National Disability Services

Contribution of the Not for Profit Sector: Submission to the Productivity Commission

Not for profit organisations are an integral part of the social fabric of Australia; they connect with the lives of Australians in diverse and important ways. Most Australians will belong to, or gain support from, a not for profit organisation at least once and probably at several points of their lives. These organisations provide services, social networks, skills development and recreation. As a whole, they help cultivate democratic habits (active participation, mutual aid, cooperation with strangers). They are at the heart of civil society.

All not for profit organisations are affected by the operation of government, although to greatly varying degrees. For some, the relationship with government extends no further than that the government sets the regulatory framework that governs them. Community service organisations are at the other end of the spectrum. They provide essential social services but their role and impact extends much further than this.

> Community services are a vital part of Australia's social and economic infrastructure and are used by most Australians at some point in their lives. Community services not only support individuals and families, but also build social cohesion, enhance equity, give voice to the needs of disadvantaged groups, mobilise voluntary effort and philanthropy and achieve systemic change. They are one of the key mechanisms by which strong, effective communities are fostered and maintained.[1]

Disability service providers—the organisations which NDS represents—receive government funding for the provision of various support services but invariably supplement their work with additional resources, including from voluntary effort and fund-raising. Their identify and mission extend beyond the delivery of government-funded services. They exist to respond to the needs of some of the most disadvantaged people in our society, needs which are not provided for by for-profit organisations. They do this in a manner which is very cost-effective for Australian tax-payers. Indeed, the provision of these essential community or social services by governments themselves would require significantly greater public expenditure.

This submission will focus primarily on the relevance of issues to providers of disability services.

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[1] The Australian Collaboration: A collaboration of national community organisations 2001, *A Just and Sustainable Australia*, ACOSS, Redfern, p. 50.

1. Scope of the study

The extraordinary diversity of the not for profit sector reflects its importance to Australian society—organisations have established (and are establishing) to meet identified needs, pursue interests, or to respond to particular issues or opportunities. It is this very diversity that makes a study of the contribution of the sector so challenging.

NDS believes it is appropriate initially to adopt a broad view of the sector for the purpose of assessing its contribution and then narrowing to consider more specific issues.

It would not be appropriate to include all not for profit organisations in an analysis of efficiency and effectiveness. The more intense a not for profit organisation's relationship with government or other funding bodies (rather than relying solely on member resources), the more legitimate is interest in its efficiency and effectiveness. Among not for profit organisations that have community service agreements with government the issue is very relevant.

It is pleasing that the Commission acknowledges the numerous reviews, inquiries and initiatives of the past decade or so which have reported on the regulation and policies which shape the structure and function of the sector. In particular, it is time for the Australian Government to begin negotiations with the sector on the detail and implementation of those recommendations from last year's Senate *Inquiry into Disclosure Regimes for Charities and Not-for-Profit Organisations* which have broad support.

2. Measuring the contribution of the not for profit sector

Conceptualising the contribution of not for profit organisations around service delivery, advocacy, connecting the community and enhancing the community endowment appears reasonable. Such a categorisation allows for the breadth of the disability sector—which encompasses community living, social inclusion, respite and employment support—to be considered and acknowledged.

The overarching framework proposed for measuring the contribution of the not for profit sector—inputs, outputs, outcomes and impacts—is appropriate and provides scope for improving measurement over time.

To date, the disability sector has been poorly supported by the (low) level of public investment in disability research, data collection and outcome measurement. Commitment within the new National Disability Agreement promises a start to addressing these deficiencies by increasing the funding for research five-fold, albeit from a very low base of only $400,000 a year.

While information about some inputs and outputs is readily available and is collected yearly, data on outcomes and impacts is relatively scant. Data collected by the ABS and AIHW provides significant information on government-funded outputs but could be improved. Increasing the frequency of ABS releases—notably Not-for-profit Organisations, Australia, and the Non-Profit Institutions Satellite Account—would assist in building a better picture of the sector. For disability, increasing the frequency of the ABS Survey of Disability, Ageing and Carers from six yearly to every three—a recommendation of the House of Representatives report *Who cares…? Report on the Inquiry into better support for carers*[2]—would significantly improve the usefulness of the data.

Other evidence on the disability sector, for example on the disability workforce, is poor—there currently exists no accurate data on the size and structure of the disability service workforce. The National Community Services Workforce Census and Survey, currently being developed by the National Institute of Labour Studies, should help bridge this knowledge gap.

A key criticism of a 2005 report by the Australian National Audit Office was that the Commonwealth State/Territory Disability Agreement (CSTDA) failed to contain measures of outcomes, effectiveness, quality and unmet need. While the CSTDA stated governments would “strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community” it contained “no indicators of the quality of life of people with disabilities, their participation in the community, their value in the community, or any related parameters.”

Many jurisdictions are now undertaking work to address this shortcoming and are considering the inclusion of outcomes (and impacts) within their quality frameworks. In addition, work commissioned by the Disability Policy and Research Working Group (State and Federal officials) will include consideration of population benchmarking, including outcomes-based benchmarking. This work, together with measures of outcomes within quality frameworks, should improve the available knowledge on the outcomes and impacts of the work undertaken by the disability sector. But it will take time and needs to approached carefully, given that when linked to performance management outcome measures will drive the direction and shape of service delivery.

Outcomes in community services are hard to measure - and particularly hard in disability services, where service users with cognitive or communication impairments often have difficulty articulating their opinions and wishes. There are, however, serious attempts in Australia and overseas to measure outcomes in disability services. Internationally, work undertaken by the Council on Quality and Leadership on personal outcomes measures, and that undertaken by US researcher Robert Schalock on measuring the Quality of Life domains, are examples. Further information on Quality of Life domains is found in Appendix 2.

In *Australia’s Welfare 2007* in the chapter on ‘Disability and Disability Services’ AIHW includes a section examining several high-level outcome indicators, covering employment and workforce participation rates, educational inclusion, community living and service-related outcomes (in particularly levels of met and unmet need for

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[2] House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, *Who cares…? Report on the inquiry into better support for carers*, Parliament, Canberra, p. xxi.

services). However, none of these indicators in themselves captures the quality of people's experience.

NDS supports the need to significantly improve the quality and quantity of information about the disability sector and the work that it undertakes. However, it needs to be borne in mind that the collection of additional data about services usually imposes additional costs on service providers. Good quality data is critical to the relationship between governments and the community services that government funds. The collection of data from service providers should thus be treated as a cost of service delivery and funded accordingly.

3. Enhancing the efficiency and effectiveness of the not for profit sector

Regulatory burden

The Senate *Inquiry into Disclosure Regimes for Charities and Not-for-Profit Organisations* highlighted the fact that not for profit organisations are burdened with inconsistent and inappropriate regulation and concluded that there is a pressing need for reform. While accountability to government is important for organisations that receive public funds, it has a downside in tying up organisations in red tape and associated compliance costs. In some respects accountability has become an instrument of departmental control which weakens organisational mission and identity. Departments need to recognise that not for profit organisations have other stakeholders (clients, families, local communities) to whom they also must be accountable.

The current excessive regulation and onerous administrative requirements adversely affect the efficiency of parts of the not for profit sector—including disability service providers—and must be reduced as a matter of priority. Over recent years, business has benefited from the recognition that excessive 'red tape' hinders its performance, with various initiatives underway to reduce the burden of red tape (in particular the Corporate Law Economic Reform Program). The not-for-profit sector has been largely excluded from this reform agenda. As a recent report commented:

> Regulation reform (alongside human capital and competition) has achieved a high national profile in Australia. It is a key element of the agreed agenda of the Council of Australian Governments (COAG). There is consensus that 'red tape' is choking business, and that reforms should be accelerated and jurisdictional differences minimised in moves to 'co-operative federalism'.
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> But these national reforms priorities are not necessarily being extended to the NFP [not for profit] sector.[3]

Cross-recognition of quality assurance and other compliance requirements is urgently needed. Some organisations in the disability sector have to meet the overlapping requirements of five quality systems. While the need for mutual

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[3] Pascoe S. 2008, *Regulating the Not-for-Profit Sector*, State Services Authority, Melbourne, p. 16.

recognition of quality and accreditation schemes was agreed by the Community and Disability Services Ministers in July 2006 it appears that little progress has been made.

The introduction of a common chart of accounts across all government departments would be a practical early measure which would immediately improve the efficiency of the sector's dealings with government. Fortunately, it has been recently agreed that the COAG Business Regulation and Competition Working Group will begin work to address this and other regulatory concerns.

Workforce

Workforce shortages in the disability services sector are reaching critical levels and are affecting the support being provided to people with disability. Action is urgently needed as nothing is more pivotal to the quality of disability services than the quality of the workforce.

NDS is pleased that the Government has begun work on the development of a National Workforce Strategy. The unjustly low status of disability support work is linked to the low status of people with disability; both need to be tackled. To improve the ability of service providers to attract and retain staff the Workforce Strategy must address:

- the low public profile of disability services as a career option;
- the perception that the work is unskilled;
- the low funding/low wage environment within which the sector operates (exacerbated by indexation rates which have not kept pace with general wage adjustments); and
- the lack of national workforce data to inform planning.

While the current economic downturn will temporarily lessen the pressure of workforce shortages, which have been severe in recent years, there are structural issues which will result in significant workforce shortages (based on current service delivery models) into the future. The disability sector will need to find ways of managing this if it is to be well-equipped to respond to future demand.

Future workforce shortages will change the way disability support services are organised. While greater attention on individualised services (and funding models) will encourage a move to a greater use of one-on-one support, workforce shortages are likely to push in the opposite direction (to group-based support). The relative impact of each of these trends is not possible to predict.

The expected workforce shortage will not be confined to the disability sector; it will be experienced in all human service fields. Demand for workers will be so intense that it is likely to change models of support services.

In some cases the shortage of labour will lead to increased and innovative reliance on technology (for example, video-conferencing to support families who have children with disability); however, the disability sector's capacity to substitute labour for technology is limited because of the centrality of the human relationship to disability work.

Transfer of government services

In 1995, the Industry Commission noted that the government “could expect significant cost savings by making greater use of the community sector in the provision of government services”. The Commission found that, in general, non-government organisations are significantly more effective providers of services than equivalent government agencies. For disability services, this finding is reaffirmed in the annual *Productivity Commission Report on Government Services*.

Because not for profit disability organisations are more efficient in expending public funding than government services, governments wanting to reap efficiency improvements would gain far more from transferring services to not for profit organisations than by further squeezing the sector for productivity gains.

4. Service delivery

Impacts of government contracts

Standards of service delivery should not (but often do) mean standardisation (homogeneity). Government contracts for service delivery are increasingly prescriptive, despite governments giving in principle support to the value of flexibility and client-centredness. This trend is exacerbated by the absence of negotiation—governments, by and large, present contracts to the sector to be signed. These contracts generally pay excessive attention to processes and inputs; less attention is paid to outputs and outcomes. And the community development work that is required to support the capacity of a community to respond to and meet the needs of people with disabilities is neither recognised nor funded. Government contracts have become so highly prescriptive they can result in the not for profit sector being perceived as an arm of government. This blurring of the boundaries is counter-productive.

While the diversity of the not for profit sector disability sector sometimes appears as messiness and inefficiency to the bureaucratic eye, it is linked to the independence, innovation and local responsiveness of service organisations. This diversity, however, is threatened by contractual arrangements which offer little capacity for piloting new approaches. In addition, prescriptive contracts can minimise the scope organisations have for ‘value-adding’ to the services they provide. Indeed, Australian Disability Enterprises, pushed to focus on commercial viability, have often had to scale down the additional services and supports they provide—such as assisting supported employees with their social, health or financial concerns.

Disability is a permanent or long-term condition and the building of relationships is the core of disability work. Governments’ purchasing arrangements can cut across this. The potential for services users to experience disruption at the completion of a contract is high if a change of provider is to occur. Clients need to establish relationships with new service providers and their staff, and may need to alter or adjust their connections with local communities. New service providers may need to establish these community connections. These transactions costs can be high but will often be difficult to measure. They can be minimised if non-government organizations that meet agreed benchmarks are exempt from having to re-tender for the services they provide.

Improving funding and contractual arrangements

A sustainable disability service system is essential to support people with severe disability to have choice in their lives: to decide what they will do, when, how and with whom they will do it. A vibrant sector looks for opportunities for people with disability and helps maximise the benefits of these. It seeks purposeful engagement with local communities and supports the personal networks of people who cannot do so unaided. But to do this work, the sector requires a fair level of funding which reflects the actual costs of service delivery. Years of inadequate funding, exacerbated by ‘productivity cuts’, has undermined the sector’s ability to provide responsive and flexible supports.

High quality disability support services require flexibility, which is a core value of contemporary service design. The idea of ‘flexible support packages’ contrasts with a ‘one size fits all’ approach which tries to fit people of diverse needs and aspirations into a square hole. Flexibility reflects the value society places on individuality, diversity and choice.

Yet there are real obstacles to achieving flexibility in practice. Flexibility requires fewer rather than more rules, but service providers face a rising tide of regulation. Typical is the situation in Queensland where the *Disability Services Act 2006* imposes a raft of new controls indicated by the Act’s size, which is 135 pages longer than the 24 page 1992 Act it replaced. This is despite flexibility being a core principle of the State’s Disability Sector Quality System.

Some strict rules are certainly necessary to ensure accountability, but layers of complex rules are counter-productive and generate inefficiencies. Excessive regulation also diverts resources from direct service delivery to administration. Disability Employment Network providers have had to comply with at least a dozen funding deeds, sets of program procedures and assessment guidelines amounting to over 500 pages.

At the other end of the spectrum is the all-too-common practice of services being delivered prior to a contract being signed.

A history of low funding has undermined the ability of non-government organizations to maintain and update infrastructure or sustain services. As Professor Mark Lyons et al write in a research paper for the National Roundtable of Nonprofit Organisations:

> In areas of social assistance such as child welfare, women’s or youth refuges and disability services, there is … great frustration about the difficulties of obtaining capital. For some, particularly in the disability services field, there is a huge unmet need for capital to massively expand the provision of group homes. Because these require specialist fittings for many of their residents, they must be purpose built or obtained on a long term lease and renovated.

> Many others, providing vocational programs, day programs and the like are unable to access the small amounts of capital needed to operate efficiently and safely, such as renewing IT systems, or replacing an ageing bus. State government support is available, but it is grossly inadequate. The problem is particularly acute for disability services, especially for the provision of accommodation.

The situation for many providers is now critical.

Every jurisdiction has queues for disability services, including accommodation support, respite, community access, therapy, employment and assistive technology. In 2007 AIHW conservatively estimated that 23,800 Australians with disability need accommodation or respite services and 9,400 people require community access services (if recreation and holiday programs are included). This demand is rising with population growth, ageing and the decreasing availability of family carers. Almost half a million Australians are the primary carers of a person with disability, with one in four carers aged over 65 years. AIHW estimates that the number of Australians with severe or profound disability will increase by 34,600 between 2006 and 2010.[4]

In recognition of the existing and growing need for disability services, a Senate Inquiry into the Commonwealth State Territory Disability Agreement (CSTDA) concluded - as its principal recommendation - that both levels of government should provide substantial additional funding for disability services.[5]

The provision of funding is not only insufficient, it is inequitable. The level of support available to individuals with similar needs varies significantly across and within jurisdictions. Among other factors, access to disability support services can depend on *how* a disability was acquired. In four States and Territories no-fault road accident insurance schemes provide a lifelong entitlement to rehabilitation and disability services for people who acquire a severe disability from motor vehicle accident. This entitlement is absent in other States and does not extend to people who acquire a disability from other causes.

NDS strongly supports the development of a national scheme which would provide universal and equitable no-fault entitlement to disability services for all Australians who require long-term support. Such a scheme would establish a safety net for all Australians.

Competitive neutrality

Concern about competitive neutrality between not for profit and for profit providers is regularly raised and is regularly over-stated as an issue.

NDS considers the tax exemptions and other concessions provided to NFP organisations, charities and Deductible Gift Recipients to be appropriate and not a cost to government revenues. Within a not for profit disability service organisation, surpluses are not distributed to individuals but are re-invested in activities associated

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[4] AIHW 2007, Current and future demand for specialist disability services, AIHW, Canberra.

[5] Senate Community Affairs Committee 2007, *Funding and Operation of the Commonwealth State/Territory Disability Agreement*, viewed at http://www.aph.gov.au/SENATE/COMMITTEE/CLAC_CTTE/completed_inquiries/2004-07/cstda/report/report.pdf .

with the charitable purpose of the organisation—there is no accumulation of private wealth.

Any surpluses that may be generated by NDS member organisations are used to support people with disability; they are ultimately expended as additional services. Suggestion that the tax concessions that assist in the generation of these surpluses should be measured in terms of ‘a cost to government’ of that they are somehow unfair to for profit organisations is inappropriate and a misrepresentation of reality.

Surpluses support the provision of services that would otherwise need to be directly funded by governments.

In its submission to the review into Australia’s Future Tax System, NDS argued for an increase to the Fringe Benefits Tax (FBT) exemption/rebate cap. Not for profit disability service providers across Australia are experiencing increasingly severe workforce shortages, exacerbated by wage levels which are limited by inadequate government funding. These shortages have intensified under recent tight market conditions and the inability of the sector to pay comparable wages.

Many disability service providers are endorsed FBT exempt employers and use the allowable fringe benefits arrangements to offer salary packaging to help attract and retain staff. The introduction in 2001 of the FBT exemption/rebate cap (set at a grossed-up value of $30,000 per employee in each FBT year) enabled eligible employers to effectively increase the value of employees’ remuneration and assisted in the recruitment and retention of staff. Low paid workers benefit.

The value of this benefit has, however, been eroded over recent years. Since 2001, the Fringe Benefits Tax exemption/rebate cap has not been increased from $30,000 grossed-up value per employee despite undertakings by the Treasurer at the time to review this cap regularly in light of changes in average wage levels. No increase has been made to this figure to allow for inflation, despite average weekly ordinary time earnings increasing markedly over these years. Unless the sector can increase the real value of the salary packages paid, workforce shortages will threaten both the viability of the sector and the quality of the services it provides.

5. Trends and developments

Individualisation

Services for people with disability are becoming more personalised and individualised—person-centred planning, individual plans, individualised funding, one-on-one community access support are now commonly part of service arrangements. This trend is expected to continue.

The use of individualised funding as a model to support people with disability is increasing. Although the trend is not uniform around Australia, it is apparent across all the main service types funded through the CSTDA (now the National Disability Agreement). While the term ‘individualised funding’ is used to describe a myriad of arrangements it is, at its most basic level:

> …public funding that is allocated to the individual, based on his/her unique strengths and needs, and placed under the control of the individual to enable them to live in the community as a full citizen.[6]

Importantly, this funding is portable—people with disability (and their families) determine how it is spent and on what services.

An organisation may at present manage a package of funding for an individual but this arrangement could change at short notice. A person with an individualised funding package can move from provider to provider, and can purchase services from a range of providers concurrently. If the use of this funding arrangement becomes more common, service providers' funding streams will become less predictable. Cash flow management is likely to become more difficult (particularly as payment may be received up to 2–3 months after service delivery), the need to manage 'bad debt' will become necessary, and the servicing of fixed costs will be more difficult. The question of how disability service providers will maintain infrastructure and administrative functions within a demand-driven model becomes critical. And, importantly, individualised funding will add to the administrative burden on providers by requiring additional financial accountability and reporting.

A detailed discussion of individualised funding, including its implications for disability service providers, is contained in the Appendix 1.

Environmental impacts

The financial impost on not for profit organisations of responding to environmental challenges has received minimal attention. Environmental responses will add to the costs of the sector; costs associated with the implementation of new technologies, new infrastructure and possibly some form of emissions/carbon taxation.

Some—limited—information about the impact of emissions taxation (or trading) is available from an analysis by The Australia Institute, which concluded that the introduction of some form of carbon pollution reduction scheme (CPRS) would result in increased costs to the community services sector which should be compensated (or would need to be borne by the workforce). It noted:

> Put simply, as a result of the CPRS the costs of providing community services will likely rise by between 0.9 per [sic] and 1.4 per cent, depending on the extent to which community sector workers are willing to take a real reduction in their incomes[7].

Asking an already low paid workforce to take a wage reduction is not acceptable and would exacerbate the existing workforce shortages.

Further work on this is required as a matter of urgency.

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[6] Dowson, S & Salisbury, B, 1999, *Individualised funding: Emerging policy issues*, p. 3. viewed at http://www.ndt.org.uk/docsN/IF_Policy_issues.pdf on 01/02/08.

[7] Richardson, D. 2008, *Who are the (un)intended losers from emissions trading?* The Australia Institute, Canberra, p. 6.

Complex business environment

Disability service providers face a demanding future: a rising tide of regulations, intensifying competition; increased accountability and reporting requirements from governments; raised expectations of clients about their degree of voice, choice and control. The financial pressure on organisations is increasing with the economic downturn.

To survive, or indeed thrive, in this complex world, service providers require systems to collect and manage data; skills in winning tenders and negotiating other work; ability to identify evidence of outcomes; sound internal auditing systems; and well-developed business planning and financial skills. They have to make astute judgements about the optimal structure and configuration of their organisation.

Service providers need to work out how to comply with stringent obligations regarding occupational health and safety without compromising their mission to expand the opportunities and choices available to people with disability.

The increasingly complex business environment within which disability service providers operate has the potential to distract attention from the mission of the organisation to compliance and risk management. Flexible and responsive service delivery to disadvantaged Australians could be compromised.

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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 more than 650 not-for-profit 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.

APPENDIX 1

Individualised Funding: what it requires to work

Purpose of this paper

The use of individualised funding to support people with disability is increasing. Although the trend is not uniform around Australia, it is apparent across all the main service types funded through the CSTDA. Over the three years to 2005-06 the individualised funding of respite, for example, rose from 6% of service users to 28%; accommodation support from 21% to 37%; and community access from 15% to 29%.[8] All disability employment services have now moved to case based funding—a quasi-individualised model. In their 30 May 2008 communiqué Federal, State and Territory Disability Services Ministers agreed that “access to services would be provided on a case-based approach, to ensure people with disability receive appropriate services when needed.”

The rise of individualised funding is driven by attractive values such as consumer choice and personal empowerment. But the design, implementation and management of individualised funding models—depending on which version is chosen—can raise complex and contentious issues.

The purpose of this paper is to help identify those issues and to outline the conditions required for individualised funding to function effectively for consumers, service providers and governments.

Background

Origins

Individualised funding seems to have its origins in the 1970s in British Columbia. There, a number of families wanting to secure self-determination for their sons and daughters with intellectual disabilities—to enable them to move out of institutions—negotiated arrangements for funding to be provided at an individual level. At a similar time, some people with physical disabilities began demanding the ability to create their own support system by hiring and paying their own staff.[9]

Since this time, aided by deinstitutionalisation and the disability rights movement, many countries have adopted individualised funding mechanisms, to varying degrees and in a range of forms. Models now operate in parts of Europe, Canada, the USA, the United Kingdom, New Zealand and Australia.

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[8] AIHW 2007 & 2006, *Disability Support Services 2005–06 & 2004–05, National data on services provided under the Commonwealth State/Territory Disability Agreement*, AIHW, Canberra.

[9] Dowson, S & Salisbury, B, 1999, *Individualised funding: Emerging policy issues*, pp.1–2. viewed at http://www.ndt.org.uk/docsN/IF_Policy_issues.pdf on 01/02/08.

Within Australia, the introduction of Local Area Coordination in rural areas of Western Australia in 1988 marked the beginning of an interest individualised funding. This initiative was strengthened in 1993 by the introduction of the *Disability Services Act*, which established the WA Disability Services Commission and allowed for grants to be approved to individuals.

> Local Area Coordination had a clear charter, 'to support people with disabilities and their families to identify their own needs, determine their preferred services and control the required resources to the extent they desire, so they can pursue their chosen lifestyle.' There were two kinds of funding, tied and untied. Untied funding was designated for 'one-off' funding needs, were modest, and often used in an emergency, at the coordinators' discretion. Tied funding was normally for larger amounts and required individuals and families to submit a detailed plan.[10]

Most jurisdictions within Australia have now introduced some degree of individualised funding, and some are currently considering expanding the use of this approach.

Philosophical underpinnings

The impetus for individualised funding draws on two discourses: social justice and market theory.

The social justice approach emphasises 'the importance of integrating rights, across a full range of personal, social, educational and economic life experiences.'[11] It promotes the active participation of all citizens, stressing that they should not be the passive recipients of services but in control of when and how they are delivered.

The market perspective conceptualises disability service users as customers. By giving customers purchasing power individualised funding delivers what they want when they want it. Moreover, the 'amalgamation of consumer choices will shape the overall pattern of service provision'[12]. Proponents believe this will result in an efficient and effective use of public funds.

These complementary discourses mean that the idea of individualised funding attracts supporters from both sides of politics.

A recent paper by the Victorian State Services Authority, developed in conjunction with Demos, suggests that there are currently four key imperatives driving governments:

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[10] Lord, J & Hutchison, P, 2003, *Individualised support and funding: Building blocks for capacity building and* inclusion, Disability & Society, Vol. 18, No. 1, pp. 75–76.
[11] Pearson, C 2000, *Money talks? Competing discourses in the implementation of direct payments*, Critical Social Policy, Vol. 20, p. 461.
[12] ibid., pp. 460–1.

- the shift from outputs to outcomes;
- the shift from welfare to social investment;
- the shift from command and control to innovation and collaboration; and
- the shift from standardisation to personalisation and customisation.[13]

The move to individualised funding is consistent with these drivers of public sector reform.

What is it?

Across Australia and internationally, the term ‘individualised funding’ is used to describe a myriad of arrangements. At its most basic level, it is:

> …public funding that is allocated to the individual, based on his/her unique strengths and needs, and placed under the control of the individual to enable them to live in the community as a full citizen.[14]

While the concept expressed like this is simple, its effects can be complex:

> State fund-holders properly retain their responsibility for ensuring effective and equitable use of public funds, but lose their direct involvement in the spending of funds. Service providers, for their part, must finds ways to deliver quality services without the security of block-funded grants…And, last but by no means least, those who choose to receive IF [individualised funding] accept not only the power and freedom, but also the very substantial responsibilities of planning, buying and managing their supports.[15]

A reading of the literature about individualised funding uncovers an extraordinary number of terms, either used interchangeably or in association with each other: ‘self-determination’, ‘person-centred’, ‘individually-attached’, ‘individual budgets’, ‘brokerage’, ‘financial intermediaries’, ‘consumer-direction’, ‘self-direction’, ‘direct payments’ are some. Self-determination is broadly acknowledged to be the central goal or focus of individualised funding, but that term also attracts diverse definitions.[16]

In addition to the debates over terminology is disagreement about whether particular arrangements termed ‘individualised funding’ really fit the definition. Research undertaken by the Roeher Institute categorised a number of arrangements on whether they conformed to the principles of individualised funding (see Figure 1).

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[13] State Services Authority 2008, *Towards agile government*, State Government of Victoria Demos, Melbourne, p. 4.
[14] Dowson, S & Salisbury, B, op. cit., p. 3.
[15] ibid., p. 3.
[16] Turnbull, A & Turnbull, R 2006, *Self-determination: Is a rose by any other name still a rose?,* Research and Practice for Persons with Severe Disabilities, Vol. 31, No. 1, p. 1.

Figure 1: Is it really individualised funding[17]

CONTROL WITH STATE FUND-HOLDER	Individual service costs identified, but only as accounting exercise within block-funded services.	**ARRANGEMENTS WHICH DO NOT CONFORM TO THE PRINCIPLES OF INDIVIDUALIZED FUNDING.**
	Services costed and allocated individually, but assessed and controlled by fund-holder.	
	Standard allocation of vouchers issued to individuals for ‘purchase’ of services.	
	Individually determined credits which individuals can trade for services from authorized providers.	**ARRANGEMENTS WHICH ARE MARGINALLY CONSISTENT WITH IF.**
	Responsibility for service planning and funding requirements notionally passed to the individual, but overseen by ‘broker’ answerable to state fund-holder.	
	Individual allocation remains in hands of state fund-holder, but spent according to the person’s requirements, subject to contractual constraints from state fund-holder.	**ARRANGEMENTS WHICH ARE FULLY CONSISTENT WITH IF.**
	Individual allocation passed to fiscal intermediary, to be spent according to the person’s requirements, but subject to contractual constraints from state fund-holder.	
	Individual allocation of money passed to the individual, subject to binding conditions of use, with monitoring arrangements.	
CONTROL WITH INDIVIDUAL	Individual allocation of money passed to the individual with no imposed conditions of use.	

Understanding the issues

Government perspective

The administration of public funds is a key function of governments. Governments need to demonstrate fiscal responsibility for both public expenditures and for the services purchased. As Senator Ursula Stephens, Parliamentary Secretary for Social Inclusion, stated at the 2008 ACOSS Conference:

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[17] Dowson, S & Salisbury, B, op. cit., p. 6.

> The government also needs to be able to assure the Australian public that there is transparency, accountability, efficiency and value for money in the services being delivered.

In developing guidelines for individualised funding, governments need to decide on what types of services can be purchased, from which organisations or individuals, what quality standards are required and how accountability will be provided. But government's requirements are not necessarily the same as those of the individual person with disability:

> the fund-holder does have additional interests which may conflict with an individual's. The fund-holding agency has not only to ensure that IF recipients are adequately assisted, but also to *demonstrate* fiscal responsibility for public expenditures and services. This implies the need to monitor the actual use of funding—relatively easy if payments are made by the state fund-holder, or fiscal intermediary, direct to the provider agency, but risking complaints of intrusiveness when funds have been passed to the individual.[18]

Individual perspective

On evaluation, recipients of individualised funding overwhelmingly report satisfaction with the system.

> The opinions of service users in many countries have been canvassed about their experience of consumer-directed care. Responses vary of course according to scheme and service user group, but a high proportion of reactions have been positive to the idea of consumer-directed care as an option, given the right kind of support.[19]
>
> Evaluations of DPs [direct payments—one of a range of funding mechanisms] report a very high recipient satisfaction rate, particularly in comparison to conventional services…The most important aspect of this satisfaction seems to be the opportunity to exercise choice and control over support arrangements…As a consequence, many recipients report positive benefits to their quality of health and social life…Recipients report enhanced personal autonomy, emotional and psychological wellbeing, raised opportunities and a greater quality of life…[20]

However, satisfaction depends on certain conditions being met. If the allocation of funding to an individual is insufficient to enable that individual to exercise real choices and purchase what they need, then the promise of self-determination will be experienced as hollow.

> Even with effective access guaranteed, there remains the potentially difficult issue of the potential gulf between what individuals might want and what government might be prepared to endorse and fund so that there [sic] needs are actively met.[21]

In addition, people with disability (or their advocate/carer) who opt for direct payments can be overwhelmed by the administrative tasks required for the

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[18] ibid., p. 7.

[19] Social Care Institute for Excellence 2007, *Choice, control and individual budgets: Emerging themes*, Research briefing no. 20, p. 4.

[20] Spandler, H 2004, *Friend of foe? Towards a critical assessment of direct payments*, Critical Social Policy, vol. 24, pp. 192–3.

[21] Dowson, S & Salisbury, B, op. cit., pp. 9–10.

management of funds, particularly those relating to financial reporting and audit. Finding a process that satisfies governments but is manageable for individuals (and service providers) is difficult.

Service provider perspective

While disability service providers would strongly endorse the concept of self-determination by people with disability, the use of individualised budgets can present them with challenges:

- **Financial viability**
  A move away from block funding to individualised funding has administrative and cash-flow implications for organisations. The right of an individual to move easily from one provider to another reduces income predictability. The management of uneven cash flow requires service providers to have sophisticated financial skills and take on increased risk, particularly if the payment for services occurs some weeks, even months, after they are delivered. For the first time organisations may have to put in place arrangements to manage ‘bad debt’.

  In addition, there are increased administrative demands on organisations to monitor and invoice individuals for services delivered and to provide accurate reporting both to individuals and to government.

  A very real concern of service providers is how *fixed costs* will be serviced—all organisations require resources just to open their doors, prior to the delivery of any services to people with disability. The question of how organisations will maintain infrastructure and administrative functions within a demand-driven model is critical.

  And, if government shifts from funding organisations to funding individuals and families will that affect public donations, which are directed to organisations not individuals?

- **Price taking or price setting**
  The notion of a market assumes a price mechanism based on the interaction of supply and demand, with suppliers free to set prices constrained by the pressure of competition. However, in current Australian approaches to individualised funding, governments have retained their role as price setters.

  Arguably, a continuing role for government is justified by the imperfections of the market —the lack of information available to consumers, the limited choice of providers, and disadvantages to rural and regional people by lack of competition and higher service delivery prices. But if government continues to set prices it should cover the full and reasonable costs of service delivery, with appropriate annual indexation. Currently, this is not the experience of providers.

  Moreover, families may be unhappy to pay a service charge (for example, for a therapist) that includes the cost of travel to the home, not just the time spent in the home.

- **Workforce**
  A concern raised overseas about individualised funding is that it does not support staff training at a time when the changing roles of direct support workers require increased investment in training:

  > A…staffing concern is how agencies which have traditionally received funding for staff training will continue to address this need. Even if individual budgets have a training component built in, there remains a concern about whether this will be sufficient to address the issue of minimum standards that most agencies will probably wish to ensure in their staff.[22]

  > Major changes have also occurred in the expectations and roles of direct support professionals [DSPs]…Today, in addition to meeting peoples' basic health, safety and care needs, DSPs have responsibilities to support people to develop and achieve their own personal goals, to balance risks with choices, to connect with peers, friends and family members, and to be full and active citizens in their communities. They carry out these expanded responsibilities with less supervision and increasingly while working alone. These expanded responsibilities and increased isolation of DSPs have not been accompanied by increased qualifications, education or training. As a result, many DSPs report that their training has been insufficient to prepare them for their job responsibilities.[23]

  A recent report highlights the need to investigate the systemic impact of a growth in consumer-directed care on workforce training:

  > In the US, it could be argued that movements to empower consumers have occurred at the cost of, or without substantial consideration of, broader implications for skill sustainability…There is, as yet, little research available to give insight on the impact of consumer-directed care on skill and training levels within the personal care industry…The only evaluation that addresses skill in its terms of reference found that…the greatest growth in the personal care assistant labour market occurred among workers with absolutely no formal training or skill in caregiving (Paraprofessional Health Care Institute 2003).[24]

  An additional concern of providers is that an increase in individualised support arrangements may result in a greater use of casual labour: for example, to meet demands for out-of-hours services and for services to be provided for short periods of time. Staffing these arrangements is already known to be more difficult than those occurring in 'regular' hours'.

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[22] ibid., p. 8.

[23] Hewitt, A. 2001, *Issues in the Direct Support Workforce and their Connections to the Growth, Sustainability and Quality of Community Supports*, p. 2 viewed at http://ww.ancor.org/issues/shortages/issues_in_the_direct_support_wor.htm on 01/03/2008.

[24] Community Services and Health Industry Skills Council 2008, *Identifying paths to skill growth or skill recession, Executive summary*, CSHISC, Sydney, *pp*. 11–12.

- **Standards and accountability**
  Governments in Australia require funded organisations to meet the Disability Service Standards. The improvement of quality assurance systems, based on the Disability Service Standards, has been identified as a priority for the next CSTDA.

  Quality service delivery is in the interest of all parties: people with disability, service providers, governments and the broader community. There are, however, costs associated with implementing and operating appropriate systems. These systems are likely to become even more complex as jurisdictions move to incorporate outcomes as a key component of their quality framework. Measuring outcomes in an individualised funding system has the potential to increase the costs of compliance.

- **Crisis management**
  As part of their regular business, service providers support people with disability through crises—by providing additional hours of support, by changing support arrangements and by providing different types of services. Block funding provides the service provider with flexibility to manage these circumstances. If individualised funding is to work, it must be flexible enough to allow a response to unpredicted events to be put in place quickly and easily.

  > A possible response … is to either have a crisis component funded as a percentage of each individual plan, or to make a crisis budget available to agencies (or individuals) which could be accessed via negotiations with government.[25]

- **Community development**
  A consequence of the increasing support provided to people with disability within the community is an increased requirement for community development work. It is not clear how community development work is funded under models that attach budgets to individuals.

Making it work

Principles

Work done by the National Development Team in the United Kingdom indicates that an individualised funding system needs a foundation of strong principles:

> Although there are some core elements in both the In Control programme and the IB [Individual Budget pilots], both initiatives are weak on centrally-defined, over-arching principles and structures. As a result many aspects of local projects are left for local people to decide. At first, this seems to make good sense. It seems to offer a more creative approach, and developing local projects from 'the bottom up' should give local users and carers more chance to influence what happens.
>
> But in reality there are two flaws. Firstly, it means that a lot of time is wasted 'reinventing wheels'. Some very important principles and practical lessons have emerged from international experience…Secondly, a bottom-up approach is unlikely to put decision-making in the hands of people who use services…Experience in the UK, and

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[25] ibid., p. 8.

> internationally, demonstrates how easily IF systems are downgraded at the planning stage, or drift back into old habits, because there is not enough understanding of, or commitment to, the core principles of IF.[26]

The development of a set of principles agreed by individuals, governments and service providers is important to guide the development and evaluation of a funding model

System design

- **Obtaining funding: eligibility, assessment, planning & allocation of funds**

The design of access arrangements requires careful consideration in relation to eligibility, assessment, planning and allocation of funds.

Eligibility is relatively straightforward; but assessment of need is more complex. It raises the question of whether an allocation of funds should be based on an assessment of support needs using some assessment tool, or whether it should be determined on the basis of a plan or vision to achieve explicit outcomes.

> It [individualised funding] requires that funding be allocated to meet individual needs for support that are defined in relation to a person's vision/direction, and to their plan for getting there. We have naturalized a categorical, impairment-based approach to funding where people get funding depending on an assessment of their functional needs. So if we have a system for allocating funds on the basis that a person has, say a level 1,2,3, or 4 need, then we may be allocating funds on an individual basis, but we are not putting in place a system of individualized funding that can meet the test of self-determination.[27]

Related to this is a question about the size of the individual's budget. This will be vigorously debated as governments move away from block grants based on costs associated with the delivery of group activities. Disaggregating this funding without a substantial injection of new funds would curtail the choices available to people.

The role of planning within an individualised funding model also generates debate. Some advocate that planning is the key to self-determination so should precede resource allocation. Others insist that a resource allocation should occur before planning. A finding from the Victorian individualised funding initiative, *Support & Choice*, supports the latter approach:

> Participants/families were clearly more satisfied with the planning process and more in control of their plan when they were provided with a funding range to plan around. This gave them the opportunity to develop realistic goals and priorities, created a greater likelihood of plans being fully accepted by the verification panel and generated more commitment and ownership of the plan. This finding highlights a tension between pure person-centred planning approaches, which encourage dreaming without boundaries,

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[26] The National Development Team, *Individualised funding and support brokers,* pp. 3–4, viewed at http://www.ndt.org.uk/projectsN/IF.htm on 03/02/08.

[27] Bach, M 2000, *Individualized funding and self-determination: making sure the means does not become the end*, p. 8, presented at the First International Conference on Self-determination and Individualized Funding, viewed at http://members.shaw.ca/individualizedfunding/Articles%20for%20download/Self-Determination%20-%20Michael%20Bach.doc on 20/03/08

and the provision of individualised funding within constraints such as the available budget.[28]

There are related questions about whether there is a need for a formal planning service which is independent; how any planning service would be funded; and whether all people accessing individualised funding would need to use such a service. Within the literature, there is broad consensus about the need to have planning services available to support those individuals who would like assistance. There is considerable agreement that this service should be separate from the funding allocation process (be located outside government) but less agreement about the role of service providers in this task.

Should individuals have free access to a government-funded planning service or should planning be one of the possible services an individual with funding may choose to purchase? A rights perspective would suggest that the decision to pay for planning should sit with the individual, but others argue that until people have experienced the benefits of good planning they are unlikely to value it highly enough to purchase it. Related planning questions are whether individuals should be required to use authorised planners—either to assist with the development of a plan or sign off on it with respect to it meeting certain requirements—what level of resources should be allocated to planning, do plans have to be lodged or verified (if so, where), and what role do planners have, if any, to monitor the delivery of support against the plan.

- **Using funding: purchasing, quality, flexibility & portability**

Once in receipt of funding, an individual will be at a point of being able to purchase services. Guidelines about the operation of the program will need to cover elements such as:

- what can be purchased;
- from where;
- how closely the purchases have to relate to the plan;
- how the plan will be managed;
- how portability will be managed;
- how crises will be funded; and
- whether people will have the ability to 'bank' funds to use at another time.

The decision about what can be purchased is an important one. What connection does a purchase need to have to an individual's requirement for support? Some purchases in an individualised funding environment are likely to be from generic services, where standard consumer protection processes will be in place. But the question of where personal support services are sourced from is more complex. As the funding will be provided through the CSTDA, there is a strong case for services purchased being required to meet the Disability Service Standards.

In the United States, research suggests that the option to employ family carers and friends has put downward pressure on working conditions:

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[28] Lime Management Group 2005, *Evaluation of Support & Choice Implementation*, A report for the Victorian Department of Human Services, p. 81.

> Paid family carers and friends play a key role as independent workers, accounting for the majority of providers…Family caregivers were more likely to feel close to beneficiaries, but reported more emotional burden than other individual providers…The California study illustrates the typical compensation problems facing home care workers, with virtually all individual providers reporting no fringe benefits [such as paid sick leave, paid annual leave and paid travel costs].[29]

Clearly, the presence of a plan should influence the types of services purchased—the question is how closely? Does the presence of a plan 'lock in' purchase decisions until an application to alter it is made or some review is undertaken, or should individuals have the discretion to alter these decisions without an approval process? The greater the flexibility given to this element of the model, the greater the control invested in an individual but the greater the accountability challenges will be. And clearly, if almost total flexibility is provided to the individual to be able to make and change purchasing arrangements it can be questioned whether a plan is needed in the first instance.

A related consideration (important for the financial and workforce management of organisations) is the length of the notice period required for the termination of services being provided (common in contracts for services such as gymnasium membership).

The options regularly put forward for the management of a plan include directing the funding to an individual (or advocate/carer), to a financial intermediary or to a service provider. Individuals self-managing their package have the ability to direct all the funds to support arrangements—a benefit often raised by supporters. However, all organisations undertaking the management of individualised funding packages (direct service providers as well as financial intermediaries) will incur costs and should be compensated. The amount of this compensation, whether it is capped and whether it should be paid by the funding body or from an individual package are decisions which need to be made.

Crises will occur in the lives of people being supported through individualised funding models—responses must be rapid, flexible and appropriate. The funding of these arrangements needs consideration as a response will sometimes require resources greater than what is available and may need to be accessed immediately. Complex approval processes are not appropriate. Some crises are likely to be the result of an individual 'overspending' (or perhaps spending on non-approved items) rather than the need to alter support arrangements in an emergency. Appropriate management of these cases is critical to ensuring ongoing public support for individualised funding arrangements.

Related to the arrangements developed for the management of crises is whether individuals should have the ability to 'carry over' some unspent funds from one year to the next. The ability to do this would provide individuals with greater flexibility, possibly even to manage crises, should they occur.

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[29] Wiener, J & Brown, D 2004, *Home and community-based services: A synthesis of the literature*, RTI International, Washington, pp. 21–22.

- **System support: prices, accountability & sustainability**

People supported by individualised funding will be best served by the existence of a robust disability services system which offers choice and flexibility. Related to this is the need for infrastructure and sustainability funding separate from individualised budgets. This has been proposed internationally:

> …"viability" concerns begs the larger question of just how much financial support, outside of revenue generated from individual contracts, that agencies should expect from government to maintain administrative integrity, and thus the ability to respond to what will undoubtedly be a changing marketplace. It seems unfair, and poor public policy for that matter, to place agencies in a vulnerable position because of the whims of the marketplace. It is for this reason that some observers have proposed what is referred to as the 85/15 model. In this approach, the funding body provides community agencies…with up to 15% of their anticipated yearly operating costs, thus ensuring some ongoing capacity to respond to issue impacting agency functioning…The remaining 85% of operating revenues are supplied from contracts with individuals.[30]

Individualised funding will certainly result in increased costs associated with reporting and accountability (invoicing and processing payments, reporting to individuals as well as to governments, and monitoring a greatly increased number of service agreements). These costs should not be borne by providers without recompense, nor is it desirable that the supports available to individuals should be diminished to fund them. Processes that provide sufficient information about the expenditure of public money without being administratively complex and time-consuming need to be developed.

Individualised funding models are more expensive to operate than block-funded models. Transition arrangements need to be implemented and the ongoing existence of a robust service system needs to be ensured. People with disability need to have choices—about the types of supports, about the providers of supports, about the location of supports. Quality must underpin these choices.

Conclusion

The development of individualised funding is part the continuing move towards community living, the empowerment of people with disability and the rejection of a 'one size fits all' approach to service delivery. These are goals which NDS supports.

However, individualised funding is not the only means of achieving these goals. Practices such as person-centred planning, for example, are re-shaping services to reflect the needs and aspirations of individuals, without relying on individualised funding. Moreover, if poorly implemented, individualised funding could actually restrict individual choices and service flexibility. This would occur if individual budgets were inadequate; or if the financial viability of services were undermined; or if the quality of services were depleted; or if the funding model could not accommodate unpredicted circumstances.

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[30] Dowson, S & Salisbury, B, op. cit., p. 8.

To avoid these pitfalls the design and implementation of individualised funding must be carefully done and evidence-based.

> In all, over fifty IF projects have been developed worldwide. Not all of them have been very good, but nevertheless they offer an enormous amount of learning about what works and what doesn't work. And, of course, alongside these developments there has been an international community of people debating and refining the ideas in the light of experience.[31]

NDS recommends that the following statements be used to shape the development of new individualised funding models in Australia:

- transitional funding is provided to disability service providers to ensure their financial viability during the introduction of the new funding model;
- funding ensures that well-run organisations are sustainable;
- organisations undertaking financial management on behalf of individuals are compensated for doing so;
- key stakeholders are involved in establishing the principles underpinning the development, implementation and evaluation of an individualised funding model;
- the introduction of new individualised funding models is incremental, allowing time for review and refinement;
- the allocation of resources is based on an assessment of needs, which can be moderated by factors such as a person's goals and existing support arrangements;
- a mechanism to appeal the allocation of funds is in place;
- a re-assessment/re-application process exists to respond to the changing needs of an individual;
- a nominal allocation of funds, at least within a band, is made prior to the development of a plan for the expenditure of funds;
- the funds allocated are sufficient to provide real choices for people with disability;
- planning services are available to support people who would like to use them and should be independent of government;
- when necessary, people undertaking planning are supported to think broadly about aspects of their lives;
- approval processes for plans, including changes to them, are simple and quick to implement;
- arrangements for dealing with a crisis are flexible, quick to implement and provide additional funding when needed;
- unspent funds are able to be 'banked' for future use;

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[31] The National Development Team, *Individualised funding and support brokers*, p. 2, viewed at http://www.ndt.org.uk/projectsN/IF.htm on 05/02/08.

- allocated funds are used for disability support and not for gambling or illegal purposes;
- clear agreements or contracts between individuals and service providers exist;
- individuals wishing to terminate a contract with a service provider provide a reasonable notice period;
- personal support services are purchased from organisations that meet relevant quality standards;
- family members are used as paid carers only in circumstances where there are not obvious alternatives;
- if family members are to be paid for services they must be employed by an organisation that meets relevant quality standards; and
- prices for services cover the full cost of delivery.

There are issues on which NDS has not yet formed a position but considers important in the development of individualised funding. These include:

- What services should be supported and available outside an individualised funding model? Planning, case management, case coordination, community development, therapy and transport have all been suggested as needing special funding arrangements.
- Is there a need to define what constitutes ‘disability support’?
- How should an assessment of support needs be determined and influenced by an individual’s goals and personal circumstances?
- What level of funding, in an environment of unmet need, should be available for planning services?
- Should disability service providers have the ability to set their own prices?
- How should transitional and sustainability funding be structured?

The importance of individualised funding in the achievement of self-determination demands that models are well-structured to ensure good outcomes for people with disability. This will require a viable and dynamic disability sector into the future.

August 2008

APPENDIX 2

Quality of Life Outcome Measures in Disability Services

1. About this Submission

This submission aims to inform and direct key decision makers in the development of Quality of Life Outcome Measures for Disability Services System across Australia. ACROD, as the industry body for disability services, strongly supports Quality of Life Outcome Measures as a process to determine the effectiveness of disability services. The current system of service monitoring tends to focus on service outputs, such as the number of people and hours serviced, without an effective measure of the impact of services on actual outcomes experienced by people with disabilities. The measure of Quality of Life Outcomes has the potential to provide governments, people with disabilities and service providers with data that evaluates the effectiveness of disability services individually and the disability service system as a whole.

Quality of Life Outcome Measures are already being used to provide data on disability services and service systems (see Maryland USA, as described later in this paper). However ACROD acknowledges that substantial research is required to identify a simple, cost effective methodology to apply such measures in a consistent and nationally coordinated manner that is relevant to the Australian context. Following the development of a quality of life outcome measurement system, it is critical that disability service providers are adequately resourced to implement and develop services accordingly.

This submission provides a foundation to inform the commissioning of a research project to develop a suitable quality of life outcome based disability service system across Australia.

2. What is quality of life?

There are a variety of definitions for quality of life. Schalock and Alonso[32] identify the following conceptualisation principles.

Quality of Life:

a. is composed of the same factors and relationships for all people
b. is experienced when a person's needs are met and when one has the opportunity to pursue life enrichment in major life settings
c. has both subjective and objective components; but it is primarily the perception of the individual that reflects the quality of life he or she experiences
d. is based in individual needs, choices and control
e. is a multidimensional construct, influenced by individual and environmental or contextual factors.

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[32] Schalock, R.J. and Alonso, M.A.V. (2002). Handbook on Quality of Life for Human Service Practitioners American Association on Mental Retardation.

Leading academics in the area are steering away from a universal definition and focusing on an agreed understanding of the core domains that make up the quality of life construct. The core domains may differ slightly, depending on the researcher, however it is agreed that there is ample consistency across their work. The core domains according to Schalock and Felce[33] include:

1. Emotional wellbeing—such as contentment, self concept and a sense of safety and security.
2. Interpersonal relationships—such as interactions and relationships.
3. Material wellbeing—such as financial security and housing.
4. Personal development—such as personal competence.
5. Physical wellbeing—such as health status and leisure.
6. Self determination—such as autonomy and personal control.
7. Social inclusion—such as community roles and social support establish participation in community life, preparing to make purchases, caring for their health and well-being, taking part in culture and recreation as well as social relations and community involvement"
8. Rights—such as human rights and legal status.

It is important to note that 'quality of life' while having much commonality across individuals and communities, is individually referenced concept. Therefore, what one person defines as quality of life is likely to differ for another person. It is important, therefore, when considering quality of life to understand firstly what is important to an individual (what Schalock calls person referenced) then consider community standards of quality of life. It is finding a balance between these two aspects of quality of life that ensures quality of life measures are not used to impose community ideals on individuals.

3. Why Measure Quality of Life?

There were 200,493 Australians with a disability who used CSTDA-funded services during 2004–054. Disability services strive to improve the quality of life of the people with disabilities. This is consistent with the objective of the Commonwealth State/Territory Disability Agreement (CSTDA) 2002-2007[34], which states:

'The Commonwealth and the States/Territories affirm their commitment to the principles and objectives of the Disability Services Act 1986 (Commonwealth) and their respective State or Territory legislation, and agree on the following objective to underpin the national framework for services for people with disabilities—'The Commonwealth and the States/Territories strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community'.

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[33] Schalock, R.L. and Felce, D. (2004) Quality of Life and Subjective Wellbeing: Conceptual and Measurement Issues. In Emerson, E. Hatton, C., Thompson, T. and Parameter, T.R. (261-277). The International Handbook of Applied Research in Intellectual Disabilities. John Wiley & Sons

[34] Commonwealth State/Territory Disability Agreement (CSTDA) 2002-2007
http://www.facs.gov.au/internet/facsinternet.nsf/via/cstda/$file/cstda_June06.pdf

In its position paper[35] on the Commonwealth State/Territory Disability Agreement (CSTDA), ACROD argues:

Improving the quality of life of people with disability is a central aim of the CSTDA. A substantial project to investigate the best approach to measuring quality of life outcomes should be undertaken early in the life of the next Agreement.

The Auditor-General Audit Report No.14 2005–06 Performance Audit into the Administration of the Commonwealth State Territory Disability Agreement found that the Commonwealth State Territory Disability Agreement (CSTDA) includes no indicators or measurement of quality of life despite this being the intention of the Agreement. The report also identified strong support for the development of quality of life indicators across jurisdiction.

In an environment where resources to provide disability services are limited (and demand is high) it is critical that governments, disability services and people with disabilities, are able to understand and accurately measure their effectiveness. Consistent with the goal of the CSTDA, the effectiveness of disability services needs to be understood in the context of how services impact on the quality of life of service recipients. Furthermore, the nature of disability services require that measures of service effectiveness are valid and accurate, as failure to do so can have devastating impact on people's lives and result in inefficient use of limited resources.

Despite the importance of understanding and accurately measuring the effectiveness of disability services on the quality of life of people with disabilities, there is still no methodology for doing so that is applied consistently across the Australian Disability Service System. The Auditor-General Audit Report No.14 2005–06 Performance Audit into the Administration of the Commonwealth State Territory Disability Agreement found:

> "…the performance information framework contained in the CSTDA includes no indicators of the quality of life of people with disabilities, their participation in the community, their value in the community, or any related parameters, despite the objective directly aimed at enhancing quality of life. Therefore, the performance information framework contained in the Multilateral CSTDA does not require the collection of data that can clearly indicate whether, or to what extent, the CSTDA is meeting its objective. …

Administration of the Commonwealth State Territory Disability Agreement Department of Family and Community Services Australian National Audit Office The Auditor-General Audit Report No.14 2005–06 Performance Audit.

Quality of life measures provide a framework for understanding the effectiveness of disability services. While Quality Assurance systems currently support the disability service system they tend to focus on service processes rather than individual outcomes.

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[35] ACROD National. Turning Principles into Policy Proposals to improve the Commonwealth State/Territory Disability Agreement August 2006

> The challenge for disability administrators is to be clear about whether they are interested in the measurement of quality of service, quality of life or both, and the consequences of this decision. At present service goals are often couched in terms of quality of life (Australian Institute of Health and Welfare 2000) and quality assurance activities are directed toward quality of service (i.e. Use of the DSS). If disability administrators wish to monitor quality of life – they will have to determine just how much influence disability services can be expected to have on the dimension of measured quality of life (International Association for the Scientific Study of Intellectual Disability, 2000). The focus for quality assurance will have to shift from services to individuals, and the combined impact of services, often from numerous providers, on those individuals[36].

Effectively measuring the impact of disability services on the quality of life of people with disabilities has the potential to:

- evaluate the effectiveness of disability services;
- protect people with disabilities;
- improve the effectiveness and accountability of resource allocation; and
- inform disability service system improvements.

This in turn can provide:

- governments and citizens with confidence that resources allocated are used effectively;
- disability service providers with confidence that services are achieving positive outcomes;
- disability service providers with information for service planning, development and improvement; and
- people with disabilities and their families with confidence in disability service outcomes and government spending.

4. How do Disability Services Impact on Quality of Life Domains?

Disability Services are likely to have only partial scope of responsibility for a person’s quality of life, as factors outside the service providers control may also impact on an individual (such as ill health, family situation or poverty). The challenge remains to establish strategies to isolate and determine the impact of disability service on an individual’s quality of life without be penalising services for the outcomes outside their control.

The Quality of Life domains provide a framework for considering the impact of disability services on the quality of life of people with disabilities. However some commentators (such as Schalock) suggest that not all domains need to be measured to indicate overall quality of life.

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[36] Jones, G.P., Lawn, R., Mattika L., and Tossebro, J. (2003) International Innovations in Monitoring Service Quality. In Bradley, V. J. and Kimmich, M.H. Quality Enhancement in Developmental Disabilities Challenges and Opportunities in a Changing World. (235-255). Paul H Brookes Publishing Co. Maryland

Examples of the impact of disability services on quality of life domains for people with disabilities are likely to include:

1. Emotional wellbeing—Disability services will impact on a person's emotional wellbeing. For instance, people with cognitive impairments may prefer a structured environment to gain a sense of personal safety therefore services can be arranged in consistent ways that promote stability. Similarly, attention to creating the right relationship between disability support workers and the person requiring support will need attention, if emotional wellbeing is to be achieved.

   Indicators of a services impact on emotional wellbeing may include life satisfaction surveys, incidents of challenging behaviour or mental health indices.

2. Interpersonal relationships—Disability services may impact on interpersonal relationships in the lives of people with disabilities. For instance in employment services the service provider will aim to foster positive relationships between the person with a disability and co-workers. In disability accommodation services the support worker(s) may have a role in developing and maintaining interpersonal relationships, in conjunction with the person with a disability whom they support. For example through creating a welcoming environment for visitors and extended family.

   Indicators of interpersonal relationships could include number of friends, established support networks and contact with family members.

3. Material wellbeing—Disability services may impact on a person's material wellbeing. For instance a disability service may safeguard a person's material wellbeing through support with budgeting, acquisition of personal possessions and tenancy of suitable housing. Employment services provide a critical pathway to material wellbeing for many people with disabilities.

   Indicators of material wellbeing include income, employment status, home ownership and other assets.

4. Personal development—Most disability services have a strong impact on an individual's personal development. For example, employment services support people with disabilities to gain and maintain competence related to employment. Accommodation services build on a person's existing competencies to support them to maximise their potential in aspects of daily living and maintaining a home.

   Indicators of person development include skills/competencies review and continued educations activities.

5. Physical wellbeing—Disability services may have a role in supporting people with to develop and maintain physical wellbeing. For example disability accommodation services may support people to access adequate medical services and to have a healthy lifestyle such as regular exercise and a healthy diet.

   Indicators of physical wellbeing include doctor's visits, weight and exercise.

6. Self determination—Disability services are likely to impact on an individuals self determination. Support arrangements can be organised in ways that promote a persons autonomy and control. For example, in the provision of disability accommodation services, supports should be provided in ways that create opportunities for choice, control and the creation of dominion in relation to 'home'.

   Indicators of self determination include decisions made, control and civic participation such as voting.

7. Social inclusion—Disability services are likely to have some impact on an individual's quality of life in relation to social inclusion. Support services can be organised in ways that promote social inclusion by employing strategies to connect people to their community and allow people to develop valued community roles.

   Indicators of social inclusion include involvement in local community activities and community roles.

8. Rights—Disability services will impact on an individual's rights. Services can be organised in ways that protect people's human and legal rights. This will include providing adequate safeguards to ensure services manage a person's safety and balance it with the concept of 'dignity of risk'.

   Indicators of rights include decisions made, guardianship and keys to home.

Disability services strongly influence the achievement of personal outcomes related to each of these quality of life domains. The effective analysis of these domains must be strongly grounded in the actual experience of people within disability services rather than measuring service inputs, outputs or processes. While this poses some challenges there are methods already being administered in many individual services and at least across one service system internationally.

5. Quality Of Life Measurement Tools

Substantial work has been done in Australia (see Quality of Life Assessment for People with a Disability 2002[37]) and internationally (see Schalock and Alonso[38]2), to develop and evaluate instruments for measuring quality of life outcomes. Further work is required to determine the relevance and application of international instruments to the Australian context. Similarly work is required to develop effective subjective and objective measures that are applicable to people with a range of disability types.

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[37] Victorian Government Department of Human Services. Quality of Life Assessment for People with a Disability 2002 Performance, Planning and Research, DisAbility Services Division, Victorian Government Department of Human Services, Melbourne, Victoria.
http://nps718.dhs.vic.gov.au/ds/disabilityimages.nsf/images/QualityofLifeFinalReport/$file/QOLFinalReport.doc

[38] Schalock, R.J. and Alonso, M.A.V. (2002). Handbook on Quality of Life for Human Service Practitioners American Association on Mental Retardation.

Schalock and Alonso[39] recommend the following principles when measuring quality of life:

1. Measures the degree to which people have meaningful life experiences they value.
2. Measurement enables people to move toward meaningful life experiences they value.
3. Measures the degree to which life domains contribute to a full and interconnected life.
4. Measurement is undertaken within the context of environments that are important to people; where they live, work and play.
5. Measurement for individuals is based upon both common human experiences and unique, individual life experiences.

Example of Systemic use of Quality of Life Measurement Tool

The US State of Maryland through the Developmental Disabilities Administration (DDA) uses a quality of life measurement tool to report against the outcomes of disability service providers across the state. The DDA through The Arc of Maryland use the Consumer Quality of Life Survey to interview around 1400 people (or other stakeholders) annually, about their quality of life and satisfaction with services. The survey interviews people who receive services and interviews are carried out by people with developmental disabilities. The survey issues statewide findings and recommendations to DDA. The survey has been implemented in Maryland for almost a decade.

Example of the findings for Ask Me!sm Consumer Quality of Life Survey 2004[40] are:

- 78% of individuals who were randomly selected agreed to participate - a total of 1540 people interviewed from 44 providers.
- One-fourth of the individuals interviewed are labeled with severe or profound retardation.
- 94% reported positive scores on their physical and positive emotional well being. Most people surveyed reported a good quality of life that has improved over the past four years.
- Self- determination and rights are the areas requiring the most needed attention. Fifty-one percent (51%) of people interviewed said they had little or no choice in picking whom they live with. Self-determination scores increased only in FY 2004 and rights has not changed over four years.
- Transportation availability and employment services offer the greatest predictions of people's quality of life, and are therefore logical areas to consider for service enhancements.
- Cognitive ability offered less prediction of people's quality of life than did the availability of transportation.

Examples of quality of life measurement tools include:

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[39] Ibid.

[40] http://www.thearcmd.org/programs/ask_me.html

- Quality of Life Questionnaire (QOL-Q)[41] was developed after 12 years of research by Schalock and Keith. It aims to help all human service professionals, including educators, practitioners, advocates, program administrators, policy makers, researchers and consumers, to evaluate existing programs and services, and devise new ones.

  QOL-Q measures apply the concept of quality of life across eight core domains: 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 and three duplicated questions to measure inter-item agreement. Peer interviewers are trained to assess consumer-perceived quality of life—when people cannot respond for themselves, two proxies are interviewed and their responses averaged in order to increase the reliability and validity of information.

- Personal Outcomes Measures (POMs), developed and refined by The Council on Quality and Leadership in the USA[42], shift the definition of quality from organisational processes and services to the impact of those services on the lives of the people supported.

  POMs covers 25 outcomes across seven domains: identity; autonomy; affiliation; attainment; safeguards; rights; health and wellness. Two things are measured for each of the 25 outcomes: the outcome for the person as defined by the person; individualised supports to assist the person to achieve each outcome.

  The process involves: meeting and conversing with the person served; interacting/observing the person served in different natural environments; meeting with family/friends/staff; reviewing records (if necessary). The results of over 5,000 interviews are held on an international database. Accreditation is granted after the standards published by The Council are used to review and revise all organisational policies, procedures and protocols.

  POM's is being implemented by some disability service providers in Victoria. Trials by the Tasmanian State Disability Services found that there are some challenges (costs involved in modification) in using POMS across the Tasmanian disability service system.

- Supports Intensity Scale (SIS)9, developed and published by the American Association on Mental Retardation in 2003, evaluates the practical support requirements of a person with intellectual disability. It is designed as a tool to measure the relative intensity of support that each person with developmental disabilities (eg, cognitive/intellectual disabilities, autism, cerebral palsy) needs to fully participate in community life.

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[41] Schalock, R.L. Quality of Life Questionaire (QOL-Q) http://www.idspublishing.com/life.htm

[42] The Council on Quality and Leadership (CQL) *Personal Outcome Measures*^{SM}
http://www.thecouncil.org/measuring_performance

The SIS is intended to be used in conjunction with person-centred planning processes, to assist planning teams in developing individualised support plans that are responsive to the needs and choices of persons with disabilities. It aims to link the goals and aspirations of the person with disability to the individualised supports they require to achieve those goals, and to monitor progress. The SIS can also be used in conjunction with quality of life outcomes measurement tools.

The SIS is administered using semi-structured interviews by a qualified interviewer with two or more respondents who know the person with a disability well. Ideally, it is preferred that the respondents be people whom the person would select and who are supportive of the person. The interviewer should be a professional who has completed at least a bachelor's level degree and has experience working in the field of disability.
The SIS is being used by some disability service providers in Victoria.

6. Scope of Suggested Research Project

Measuring quality of life outcomes for service users poses some challenges however there are several existing designs which claim to do it well. The proposed research project should build on existing knowledge to identify an efficient methodology for measuring quality of life.

A measurement system for the Australian disability service system should:

1. involve a nationally consistent approach;
2. include subjective and objective dimensions of measurement;
3. be administratively simple for governments and service providers;
4. closely involve service users;
5. should not be resource intensive; and
6. should be supported by adequate resources for its implementation.

The scope of the Quality Of Life Outcomes research project should include:

1. The identification of the domains and indicators of quality of life that need to be measured to adequately determine the effectiveness of Australian disability services.
    a. This should include:
        i. The weighting of particular domains.
        ii. The weight of individual referenced quality of life outcome (i.e. what's important to the person) and community standards.
        iii. The links between the quality of life domains and the Disability Service Standards?

2. The development of an effective methodology to measure quality of life.
    a. Considering the benefit of random sampling.
    b. The links between any methodology and existing quality assurance measures.
    c. The consideration of both subjective and objective measures.

Conclusion

ACROD, in its submission to the senate review of the CSTDA, advocates for a substantial project, early in the life of the next CSTDA Agreement, to investigate the best approach to measuring the impact of services on the quality of life of people with disabilities. ACROD, as a key stakeholder, has provided this submission to direct such a project.

It is important that the proposed research project involves key stakeholders including ACROD as the peak body for Disability Service Providers. The Auditor-General Audit Report No.14 2005–06 Performance Audit into the Administration of the Commonwealth State Territory Disability Agreement found that involvement of key stakeholders in similar projects has not always been evident. In collaboration with the FACSIA and all jurisdictions, ACROD would be pleased to guide the project. ACROD strongly encourages the involvement of national and international academics with specialist knowledge in this area. ACROD's National Accommodation and Community Service (NACS) Conference 2006 featured key note presenter Dr Bob Schalock who has contributed to the use of quality of life methodologies in some Australian Disability Services. The conference gained support from delegates representing a range disability service provider's across the country willing to contribute to the implementation of quality of life outcome measures in the Australian context.

Finally ACROD remains committed to the development of an effective Disability Service System and look forward to providing further contribution in the development of a Quality of Life Outcome Measurement System.