers	78	
Total transfers in	571	
Flows Out		
Stopping Cases	1,025	
Transfers out of PWD		
Expected-to-Work	4	
Expected-to-Work Medical Condition	2	
No Employment Obligations	9	
Persons with Persistent Multiple Barriers	1	
Total transfers out	17	
Long-Term Cases ⁴	79,766	87.7%

Family Composition	Cases	%
Single Men	45,641	50.2%
Single Women	34,326	37.7%
Couples	3,368	3.7%
Two-Parent	1,936	2.1%
One-Parent	5,674	6.2%
Total	90,944	
Age	Cases	%
<19	594	0.7%
19 - 24	8,198	9.0%
25 - 29	7,250	8.0%
30 - 34	7,709	8.5%
35 - 39	7,732	8.5%
40 - 44	8,992	9.9%
45 - 49	11,234	12.4%
50 - 54	14,459	15.9%
55 - 59	13,780	15.2%
60 - 64	10,583	11.6%
65+	413	0.5%
Total	90,944	
Region	Cases	%
Vancouver Island	19,814	21.8%
Vancouver Coastal	20,525	22.6%
Fraser	28,149	31.0%
Interior	17,904	19.7%
North	4,553	5.0%
Total	90,944	
Characteristic	Cases	% of PWD
Immigrant	2,410	2.6%
Economic Class	782	0.9%
Family Class	362	0.4%
Refugee	1,266	1.4%
Earned Income	14,684	16.1%
Average Income Declared ⁵	\$516	

Notes:

- 1) A starting case is defined as a case in receipt of income assistance in the current month but not on income assistance in the previous month.
- 2) A new starting case is defined as a case in receipt of income assistance in the current month but not on income assistance within the previous 12 months.
- 3) A cycler is a case in receipt of income assistance in the current month, not on income assistance in the previous month but has been on income assistance at some point in the preceding 12 months.
- 4) Long-term case is defined as a case that has been on income assistance for a minimum of 24 months out of the previous 30 months.
- 5) Average income declared is average declared earnings among those who declare.



Measuring Outcomes for People With Disability





October 2012

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About National Disability Services

National Disability Services is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes over 780 non-government organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

This Paper is produced by NDS's National Policy Research Unit. NDS gratefully acknowledges the support of the NSW Government in establishing the National Policy Research Unit.

This policy paper has been prepared for the Australian Government, represented by the Department of Families, Housing, Community Services and Indigenous Affairs. The views expressed in this publication are those of National Disability Services and do not necessarily represent the views of the Australian Government.

Measuring Outcomes for People With Disability

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Introduction

This paper aims to investigate how disability service providers can best measure outcomes for the people with disability they assist. It is intended to help identify options for developing current practice and determine NDS members' need for tools, resources and other forms of support. The paper's evidentiary base is partly informed by a NDS member survey conducted in April 2012 and the findings from this will be used to inform NDS's future work in this area. Services are strongly encouraged to develop the capacity to track outcomes for people they support. Demonstrating positive outcomes will be a key attribute for organisations operating under a National Disability Insurance Scheme.

The revised National Quality Framework for Disability Services and their State based quality standards frameworks place significant emphasis on individual outcomes. Understanding the impact of different services and supports is key to developing a reliable evidence base. Funding bodies and people with disability, their families and carers exercising greater choice and control will place greater emphasis on the achievement of individual outcomes as part of enhanced accountability frameworks implemented to ensure competition and responsiveness to consumer preferences.

The paper also provides resources that service providers may find useful in terms of reviewing or developing an organisational approach to outcomes measurement.

The key issue raised by this discussion is whether there is value in developing a tool or set of tools that assists not for profit disability service providers to capture and reflect outcomes for consumers. The central conclusion of this paper is that there is both merit and support for the development of an industry endorsed set of tools.

What are outcomes?

Outcomes are the results or changes that result from an activity. For disability services a fundamental outcome is the results achieved by people using their services. The impact on service users' quality of life is identified as the ultimate outcome measure of disability support services. As direct and indirect beneficiaries of disability services, the outcomes experienced by families and carers also reflect the results of service delivery.

However, it has been suggested by some disability service providers that the term 'Outcomes' is not one that has meaning to people with disability and should be changed to something like 'Individual Goals'. The notion of services supporting people to achieve their individual goals is consistent with the proposed content of the National Disability Standards. For the purposes of this paper, Outcome(s) is the preferred descriptor.

Why are outcomes important?

Funding bodies and service providers have traditionally monitored service delivery by measuring inputs (eg funds, staffing) and outputs (eg hours of service and number of clients). The expectation has been that if certain inputs are provided and outputs delivered within the relevant standards framework, then desired outcomes will be achieved for people with disability.

In Australia and internationally, attention is increasingly being placed on whether the services and programs actually provided achieve results for service users and whether government funding delivers results for the community. The need for service providers to focus on individual outcomes is due to changes in funding and accountability arrangements and an increasingly emphasis on choice and control by consumers. Facilitated by individualised funding models and person centred approaches, people with disability will increasingly be enabled to choose their preferred provider, most likely those that track and respond to service user preferences by measuring and demonstrating individual outcomes achieved. Other providers with a less compelling story are likely to find their future viability challenged.

What attention is being paid to outcomes in the Disability Sector?

The increasing focus on outcomes is reflected in the National Disability Agreement (NDA), National Disability Service Standards and Quality Framework, and the proposed National Disability Insurance Scheme.

National Disability Agreement (NDA)

The NDA identifies three societal outcomes to be achieved through the Agreement. These are:

- People with disability achieve economic participation and social inclusion;
- People with disability enjoy choice, wellbeing and the opportunity to live as independently as possible; and
- Families and carers are well supported.

The National Disability Agreement acknowledges the difficulty in measuring achievement of these outcomes and includes a commitment from all governments to formulate better outcome measures and associated data collection processes over time.

National Disability Service Standards

New National Disability Service Standards are currently under development as part of the National Quality Framework for Disability Services in Australia. The current Standards remain unchanged since their adoption in 1993 and are regarded as outmoded. One of the key goals of the project is that:

The revised National Standards for Disability Services should have a greater capacity to provide and measure real and meaningful outcomes for service users – both people with disabilities and their families and carers.

The <u>revised standards</u> have since been released for public comment in draft form. There is a specific standard entitled "Individual Outcomes":

Outcome: I reach my goals with the help of my service

Service Standard: Services and supports are assessed, planned, delivered and reviewed to enable the achievement of individual life goals.

The standard includes the practice indicators:

Services work with an individual to identify their needs, strengths, life goals and plans, delivers and regularly reviews services or supports to meet them.

Service planning, provision and review is collaboratively undertaken with an individual and their family, carer or advocate

Service planning and delivery is responsive to diversity in individuals

Within the Standard, NDS has suggested changing the term 'life goals' so that it does not exclude disability employment services. Suggested alternatives are 'life or work goals' or just 'goals'.

The Standards have been reduced from the existing set of eight (eleven for employment services) to six. The inclusion of a specific Standard on outcomes will effectively ensure that all service providers adopt outcomes measurement policies and procedures.

The Proposed National Disability Insurance Scheme (NDIS)

The Productivity Commission Inquiry Report (2011) *Disability Care and Support* emphasises the achievement of consumer outcomes. The report also identifies an effective evidence base as critical to ensuring the NDIS's financial sustainability, the provision of cost effective services and interventions and good service provider performance. The Report states:

Consumer outcomes represent the most direct form of observing service quality, and should be a key feature of an NDIS quality assurance framework.¹

To inform the evidence base of the NDIS, the Report recommends the systematic collection of data on outcomes of particular services or interventions for people with disabilities. This data would be monitored and evaluated, with a view to analysing the efficacy of the various kinds of disability supports. Specific outcome areas identified by the Productivity Commission include: employment, education, social participation, capacity for self-care and the measures that contributed to those outcomes.²

The Steering Committee for the Review of Government Service Provision (2011) also has recommended that the current framework for disability service quality data be supplemented by national measures for:

- An indicator on quality of life;
- More comprehensive social and community participation data; and
- Service user and carer satisfaction with service quality.³

What should outcomes measure?

Outcomes monitored by disability service providers are likely to include:

- Individual outcomes for people with disability receiving support
- Family and carer outcomes (where appropriate);
- Corporate outcomes;
- Financial outcomes:
- Human resources outcomes;
- Risk management outcomes; and
- Service provision outcomes sought by funding bodies.

This paper focuses primarily on individual outcomes for people with disability. However, the paper also considers service provider outcomes, as these are thought to support their primary focus and are a matter of importance for funding bodies. The outcomes identified above include those sought from service providers by funding bodies.

The challenge of outcomes

A key focus of the National Disability Service Standards is to ensure that "services and supports are assessed, planned, delivered and reviewed to enable the achievement of individual life goals"⁴. The measurement of social results or impact at an individual level may be an uncontentious concept, but it is methodologically challenging.

Challenges presented by outcomes include:

- Outcomes may not be easily measured by some predefined measurement tool.
- There is a risk that service providers could be held accountable for (poor) outcomes that are beyond their control.
- It may not be clear what level of achievement of an outcome is acceptable or desirable and hence arbitrary targets or indicators and benchmarking may be required.
- There can be a tendency to measure outcomes that are easy to measure at the expense of other more important ones.
- The same outcome can be measured in different ways based on different definitions or tools that produce different results.
- Peoples' perspective about whether an outcome has been achieved and the extent to which it has been achieved can differ.
- Measurement of outcomes may be undertaken before sufficient time has elapsed for change to be observed.
- Outcome tools/instruments may not be suited for all individuals, e.g. people with severe intellectual disability, other cognitive impairment, severe communication limitations or children.
- The introduction of outcomes measurement may require a significant organisational culture shift.

Criteria for selecting outcomes measurement tools/instruments

Ideally, tools used to measure outcomes will be reliable, valid, sensitive enough to reflect changes that result from disability provider services, practical to use, affordable, efficient to administer and applicable for disability service users. The ability of outcome measurement tools to meet each of these criteria varies.

Table 1: Criteria for outcomes measurement tools

st	Reliable	 Ability to produce the same result on a retest. Ability of different assessors using the same tool to obtain the same result.
Robust	Valid	Ability to measure what the tool is intended to measure.
Ř	Sensitive	The extent that the outcome measure is able to be influenced by disability services and reflect changes that may occur as a result of the service.
Practical	Affordable and Efficient	 Simple to administer and score. Feasible to use given: purchasing cost; time to administer; staff training; and time to analyse results.
<u>a</u>	Applicable	 Suitable for use by the intended user group. Enables benchmarking of results.

An analysis comparing a sample of tools available for measuring quality of life outcomes of people with disability and their families against these criteria is presented in Attachment A.

Quality of life

"Quality of Life" as a concept is central to individual outcomes. Leading commentators on measuring personal outcomes advocate that quality of life should be used as the 'yardstick of service quality'. Quality of life measures are increasingly being used to plan, deliver and evaluate services for people with disability, reflecting a growing appreciation of organising services to meet individuals' outcomes as the central focus of service delivery.

However, quality of life is a complex construct. In preparing this paper NDS found over 44 definitions and over 800 tools for measuring "quality of life" (including some developed for people with intellectual or other cognitive disability and some for use by families). Common themes, however are clear, in that most quality of life conceptions incorporate features of wellbeing, positive social involvement, "normalisation" and opportunities to achieve personal potential.⁶

A review of quality of life instruments undertaken for the Victorian Department of Human Services (2002) identified 35 possible instruments for "systematic and regular measurement of quality of life of people in the disability service system that could support assessing service outcomes, service monitoring and planning, client planning and evaluation". The study concluded no one tool was available to meet all the desired applications. The tools identified as best for different purposes are shown in the table below. Further technical analysis of the general issues and challenges raised by the use of Quality of Life Tools are examined in Appendix A below.

Table 2: Summary of best available resources.

Potential Assessment Purpose	Tools
Whole system client outcomes performance monitoring	Core Indicators Project
Benchmarking client quality of life to whole population norms	Comprehensive quality of life scale (Cummins)— now refined as the Personal Wellbeing Index
Client outcome focused accreditation	Personal Outcome Measure (POM)
Individual quality of life outcome monitoring by disability services Individual person-centred planning aid Service quality improvement	University of Toronto Quality of Life Profile for People with Developmental Disability

Details on these and other tools are included in the Attachment A. Furthermore, Attachment B includes a comparison of domains covered by the various instruments.

Issues relating to people with severe intellectual or cognitive disability

There are a number of quality of life instruments for people with intellectual and or other cognitive disabilities. However, these tools still require a level of cognitive ability that is beyond the capacity of some people with disability using the disability service system, and supporting people with a cognitive impairment to respond introduces additional complexities relating to agency and use of proxies.

Quality of life tools tend to be based on domains tested across populations. However, for many individuals there is no way to really know if the issues being addressed are of importance to people with severe intellectual disability or other cognitive impairment.

Some quality of life tools specifically designed for people with intellectual disability incorporate pre-testing to ensure competence in responding to questions. While this is desirable it increases testing time.

The use of a proxy or third party response is considered more reliable for reporting objective measurements than subjective feelings. While some quality of life tools can be used with proxies, international consensus reached by a group of expert members of the Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities advise that proxies' responses are not valid as an indication of another person's perception of his or her life. The group recommends observation as a preferable approach. The group accept that measurement of a person's quality of life from another person's perspective could be useful in some instances where people are not able to communicate or make life decisions but the results should not be treated as the perception of the person with disability.^{8, 9} Some suggestions from the literature for measuring outcomes for people with severe intellectual or other cognitive disability include:

- Ensuring the quality of life tool includes a screening for appropriateness;
- Not relying on staff assessments;
- Including a process of building engagement and trust over time.

Use of outcomes measures in FaHCSIA funded disability programs

FaHCSIA funds several disability specific programs. These include Australian Disability Enterprises (ADEs), Advocacy services, Children's services and various sensory and information services. As a Government Department and funding body, FaHCSIA has traditionally tended to measure outputs, as opposed to outcomes, for example the Minimum Data Set (MDS). For the new FaHCSIA ADE funding agreement from 2012 – 2015, there have been eight new Activity Performance Indicators (APIs) introduced, across a range of ADE employment and support activities.

Following a process of consultation with NDS and the ADE sector FaHCSIA has recently developed a set of new Activity Performance Indicators in an effort to encourage improved outcomes for supported employees. The indicators will be included in the new three year ADE funding agreement and aim to ensure a higher standard of service delivery in the following areas; wages, working hours and employee skills development.

The specific APIs and their targets are as follows:

- Percentage of supported employees across all outlets working full-time (at least 35 hours per week) – target 30 per cent
- Average number of hours worked per week by your supported employees across all your outlets – target 26 hours per week by the Activity end date
- Percentage of supported employees across all outlets where their annual average wage has increased by more than the percentage increase in Average Weekly Ordinary Time Earnings (AWOTE), or who already earn the national minimum wage – target 90 per cent
- Percentage of supported employees across all outlets exiting to open employment – target 5 per cent by the Activity end date
- DEA funding as a percentage of total revenue of the organisation target 40 per cent or less by the Activity end date
- Percentage of supported employees across all outlets with AQF qualifications target 50 per cent by the Activity end date

- Percentage of support staff with Certificate III in Disability Services, or a recognised equivalent or higher qualification – target 50 per cent by the Activity end date
- Percentage of supported employees who have training identified in their
 Employee Assistance Plan and have also achieved the specified training. target
 100 per cent

NDS and the sector have expressed concerns that the proposed indicators will place pressure on ADEs to cease employing people with disability whose levels of required support may lower the likelihood of achieving the targets. Compliance with the indicators may lead to ADEs acting against their Mission and drive perverse outcomes and unintended consequences.

While there is clearly merit in measuring and tracking most of the new APIs, ADEs should be provided scope to demonstrate that inability to meet the targets may be due to the higher supports required by particular employees, resulting in them working lower than average hours and receiving lower than average wages.

Government-determined policy settings are key influences on the performance of ADEs. While some of these policy settings are enabling influences, others are adverse. For example, current policies which prevent the joint funding of an ADE and a Disability Employment Service for the same person deter supported employees from trying open employment. Similarly, a lack of appropriate program options prevents many ageing supported employees from retiring. These were issues clearly identified in the 'Vision for Sustainable Supported Employment' report to government. To judge the performance of ADEs before these policy issues have been rectified is premature.

The new Disability Service Standard on Outcomes could be adopted as the key measure of employee satisfaction, with possible minor amendments to focus on the achievement of an individual's specific employment goals:

Outcome: I reach my (employment) goals with the help of my service

Service Standard: Services and supports are assessed, planned, delivered and reviewed to enable the achievement of individual (employment) life goals.

This Standard could also be used as a measure of the ability of ADEs to achieve positive, life experience enhancing results for supported employees.

The monitoring of outcomes achieved under this Standard will continue to take place under the Quality Assurance system for ADEs and Disability Employment Services (DES).

For the National Disability Advocacy Program (NDAP) current indicators cover the number of people with disability assisted and the result(s) of the assistance provided. A more detailed set of indicators is currently being developed in consultation with the sector.

User Outcomes Based Quality Monitoring

A range of quality of life tools are currently being used by service providers' across Australia to monitor their outcomes. These approaches can utilise quality of life instruments that have been tested for reliability and validity. Responses (evidence) are gathered in a rigorous and consistent manner from the person receiving services or their proxy. In some methodologies the individual's responses are supported by information from other sources such as document reviews.

Other approaches include quality frameworks that incorporate standards relating to service user outcomes. Quality frameworks may include a range of predefined user outcomes that are considered to be influenced by disability service providers – these outcomes have some similarity with the domains covered by quality of life tools but are usually not tested for reliability or validity. Data to support the outcomes is not usually gathered in a rigorous and consistent manner across organisations and evidence used to verify the outcome will often vary between organisations.

Examples of approaches being taken to use quality of life tools to measure service provider quality include:

- The <u>Ask Me! Quality of Life Questionnaire</u> is being used to monitor community services funded by the Marylands Developmental Disabilities Administration (USA).
- In Nebraska USA, the <u>Quality of Life Questionnaire (Schalock and Keith)</u> has been used to profile community providers on a biennial basis.
- The <u>Personal Outcomes Measures</u> tool is used in the Council of Quality and Leadership accreditation process by providers in the USA, Ireland, Canada and a small number of organisations in Australia. A Personal Outcomes Measures Trial in Victoria demonstrated that the tool was an effective way to verify the quality of disability support provision and reorient the disability support sector. However, the cost, unless subsidised by Government, may restrict many disability service providers' use of this tool. Disability ACT is beginning to incorporate Personal Outcomes Measures principles into quality improvement processes, particularly the new framework for service funding agreements. Some initial service provider training has been conducted. This training is being complemented by training in Optimal Individual Service Design.
- Western Australia Quality Management Framework has developed client focused and aspirational outcomes, performance indicators and response chains (steps or sequence of activities that need to be undertaken to achieve a desired outcome) for various disability service types (eg accommodation, advocacy, alternatives to employment, family support services, recreation services, disability professional services and local area coordination.) Initial baseline assessment is to be used to set the expectation for disability service providers' performance quality.

- The Victorian Quality Framework involves a participatory approach of negotiating outcomes with each person to determine what constitutes a good outcome for them. The approach incorporates a framework of 16 life areas that are considered to be related to the wellbeing of all Victorians, as well as an evidence framework. The 16 life areas (see Attachment C) could be considered to be a quality of life model.
- The Tasmanian Operational Framework for Disability Services is framed around service user outcomes. An appropriate outcome measurement is yet to be developed. Once developed, outcome measurement is to be embedded into all levels of the service system: in service agreements; quality and performance management framework.
- The recently released draft National Disability Service Standards contains a specific standard identifying measurement of meaningful outcomes for service users.

Individual measurement of outcomes

Another approach to assessing outcomes can be to periodically measure achievement of an individual's agreed personal goals. This approach ensures a direct link between service intervention and the outcomes measured. However this individualised approach limits the ability to compare results across an organisation or to benchmark with others. An example of an outcomes measurement tool of this type is <u>Goal Attainment Scaling</u>. For the purposes of this paper, these types of tools are considered to fit under the category of Quality of Life tools.

Organisational Focus on Outcomes

There are a range of frameworks to help organisations focus on outcomes for the individual. As discussed above quality frameworks are one example of this. Other approaches include:

- Results Based Accountability Framework: Management tool for results based decision-making.
- Return On Social Investment: A framework for measuring the social value of an activity, program or organisation.

These system/organisational approaches, while not necessarily incorporating quality of life measurement, can help focus an organisation on the impact of its services on people's lives.

The approaches can help align resources and strategies, and improve performance and accountability to enhance personal outcomes for individuals.¹¹

What are the implications for disability service providers?

Person centred models of care place an increased focus on the outcomes achieved for people with disability. This approach is evident in changes being made to the administration and funding of disability services. If disability service providers are to be measured in terms of their outcomes, there is a need to plan and provide services in relation to those outcomes.

The move toward outcome measurement can therefore be seen as part of a fundamental shift in service provision. The focus needs to be reflected in service vision, culture, leadership, service delivery, monitoring and evaluation. Factors that limit this focus need to be identified and addressed. (The NDS Progress for Providers Tool, a self-assessment tool developed to assist disability service providers monitor their progress in delivering personalised services, is one example)

Outcome measurement requires investment in terms of time, resources and expertise. The resources required include allocations made for staff involvement and staff skill in collecting, analysing, reporting and utilising outcome information.

Everyone involved in the provision of a service needs to be actively involved in outcome measurement. This includes: commitment and leadership from senior management; a person to lead the process; staff considering the process as worthwhile and perceiving the value of the information fed back to them; and people with disability need to help steer the process by defining the outcomes important to them and their relative importance, to help analyse findings, and to help plan what action should be taken.

Additional research is required to determine the relationship between different disability services types and quality of life domains and to identify a simple cost effective methodology to apply outcome measures in a consistent manner across disability services. As a preliminary step in this process, NDS is keen to further analyse the experience of disability service providers who have incorporated quality of life tools into their current practice.

A focus on outcomes should not be pursued at the exclusion of measures of input, process and output. Positive outcomes are unlikely to be achieved without good processes. In addition, outcomes may not necessarily address key concerns people with disability have about some aspects of the service (eg access, timeliness of service, etc). People with disability need to be involved in determining what is important to them in terms of service delivery experience and outcomes. The various quality frameworks in place across the country provide a basis for this purpose.

Results of the NDS survey on Outcome measurement by Disability Service Providers

NDS conducted a member survey on Outcomes Measurement by Disability Service providers in April 2012. The results are summarised below:

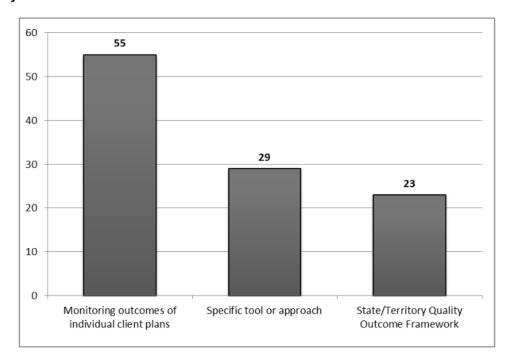
A total of 96 responses were received for the NDS survey "Measuring Outcomes for People with Disability".

Key findings

74% of organisations responding stated that they did measure outcomes for people with disability and the other 26% were currently not measuring outcomes.

Many of the organisations that measure outcomes indicated how they did this and a number of respondents utilised more than one method.

Figure 1: Most common ways organisations measured outcomes for people with disability.



Note: The total number of responses adds up to 117 as a number of providers used multiple methods of measuring outcomes.

Of the 25 organisations (26% of respondents) that did not measure outcomes, 22 provided reasons, including:

14 responded they were unfamiliar with the tools available and their merits;

- 5 respondents stated that measuring outcomes was not a current priority for their service because of perceptions of cost effectiveness;
- 3 had never considered this; and
- 2 had other reasons, including the reporting requirements and the organisation's perception of the value and or merit of outcome measurement.

The majority of respondents (72%) to the poll outlined challenges they faced in measuring individual outcomes for their organisation, including:

- Administrative burden, time/resources and cost;
- Difficulty identifying an appropriate tool that is relevant;
- Workforce staff compliance, training, capacity and consistency in approach;
- Limitations of current systems, e.g. complexities of data collection and input;
- Outcomes were considered notoriously difficult to quantify;
- Changing the culture across the whole of organisation; and
- Lack of a shared understanding from Government about good outcomes.

Next steps

Many of the respondents to the poll had a number of ideas of support NDS could provide in relation to measurement of individual outcomes. The majority of organisations indicated that they would like information about available tools and their cost- effectiveness, as can be seen in Figure 2.

Several organisations provided specific written examples of their approach to outcomes measurement, including one member organisation that provided extensive detail on the work conducted in this area (including the development of their own unique approach) over a period of eight years.

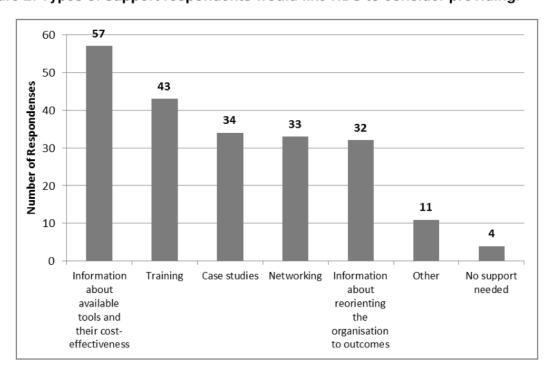


Figure 2: Types of support respondents would like NDS to consider providing.

Note: The total number of responses adds up to 214 as a number of organisations provided more than one response.

Other ideas organisations had in response to the types of support NDS could provide is summarised as follows:

- Research and advocacy;
- Resources and information on existing tools; and
- Funding support, especially for smaller organisations.

NDS will continue to assist members to develop their capacity to measure outcomes for people with disability.

These results demonstrate that there is a clear interest from organisations in a set of low or no cost tools for measuring individual outcomes and an emerging appreciation of the need to find robust ways to track consumer preferences.

For Organisations wanting to implement outcomes measures

Organisations that are new to this area should consider the following websites:

<u>Cupitt, S. and Ellis, J. Your project and its outcomes. Charities Evaluation</u>
 <u>Service</u> - A simply written booklet for those wanting to begin to plan, monitor and evaluate outcomes.

Additional information on Quality of Life

 <u>Australian Centre on Quality of Life</u> – A website providing resources and facilitating research into quality of life. Contains a number of links to useful resources.

Additional Information about specific quality of life tools:

- Personal Outcome Measures
- University of Toronto Quality of Life Profile (QLP)
- Ask Me Quality of Life Questionnaire
- Personal Wellbeing Index
- Family Quality of Life Survey
- Beach Centre Family Outcome Quality of Life Scale
- The Outcomes Star
- Goal Attainment Scaling

Additional information about organisational tools and methodologies:

- Results Based Accountability (RBA)
- Social Return on Investment (SROI)
- National Core Indicators (NCI)

NDS resources are available to assist members in the measurement of other organisational outcomes. These include:

- It's your business;
- NDS ACT Governance Better Practice Guide;
- NDS VIC Resources for Boards of Management; and
- Victorian Risk Management.

Appendix A: Quality of life tools – general issues and challenges

Quality of life is an individually defined concept. Quality of life measurement tools need to incorporate individual ratings of the importance of various domains.

Literature supports quality of life tools including both:

- objective measures (e.g. income, employment and participation) and
- subjective measures (e.g. satisfaction, self-determination, wellbeing, and happiness).

Subjective measures of wellbeing incorporate cognitive and affective components and are central to the concept of quality of life. The interplay between objective and subjective measures is difficult to understand as the correlation between these two measures is low. Quality of life tools attempt to work around this problem by having individuals rate the importance of particular quality of life domains. For example, if an individual rates the objective measure of material wellbeing (income) as unimportant then the objective and subjective measures of material wellbeing will be given relatively little weight in their total quality of life score. Quality of life is assumed to be a single construct that is a product of the person's objective life circumstances, satisfaction with those circumstances and perceived importance of various life circumstances. ¹³

Personality/disposition has been found to be a significant influencer of a person's subjective quality of life. People, including those with disability tend to have high levels of satisfaction with their quality of life ('the disability paradox'). The measure tends to be remarkably stable at this high level over a person's life. ^{14,15} Cummings (1995) suggests there could be a homeostatic mechanism that ensures people feel satisfied with their lives under relatively stable but diverse living conditions. ¹⁶ This has significant implications for interpreting the results of Quality of Life measures.

In addition, the measurement of quality of life appears to be relatively insensitive to changes in people's circumstances such as changes in income, material standards of living, health, education, friends, marital status, and employment status.¹⁷ Lifestyle changes have been found to produce a short term impact that lasts less than six months after which the person reverts to their dispositional level of subjective wellbeing. This implies attempts to use quality of life measures for disability service outcomes, particularly for long-term service provision, may lack sensitivity.

Collecting subjective quality of life measurements tends to be time consuming and therefore costly. Depending on the reason quality of life outcomes are being monitored, periodic sampling may need to be used to manage costs while retaining validity.

Quality of life tools – general issues and challenges when used to measure outcomes of disability services

Disability services are likely to have only partial scope for impacting a person's quality of life. There are many other factors in the person's life that may also impact their quality of life, such as deteriorating health and ageing. ¹⁸

The domains captured by quality of life tools need to reflect the purpose of the outcomes that are being collected. The domains needed to monitor outcomes at a program funding level may differ from those used by service providers to monitor their service. The outcomes achieved by provision of different types of disability services (e.g. accommodation versus advocacy) are also likely to vary. Hatton, Emerson and Lobb (2006) argue that general outcomes of the totality of a person's life are unlikely to be attributable to the impact of any particular service but are more useful for monitoring inequities in populations.¹⁹

It is not known if interviewer expectations and respondent acquiescence plays a greater influence in responses of people with disability than others.²⁰

When administering quality of life tools as part of program monitoring, caution needs to be taken to manage the respondents' expectations. The asking of broad quality of life questions can lead to an expectation that action will be taken to address any areas of dissatisfaction. However, limitations may be related to funding levels and program limitations rather than disability service provision.

Conceptualisation of family quality of life is limited; much of this work focuses on families during the early life stages of their child with disability. The concept of family quality of life is complex as each family member is likely to have a different perspective of the family's quality of life. The domains used family quality of life tools tend to be broader than those considered for an individual – examples of additional items that may be included are family interaction and disability related support issues.²¹

Appendix B: Quality of life Tools – general issues and challenges

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and Efficient	Application & Use	Webpage
Personal Outcome Measures	Developed as part of an accreditation system by the USA Council for Quality and Leadership (based on factors people with disability and their families said were most important to them). Strong client outcome focus.	Tool incorporating 21 measures to assess if outcomes and supports are present from the person's point of view; their priories and preferences are used to identify their personal outcomes.	The 21 Measures are organized around: My Self: Who I am as a result of my unique heredity, life experiences and decisions. My World: Where I work, live, socialize, belong or connect. My Dreams: How I want my life (self and world) to be.	Reported as valid and reliable. Involves some subjectivity in decision-making ratings are based on a number of questions and information collected through various sources May be counter-indicated for individual QoL monitoring because of lack of sensitivity within some domains and no subjective QoL component despite domains being similar. ²²	Outcomes either met/not met – resulting in limited sensitivity. Scoring considers personal relevance of outcomes by considering whether outcomes that are not present are based on personal choice.	Can be personnel intensive. Used in USA as part of accreditation process with individuals meeting with CQL staff member for a personal outcomes interview. Follow up is done by others who know the person best and documentation checks are used to further evaluate the presence of outcomes for each person.	Intended to be used as part of an accreditation process. Copies of Personal Outcome measure material available 1-9 sets, \$149 10-19 sets, \$139 20 or more sets, \$129 Training is required to understand use tool. Cost can be a barrier to wide spread use.	Can be used as a guide for person centred planning, service re-orientation and for quality/accreditation. Used with people with disability including those with a range of intellectual and developmental disabilities and mental illness. The CQL database allows benchmarking of results against over 5500 interviews. Includes a measure of social capital.	http://www.thecou ncil.org/Personal Outcome_Measur es.aspx
University of Toronto Quality of Life Profile (QLP)	Began development in 1991 for the Ontario Ministry of Community and Social Services to assess QOL among persons with developmental disabilities.	Seen as being applicable to all persons, with and without disability. Developed through analysis of literature and data from persons with and without disability. Includes a holist view of quality of life. The person's perspective of their quality of life is formed by considering the relative importance attached to each particular dimension and the extent of the person's enjoyment of that domain.	Being, Belonging, and Becoming and their sub-domains are determined by two factors: importance and enjoyment.	Reported as psychometrically sound. A publication about the tool's psychometric properties is currently being prepared. There are reliability issues due to assessor judgement.	Identified by a Report on Quality of Life Instruments commissioned by DHS Victoria as having the best conceptual basis and range of domains to cover client aspirations and most disability service interventions. ²³	Instruments can be used for interviews or self-administered. A multi method, multisource approach is used to gather information that involves interviews, checklists, observations and data provided by the person with disability, service provider and independent assessor. Used with people with physical and sensory disabilities. The long version takes about 30-40 minutes to	The cost of both the long and short physical and sensory disabilities version is \$35 Developmental Disabilities tool (includes 3 different instruments and a detailed manual for conducting the assessments) \$75. Permission to make up to 99 copies: \$50.00 Permission to make 100 plus copies: \$75.00	Suitable for people aged 18 to 64 years. Specific versions exist for: • physical and sensory disabilities • developmental disabilities • adolescents • adults • seniors. Uses include: service improvement individual person centred planning and outcome monitoring. Concepts are not always represented briefly, simply or clearly. ²⁴	http://www.utoront o.ca/qol/physSen sDis.htm

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and Efficient	Application & Use	Webpage
The Quality of Life	Developed after 12	40 items scale with 4	The domains are:	Extensively	Sensitivity	complete. The shorter version about 15 minutes to complete. Administered by	\$50.00 US	Designed for Ages: 18	http://www.idspub
Questionnaire (QOL-Q) (Schalock &Keith) ²⁵	years of research. It aims to help evaluate existing programs and to devise new ones.	subscales each of 10 questions Complex questions and response categories (involves comparison to the average person).	Empowerment/in dependence Competence/ Productivity Satisfaction Social belonging/ community integration The tool is more narrowly focused than some other measures	studied and used and used in researched. Adequate internal consistency; testretest and interobserver reliability; discriminant validity); and validity of scale (content, construct and discriminant validity).	demonstrated with higher scores	trained interviewer		and above. There is a form for school aged adolescents. Most widely employed scale for QOL measurement for people with intellectual disability. Nebraska USA has used it also for developmental disability service provider profiles. Not suitable for people with severe levels of intellectual disability that cannot respond for themselves. The instrument claims it is well suited for person-centred	ishing.com/quality oflife/

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and Efficient	Application & Use	Webpage
Ask Me! Quality of Life Questionnaire	Used as a basis for the evaluation, reporting and quality improvement of QoL in US Maryland. Agency data also used to develop state-wide provider profiles.	A survey of 56 items to study the quality of life of adults with developmental disabilities.	The domains are: Social inclusion Self determination, personal development, rights Interpersonal relations Emotional wellbeing Physical wellbeing Material wellbeing Transportation availability	Extensive reliability data.	Reported to demonstrate variation in measurements: and statistical significant increases in domains: • among community agencies and • when QA plans are developed by agencies.	Face-to-face interviews conducted by trained peer interviewers who have developmental disabilities.	The Ask Me! Survey is copyrighted. It is available at cost and includes the survey, interview protocol, and interviewer training information. The Arc of Maryland has a licensing agreement for entities wanting to become certified to use the survey.	Appears mainly to be used in Maryland USA. Used for policy, quality improvement and progressing service delivery toward self-determination and rights. Scoring has been developed for use for people who are non-communicative (using happy/neutral/ sad face). Tool includes pre-interview questions. If the person is unable to communicate two proxies are used.	http://www.bonha mresearch.com/L evel%201/AskMe. htm
Personal Wellbeing Index	Refinement of the Comprehensive Quality of Life Scale (ComQoL) (Cummins) that was developed at Deakin University for Australian population.	Based on the well-established ComQol. The ComQol is still available as the pretesting protocol to establish respondents' competence at the task and the use of cartoon figures and faces to elicit responses are useful and can be applied to the Personal Wellbeing Index. Results of surveys of the Australian population are available.	8 domains are used in the adult scale: • standard of living • health • life achievement • personal relationships • personal safety • community-connectedness • future security • spirituality-religion	Reported to be reliable and valid. Psychometric for the Comprehensive Quality of Life Scale (ComQoL) were well established with norms of people with and without disability established. The Personal Wellbeing Index needs to be trialled to establish its psychometric performance with school aged children, and people with an intellectual or cognitive disability.	Appears to lack sensitivity to service provider's intervention. D'eath et al report the instrument while reasonably accurate for groups may not be as accurate at the individual level. The service intervention in differences between elderly people living in different accommodation and parents with/without child with intellectual disability but may lack sensitivity to life changes associated with service intervention. 28	Administration takes from 10 to 20 minutes but may take longer for people with intellectual disability or cognitive impairment.	Able to be downloaded free of charge	The PWI scale can be used with any section of the population allows benchmarking to whole population norms Versions of the tool developed for people with intellectual/ cognitive disability. Incorporates a pretesting protocol to determine whether, and to what level of complexity, respondents are able to use the scale. Uses 0 to 10 Likert scale; includes alternate response formats e.g. 2, 3 or 5 blocks or faces. Proxies not to be used. Difficulties in use with people with communication difficulties	http://www.deakin _edu.au/research/ acqol/instruments/ wellbeing-index/

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and Efficient	Application & Use	Webpage
Outcomes Star	Originally developed in 2003 to measure outcomes across a series of programs and service delivery types.	Measured outcomes across a series of scales, later grouped into a star graphic. Support as well as measure a process of individual change.	Multi service/project applicability with different domains per project. They include (e.g. Autism Spectrum Star): Physical health Living skills & self care Well-being & self-esteem Sensory differences Communication Social skills Relationships Socially responsible behaviour Time and activities	Has been subject to extensive reliability and validity testing, with validity results demonstrating Key Work had become more focussed on user outcomes, more systematic and consistent, covering a wider range of issues. Reliability testing results are not yet available.	All versions are based on an explicit model of the steps that service users take on their journey to independence – "The ladder of change".	The process is highly interactive, with collection and analysis of data including active input from service users and workers the fundamental aspect of the model.	May be used in print format free of charge, licenses are available for online or commercial.	Fourteen versions of the star have been developed including for Autism Spectrum and learning disability. A vision impairment star is under development.	http://www.outco messtar.org.uk/
Goal Attainment Scaling	Developed in the 1960s as a tool for monitoring and evaluation in human services.	A method for setting goals and measuring the degree of goal achievement by creating an individualised five point scale of potential outcomes undertaken for an activity.	Specific domains (goals) can be identified depending on the project.	Testing has demonstrated that GAS is: Easy to use; Provides a clear measure of goals achieved; Goal achievement is quantifiable; and Scores for multiple goals can be amalgamated into one overall summary score demonstrating the degree of achievement of a project.	One challenge with GAS is skilful setting of goals so that goals are neither too easily attained, thereby inviting overachievement, or alternatively, set so high that goals cannot be achieved.	The versatility of GAS is such that it can incorporate goals of all types. The emphasis has to be on the logic of the structure designed. For example, goals can be hierarchical, were achievement of one goal allows another to be embarked on.	Templates are freely available in excel format.	Can be used across a wide range of projects, programs and applications.	No specific webpage. Definitive article on GAS is by Kiresuk and Sherman, 1968. http://www.detgod epartnerskab.eu/u ploads/f82aa3ab8 9e16681f2acd847 ebbeb925.pdf

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and Efficient	Application & Use	Webpage
Family Focus									
Family Quality of Life Survey (Brown et al)	Developed in 2000 through the International Family Quality of Life Project, that involved Australia, to examine the quality of life of families who have one or more members with an intellectual or developmental disability.	The FQOL Survey is available in two versions: Main caregivers of people with intellectual or developmental disabilities and General version (non-disability). These have been translated into a number of different languages.	Covers the importance, opportunities, initiative, attainment, stability, & satisfaction in 9 key areas: Health of the family Financial well-being Family relationships Support from other people Support from disability related services Influence of values Careers and preparing for careers Leisure and recreation Community interaction	Extensively field tested in Australia, Canada, Israel, South Korea, and Taiwan. Data on reliability and validity to be published in future.		Completed by the main caregiver (self-administration), or by a practitioner with the main caregiver (face-to-face administration).	Tool may be reprinted or copied for educational, service or research purposes without consent from the authors. However, the authors wish to be informed of use.	Used in research but can be used by an individual family and service practitioners to assess support needs and help with program design	http://www.surrey place.on.ca/Educ ation-and- Research/researc h-and- evaluation/Pages/ International- Family-Quality-of- LifeProject.aspx
Beach Centre Family Outcome Quality of Life Scale	Funded by the National Institute on Disability Rehabilitation Research USA. The tool measures family perceptions of the importance of different domains of family quality and life and their satisfaction with those domains.	A 25 item scale developed to assess families of children with disabilities who are aged from birth through to 21 years. Explores perceptions of importance and satisfaction with different aspects of family quality of life.	Measures 25 items and 5 subscales: Family interaction; Parenting; Emotional wellbeing; Physical /material wellbeing Disability related support	Reported to have good psychometrics properties		Completed by family. Estimated 10-15 minutes to complete.	Available free of charge. Abbreviated sample version available at: http://www.google.com.au/url?sa=t&source=web&cd=2&ved=0CCQQFjAB&url=http%3A%2F%2Fpbi.sagepub.com%2Fcontent%2F7%2F3%2F174.full.pdf&ei=MqtdTuMDiOalAtjVubMF&usg=AFQjCNE7kawHINNar448IQtpexHFX4Eccw	The tool primary focus is on measuring the impact of policy and program outcomes. It can also be used for planning, assessment evaluation. It is not intended as diagnostic tool. Accompanied by a set of other tools for planning family quality of life; assessing family relationship with service providers, and a family empowerment scale.	http://www.beach center.org/resource_librarry/beach_r esource_detail_p age.aspx?intReso urceID=2391&Typ e=Tool&JScript=1

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and Efficient	Application & Use	Webpage
Service Outcom	nes								
Results Based Account-ability (RBA)	Methodology for thinking and taking action for improving services with a focus on outcomes at the individual level and at a broader level for other stakeholders.	Management tool for results based decision-making.	Group quality improvement activity	Includes a 'Turn the Curve Exercise' that can be undertaken in less than one hour to produce ideas to improve performance. Range of implementation resources including seminar, books, software (additional cost); techniques and exercises; forms and formats	http://www.raquid e.org/index.shtml	Used in UK, USA, Europe, NZ & Australia (DOCS & FaCHSIA. Inner East Community Health Services (IECHS) and Melbourne Citymission (MCM). MCM have augmented the RBA developing the Measuring and Outcomes and Results Framework (MORF). Citymission and IECHS have won an award for Innovation in the not for profit/community sector for their work.	data show about where we've been and where we're headed? What works?	RBA/OBA intellectual property is free for use (with attribution) by government and non-profit or voluntary sector organizations. There is a similar exemption for small for-profit consulting groups. Larger for-profit organizations are required to pay an annual fee for use of RBA/OBA intellectual property based on the size of the organisation. For future details see: http://www.raquide.org/licensing.shtml	Results Scorecard 2.0 is a licensed software tool specifically designed to support the RBA Framework The Scorecard is intended to help non-profit organisations to collaborate and make data-driven decisions. http://www.resultseadership.org/scorecard/
Social Return on Investment (SROI)	SROI was developed from social accounting and cost benefit analysis given the limitations of traditional financial accounting to measure social impact. It is one of several methods for measuring the social impact of an organisation. Others include:	SROI aims to measure the social, economic and environmental outcomes of an activity or an organisation. Measurement can be undertaken retrospectively (based on outcomes that have already taken place) or to forecast SROIs the predicted social value of an activity that meets it	Stakeholders are involved to determine which outcomes are relevant.	A flexible framework with principles that involves economic modelling. The modelling involves subjective /intrinsic elements and the ratio is impacted by • quality of the assumption underlying model	Dependent on quality of modelling and assumptions.	A SROI Guide and supplements sets out a step by step approach to completing an analysis of social return. Use of accredited SROI practitioners can help ensure methodology is applied appropriately. The methodology is still being developed 30.	The approach has been criticised as being time consuming and complicated	There is growing interest in use of SROI and other similar approaches measuring social impact. The Social Value of Community Housing in Australia Report (2011) is the first time SROI has been applied across a whole sector, anywhere in the world.	http://www.thesroi network.org/about -us

Name	Development	Description	Domains	Reliability & Validity	Sensitive to change	Practical	Affordable and Efficient	Application & Use	Webpage
	Social Accounting and Audit (SAA); Logic Models (e.g. LogFrame)	intended outcomes. The approach involves placing a monetary value on outcomes, so that they can be added up and compared with the investment made. ²⁸		outcomes generated the monetary value placed on the outcomes. The SROI ratio is not easily able to be compared with other organisations/ programs.		Training on SROI is available in Australia. Interpretation provides an estimated value of return on investment.			
National Core Indicators (NCI)	Under development since 1997, to formally measure the performance of disability service providers in the USA.	NCI supports member agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks.	Five key indicators: Individual outcomes Health welfare and rights System performance Staff stability Family indicators	Data is widely used to inform policy, develop QA systems and compare performance with national averages. Also used as basis for data briefs in particular disability policy areas.	Extensive evidence of indicators ability to measure changes in individual circumstances	Intrinsic data collection requirements mean effort is needed to enter returns.		29 States in the US are now participants in the Project.	http://www.nation alcoreindicators.org/

Appendix C: Comparison of Domains used within the quality of life tools

University of Toronto Quality of Life Profile (QLP)	The Quality of Life Questionnaire (QOL-Q) (Schalock &Keith) ³¹	Ask Me! Quality of Life Questionnaire	Personal Wellbeing Index	Family Quality of Life Survey (Brown et al)	Beach Centre Family Outcome Quality of Life Scale
Being: who one is Physical Being Psychological Being Spiritual Being Belonging: connections with one's environments Physical Belonging Social Belonging Community Belonging Community Belonging Becoming: achieving personal goals, hopes, and aspirations Practical Becoming Leisure Becoming Growth becoming (Each domain addresses a number of areas)	Empowerment/ independence Competence/ productivity Satisfaction Social belonging/ community integration	Emotional wellbeing Interpersonal relations Material wellbeing Personal development Physical wellbeing Self-determination Social inclusion Rights Six questions are asked for each of the eight core domains	Standard of living Health Life achievement Personal relationships Personal safety Community- connectedness Future security Spirituality-religion	Health of the family Financial well-being Family relationships Support from other people Support from disability related services Influence of values Careers and preparing for careers Leisure and recreation Community interaction	 Family interaction Parenting Emotional Wellbeing Physical/Material Wellbeing Support for Family Member with Disability

Appendix D: Comparison of Domains used within Selected Quality Frameworks that Focus on Individual Outcomes

WA Quality Framework	Tasmanian Operational Framework	Victorian Quality Framework	Personal Outcome Measures
Accommodation Outcomes: Wellbeing Relationships and social connection Lifestyle Home Advocacy Outcomes: Individual Outcomes Capacity Building Community Connections Citizenship Advocacy Outcomes: Systematic Outcomes Citizenship Alternatives to employment Social Participation Personal Independence Life long learning Enhanced national support networks Family Support Services Outcomes Positive relationships Lifestyle of choice Support networks Wellbeing Recreation services Wellbeing Social Connectedness Welcoming Communities Disability professional services outcomes Independence Participation	 Independence Participation in the community A home Building Relationships & Social Connections Wellbeing Welcoming Communities Capacity Building Lifestyle Inclusion. WA Quality Framework (contd) Local Area Coordination Outcomes Living a rich and fulfilling life Citizenship Family resilience Community Inclusion 	 Always learning Being part of a community Being safe Building relationships Choosing supports Communicating Doing valued work Exercising rights and responsibilities Expressing culture Having fun How to live Looking after self Moving around Paying for things Where to live Draft National Quality Framework Rights Participation Individual Outcomes Feedback & Complaints Service Access Service Management 	My Self Natural support networks Intimate relationships Safe Best possible health Rights Treated fairly Free from abuse and neglect Continuity and security Sharing personal information My World Choose where and with whom they live Choose where they work Environments Integrated environments Interact with other members of the community Different social roles Choose services My Dreams Choose personal goals Realize personal goals Participate in the life of the community Friends Respect

Appendix E: Measurement of individual outcomes by Disability Services – Organisation Case Studies

The purpose of these organisation case studies is to demonstrate a range of approaches to measuring outcomes currently being taken by three NDS members. The case studies are not intended to indicate best practice but demonstrate how three organisations that offer a relatively wide range of service types (and are therefore relatively larger) have developed different approaches (e.g. developing in house tools, partnering with subject matter experts, using "off the shelf" tools) how their approach is resourced, the barriers and enablers they have experienced and key lessons learned.

Case Study One - Organisation Profile

Ability Options is a large organisation supporting over 3,500 people across NSW through a number of state and federally funded programs. Services offered include:

- disability employment services, including Aboriginal specific services, across the greater Sydney region
- supported employment through a wholesale nursery, based in the Penrith LGA
- case management service, based in the Penrith LGA
- community access and living skills support:
- supported living—drop-in, semi-independent and 24/7
- self-managed services for ages 0-6 year (pilot), and 18 to 65 —community participation and accommodation services.

Describe your approach

Ability Options is moving to ensure that each person has an outcome based plan which drives services and support. The planning review process will then measure outcomes as defined by each person in line with their aspirations. Some of the key indicators that we are looking at cover:

- community engagement and participation
- personal relationships
- quality of life

What tools are you using?

Our proposed approach has been informed by:

- Richter scale principles supporting the measurement of outcomes and distancetravelled (where are you now, where do you want to be), with questions able to be individually tailored.
- The National Personal Budget Survey (England).
- Goal Attainment Scaling, as used by ADHC in the Early Start program.

Which service types or client groups are involved?

Ability Options has a key strategic objective over the next 2 years to ensure that:

- each person we support has an outcomes based plan
- people can purchase supports and services from a variety of sources
- there are measurable improvements in people's quality of life.

What costs are involved (both direct and indirect investments)?

The costs are currently assigned to our in house Research team and links to a three year strategic objective around outcome based plans. A full-time and part-time resource has been allocated to this latter project. In developing an approach to measuring outcomes we estimate that over the last 12 months that this has involved around 3 months of resourcing from our internal research team (researching options, consulting with personnel, people with a disability and their families, developing an outcome tool, collating and reporting on the first round of data).

The collection of outcome data is being embedded in our individual service provision model and an outcome based planning process. Therefore we are working to integrate this into our service provision model. It is anticipated that an ongoing resource (part-time and possibly as part of our internal research functions) will be needed to collate, review and report on outcomes, along with an ongoing review process.

What were the main considerations in taking the approach?

The main considerations have been:

- Questions that measure key information that Ability Options is interested in as
 indicators of service outcomes—satisfaction with life; social, economic and civic
 engagement; being of and engaged in community; having unpaid relationships; being
 able to choose where supports and services are sourced from; having appropriate
 supports to achieve individual goals and aspirations
- Capacity to measure outcomes in line with what is important to each person
- Brevity of an approach that can be implemented alongside planning and review processes—simple, cost effective and one that does not take a lot of time
- This is an evolving process based on ongoing learning and a commitment to continually reviewing what works/does not work

What were the key enablers to developing your approach?

We have developed a simple survey to sit alongside planning and review processes so personnel involved in planning can easily ask people to complete either a paper or electronic response. Also, the planning process is focusing on outcomes and therefore measuring the achievement of the identified outcomes.

The aim is to measure change over time and to focus planning on where each person wants to be in 6 or 12 months, with follow-up in 6 or 12 months to see where they are, and adjusting services and support accordingly.

The analysis of this information and subsequent reporting will be completed as part of research and policy functions within Ability Options. There is still more work to be done on how this information will be consolidated and reported.

What were the barriers, if any, and how did you overcome them?

We continue to grapple with the measuring of outcomes. We have researched and reviewed a variety of tools. Issues with existing tools are that:

- they are not flexible enough to account for individual circumstances
- they can be costly and resource intensive to implement

We have identified that any approach that is overly time consuming or complex is less likely to be adopted or completed; and, particularly in the context of people who have their own package for which they determine expenditure, any process that costs them resources will not work.

What key lessons would you offer other organisations looking to develop effective approaches to outcomes measurement?

As noted, we are in the early stages of our approach and to some extent 'muddling' through and trying to work out what will and will not work. We think we have identified what will not work, but our approach to what will work will be constantly reviewed and modified.

In a changing funding environment, we believe that measuring outcomes needs to be seamless and part of the planning process, otherwise it will not occur.

If you were to do it again, what would you do differently?

One of our issues has been that while personnel actively measure outcomes as part of the planning and review process, these are not recorded in a readily accessible format that enables us to 'pick' up the information for Board reporting purposes. This is the focus of our current actions.

What key developments or refinements of your approach are you committed to making in future?

Our future approach has been described above.

Case Study Two - Organisation Profile

Nulsen is a not-for-profit organisation founded 58 years ago in Perth by a group of parents of children with profound intellectual and physical disabilities. Currently, Nulsen provides accommodation services for 112 people with severe and profound disabilities or acquired brain injury. The residents are women and men who are between 13 and 69 years old. Nulsen also provides Clinical Services, Positive Behaviour Support and Community Services through an Alternative to Employment Program.

In addition, Nulsen has a Culture and Creative Development Program which explores and support number of musical, cultural and arts related talents of Nulsen residents. Nulsen has its own Education Unit that it is used to promote awareness in schools and wider community.

Additionally, Nulsen provides Business Management and Clinical Services support to other organisations.

Nulsen employs 335 support workers and 75 administration staff including managers.

Describe your approach

To maintain and improve the quality of life of residents and services users Nulsen has a holistic person-centred approach that facilitates a better understanding of the needs of the people we support. Nulsen also has a self-funded Program to enhance their physical, emotional and material well-being along with their inclusion, personal development, self-determination and productivity.

What tools are you using?

In 2008 Nulsen created the program called Nulsen Connect. The aim of this Program is to facilitate, develop and evaluate person-centred plans for each resident and service user. The plan guides the actions of all staff that have a direct impact in all the domains of quality of life mentioned before. The tools used by the program include:

- Person Centred Plan Meeting
- Personal Profiles
- Individual Service Plans
- SMART Goals Development
- Outcomes Recording System
- Evaluation
- Report

Which service types or client groups are involved?

Nulsen Connect facilitates learning experiences that prepare support workers to incorporate a range of inclusive, communicative, leisure and health promoting activities that are appropriate, meaningful, and beneficial for Nulsen Residents and service users of the Alternative to Employment Program. Nulsen Connect works very closely with family members, and the people who know the person well to identify skills, needs, goals, dreams and aspirations which become part of the person-centred plan. The person has the support of Nulsen's Clinical and Nursing Services, Positive Behaviour Support along with Accommodation and Community Services.

What costs are involved (both direct and indirect investments)?

Currently, Nulsen Connect has two Program Development Officers and one Manager. The annual cost of the human resources for the Program is \$225,190. In addition, all the members of the Clinical Services Team and Positive Behaviour Support (11 people) support directly the creation and development and implementation of Individual Service Plans.

What were the main considerations in taking the approach?

Nulsen's CEO observed and reflected on the provision of services to people with disabilities, particularly in accommodation services. He found that for several reasons Nulsen had lost ground on some core service delivery and cultural activities that were once an important

hallmark of the organisation. It was recognised that the organisation was growing, had lost people with important historical knowledge and expertise and had not invested enough in imparting this knowledge and skills to new generations of support workers and managers. In addition, it was identified that Nulsen's Departments and Services that support residents and service users were not working cooperatively. Another consideration was to what Nulsen used to call a Lifestyle Plan Meeting did not have a person-centred approach and a system to support the development, recording of outcomes, evaluation and reporting of goals.

What were the key enablers to developing your approach?

- A participative action research project on Meaningful Activities for People with Severe and Profound Intellectual Disabilities that Nulsen supported for five people living in shared accommodation support.
- Nulsen invested in 1.5 Program Development positions to develop an approach to implement the recommendations that came out from the research project.
- A pilot program of 10 months to implement the recommendations took place. This
 program involved ten residents, accommodation and community support workers, two
 residential services managers, and the managers of Accommodation and Community
 Services.
- Training on person-centred approaches was available to the staff guiding the pilot program.
- 3 full time positions have been funded by Nulsen to facilitate the implementation and development of the program across the organisation.
- Nulsen has provided the human resources and time to connect its departments and staff who directly support the residents and services users. Actions that have facilitated this process include person-centred meetings, person-centred training, case conferences, and the creation of the Director of Direct Services position among others.

What were the barriers, if any, and how did you overcome them?

From its embryonic stage Nulsen Connect has faced challenges with the beliefs and practices of support workers and some managers. Before Nulsen Connect some staff believed that their main role was to look after the physical well-being and needs of the person. In addition, doing things **for** the residents and not **with** the residents was an ordinary practice.

It was identified that support workers, managers and Clinical Services staff needed to have a very good understanding of the needs of the people we support. Consequently, the Nulsen Connect training involved practical experiences to understand what it means to have a disability and how does it feel to be rejected, excluded and isolated. In addition, participants reviewed principles and practical use of theories and programs such as: Social Role Valorisation, Quality of Life, Active Support, Communication and Person-Centred Approach.

Most support workers, all managers and executive team have been part of the training.

Program Development Officers review plans and goals regularly with the person, managers and support workers. They identify what is working, what is not working and what they have to do to make it work.

What key lessons would you offer other organisations looking to develop effective approaches to outcomes measurement?

- Organisations need to take the time to develop their own framework to respond to the
 individual needs of their service users. In the case of Nulsen and after four years of
 continuous development we finally have a framework to plan, implement, record
 outcomes, evaluate and report on a person-centred plan for Nulsen residents, living in
 community based shared accommodation.
- Organisations need to take into account their Mission and principles to create a personcentred framework. In addition, organisations need to include the Outcomes and Performance Indicators for Accommodation, Alternative to Employment and/or Professional Services established by the entity that guides and/or supervises their services. Nulsen Connect has been based on the mission, principles and values of the Nulsen Association. The person's expected outcomes have been aligned with the Disability Services Commission Outcomes.

If you were to do it again, what would you do differently?

- Would start the process at the same time with all residents, family members, and staff.
- Would give more time to develop each step of the process.
- Would create a permanent means of communication with all stakeholders in each stage of the project.

What key developments or refinements of your approach are you committed to making in future?

The people at Nulsen with the most severe and profound intellectual disabilities are a high risk to miss out on the domains of inclusion, personal development and self-determination. Nulsen Connect is working on the development of meaningful goals to enable people with disabilities to achieve and maintain a valued quality of life as part of an accepting community.

Case Study Three - Organisation Profile

Scope is one of the largest providers of services to people with a disability in Victoria, and one of the largest not-for-profit organisations in Australia. Its mission is to support people with a disability to achieve their potential in welcoming and inclusive communities.

Scope offers a wide range of services for people with a disability, carers, employers and other groups. Central to its work is the direct support offered through various services, including: therapy and psychology, home and respite, day and lifestyles and employment placement services. In addition, Scope runs packaging and assembly businesses, and also operates a research unit, community education services and the Communication Resource Centre.

Scope supports over 7,000 people with disability and employs over 1,800 staff.

Describe your approach

The Scope Outcomes Framework conceptualises outcomes across a comprehensive set of life areas; it reflects the substantial work by Scope and its partner, Deakin University, over more than eight years to capture the outcomes of services for people with disabilities, their families and carers, and the communities with whom they engage.

What tools are you using?

Scope uses the following Tools:

- Impacts and Outcomes Scale measures the impact of services and supports across nine life domains
- Measuring Outcomes in Services and Supports Tool evaluates the degree of goal achievement and satisfaction associated with services and supports
- Family Capacity and Coping Scale evaluates the impact of services and supports in fostering the capacity and coping of families of children with disabilities

The tools are configured for measuring outcomes at the level of the individual; their data can be aggregated up for analysis at the service provider, disability system or population level e.g. for benchmarking.

Which service types or client groups are involved?

The framework is operationalised through a set of tools that evaluate outcomes of selfdirected and individualised services.

What costs are involved (both direct and indirect investments)?

Scope has invested directly in this work, which has also been supported through external research funding sources, and the contributions of Scope's partners.

What were the main considerations in taking the approach?

- Person Centred: Tools evaluate outcomes from the perspective of people with disabilities and their families, affirming the agency of people with disabilities in shaping their own lives and the contribution of people with disabilities as citizens
- Accuracy and validity: Tools accurately and validly measures the lived experiences of people with disabilities
- Meaningful: Tools yield information which leads to improved practice and actions that have a positive impact on peoples' lives
- Achievable: Measurement can be readily accomplished in the settings intended
- Accessible: Through their design and administrative characteristics, tools are easily accessed - with and without support by others - by people with a wide range of disabilities including people with intellectual disabilities

What were the key enablers to developing your approach?

- Defining which outcome areas are of focus and outcomes from whose perspective
- Systematic review of available outcome measurement frameworks and tools
- Establishment of a multi-expert stakeholder group
- Extensive development phase, ensuring tools meet the set of criteria outlined above (i.e. person centred, accurate, meaningful, achievable, accessible)
- Tools validated (to varying degrees) through formal research programs
- Evaluation leading to further iterative refinement of tools
- Brief, easy to use practice tools as an output of extensive development and evaluation process

What were the barriers, if any, and how did you overcome them?

B – barrier, S – strategy

- (B) What outcome areas should be of focus and whose perspective should we
 measure outcomes from? (S) deciding the desired areas of change, defining (and
 unpacking) these areas, identifying indicators of these changes; committing to evaluate
 from the perspective of the person with a disability
- (B) Which change indices (e.g., performance, satisfaction) should we focus on? (S)
 understanding the scope/limits of interpretation of data yielded by different indices; use
 of multiple indices
- (B) Ensuring opportunities for self-reporting for people whose disabilities are more severe in nature, including reliability in reporting; (S) focus on types of supports (e.g., easy English translation, modified visual scaling) a person may need to maximally engage with a tool and respond reliably; use of adjunct strategies (e.g. cross-validation with proxy); involvement of accessible communication experts
- (B) How can we be sure changes reflect the actions of the service or support, and not
 other factors outside of the service's reach? (S) acknowledging the difficulties in
 achieving accurate change attribution; asking about enablers and barriers to goal
 attainment as a way of mapping which factors have a bearing on outcome achievement

What key lessons would you offer other organisations looking to develop effective approaches to outcomes measurement?

- Dedicating the time needed to develop tools which are person-centred, achievable, meaningful, accessible and valid
- Evaluating tools in a range of service contexts
- Organisation commitment to supporting a service culture that embraces outcomes measurement

If you were to do it again, what would you do differently?

- Having 'outcome measurement leaders' within service organisations
- Allocating time and resources for individualised goal setting and evaluation
- Training in outcomes measurement and the use of individual tools

What key developments or refinements of your approach are you committed to making in future?

- Further refinement of accessibility characteristics of instruments (e.g. translation into easy-language format, modified response format/s)
- Further examining the validity characteristics of tools in relation to people with complex communication needs
- Examining the effectiveness of tools for detecting change for different disability types, service environments and service organisations

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