

National Industry Association for Disability Services

### Submission to the Senate Community Affairs References and Legislation Committee

### Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement

### SUMMARY AND RECOMMENDATIONS

The Commonwealth State/Territory Disability Agreement (CSTDA) needs reform. The expiry of the current five-year Agreement in mid 2007 provides an important opportunity for governments to revamp the policy and funding framework for specialist disability services.

While the current CSTDA has achieved some gains, it has failed to deliver:-

- adequate funding or budgetary planning that reflect the unmet need for disability services, the factors driving demand growth and the increasing cost of quality service delivery;
- good pathways and linkages between disability services administered by different levels of government and ease of movement of service users between jurisdictions;
- coordination of services to people who require access to other service systems – such as aged care or mental health - while receiving a disability service;
- meaningful and valid measures of quality of life outcomes for service users, which would demonstrate that the Agreement is achieving its stated purpose;
- > a consistent, robust approach to quality assurance; and

a coordinated workforce planning strategy that recognizes the key role of staff in the quality of service delivery.

The case for reform is supported by recommendations contained in last year's Australian National Audit Office (ANAO) report<sup>1</sup> - the first detailed audit of the administration of the CSTDA.

In summary, ACROD supports governments' entering into a new CSTDA, but believes that the new Agreement should incorporate changes, including:-

- the development of national benchmarks and annual targets for the provision of disability services, linked to financial incentives and penalties;
- substantial additional funding over the life of the Agreement to address existing unmet need for services and anticipated demand growth (annually reviewed);
- a revised indexation formula (or equivalent supplementation) that reflects the real and unavoidable cost increases incurred by service providers;
- > well-developed evidence-based planning, with improved data;
- public financial and performance reporting that is transparent, detailed and comparable across jurisdictions;
- a nationally consistent approach to quality assurance, with crossrecognition of systems to minimize service providers' compliance costs;
- a nationally-coordinated workforce planning strategy that underpins quality improvement;
- a commitment to measure quality of life outcomes for service users, with a project to investigate the most effective approach early in the life of the next Agreement;
- a stronger focus on early intervention, linked with COAG's initiatives in relation to children and young people;
- better pathways and coordination between service systems administered by different jurisdictions (to better support the transition of people into employment and retirement);
- a whole-of-government approach supported by central government agencies and, ultimately, led by the heads of government
- access by group home residents to Commonwealth community care programs and 'top up' funding models to improve the interface between Disability and Aged Care;
- increased investment in research and engagement with non-government stakeholders in the development of research agenda, the overseeing of research projects and the sharing of research findings;
- > coordination of an assistive technology strategy; and

<sup>&</sup>lt;sup>1</sup> Administration of the Commonwealth State Territory Disability Agreement, Department of Family and Community Services, The Auditor-General Audit Report No.14 2005-06 Performance Audit, Australian National Audit Office

use of governments' purchasing power to boost employment opportunities for people with disability.

Joint responsibility for the funding of State-administered services should continue, but in return for substantially increasing its specific-purpose funding to the States<sup>2</sup>, the Commonwealth should insist on:-

> a stronger performance management framework; and

> a progressive increase in the proportion of State-administered disability services delivered by non-government organizations, as a means of driving increased efficiency and effectiveness in the expenditure of public funding.

<sup>&</sup>lt;sup>2</sup> For ease of expression, reference to 'States' includes the Northern Territory and Australian Capital Territory.

Between the idea And the reality Between the motion And the act Falls the Shadow

- T S Eliot

The CSTDA espouses laudable principles, but has been less than effective in translating those principles into reality.

Originally shaped by the Principles and Objectives of the Commonwealth *Disability Services Act 1986* and *Disability Discrimination Act 1992* and complementary State and Territory legislation, the current five-year Agreement specifies five policy principles:-

- strengthen access to mainstream and generic services for people with disabilities;
- strengthen across government linkages;
- strengthen individuals and families;
- improve long-term strategies to respond to and manage demand for specialist disability services; and
- improve accountability, performance reporting and the quality of specialist disability services.

The CSTDA has delivered some gains. Additional unmet needs funding provided by the Commonwealth and States during the second CSTDA has continued under the third Agreement and, between 2001-02 and 2004-05, real expenditure on disability services grew by 19%<sup>3</sup>. The introduction of an annual public report has improved public accountability. The redeveloped National Minimum Data Set provides more meaningful data than its predecessor (which reported only service users on a 'snapshot day'). And some informative research projects have been undertaken.

However, these gains are over-shadowed by the CSTDA's failure to:-

- deliver the resources required to meet the substantial need for disability services across Australia;
- require multi-year budgetary planning based on demand growth and the increasing cost of service delivery;
- deliver a consistent robust approach to service quality;
- produce sufficient data to enable comprehensive and meaningful performance comparisons across jurisdictions; and
- build strong linkages and easy-to-navigate pathways between disability service systems administered by different governments; or between

<sup>&</sup>lt;sup>3</sup> Steering Committee for the Review of Government Service Provision, *Report on Government Services 2006*, Productivity Commission, Table 13A.4

Disability and other programs such as Aged Care, Health, Education and Transport.

The CSTDA lacks effectiveness, in part, because it doesn't *measure* effectiveness. In 2005 the Australian National Audit Office (ANAO) criticized the absence of a robust performance management framework in the CSTDA.<sup>4</sup> The Agreement's stated objective is that governments will "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." But it contains "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."

Ideally, all disability service programs would be entitlement programs. In reality, however, almost all are severely rationed. This has created a policy culture of gate-keeping, short-term thinking and, at worst, denial. Some governments are reluctant to collect systematic data on unmet need because they fear the extent of need that the data will reveal and they doubt their capacity to respond to it. This policy culture must change.

None of these problems with the CSTDA is insurmountable. What is needed, above all, is a determination by governments to work together, in consultation with service providers, service users and carers, to improve the situation.

ACROD supports governments' entering into a further CSTDA, but urges them to reform that Agreement substantially. This paper identifies areas where ACROD believes the Agreement could be improved.

### **PROPOSALS TO IMPROVE THE CSTDA**

## Funding to address the unmet need for disability services across Australia

Although precise and current data are lacking, hardly anyone disputes that genuine and considerable unmet need for disability services exists across Australia.

In 2002, the Australian Institute for Health and Welfare (AIHW) concluded (conservatively) that, nationally, 12,500 people need accommodation and respite places, an additional 8,200 community access places were needed, and 5,400 people needed employment support. <sup>5</sup> These estimates now require updating and ACROD supports the National Disability Administrators' (NDA) intention to commission an update of the AIHW 2002 study.

<sup>&</sup>lt;sup>4</sup> Administration of the Commonwealth State Territory Disability Agreement, Department of Family and Community Services, The Auditor-General Audit Report No.14 2005-06 Performance Audit, Australian National Audit Office

<sup>&</sup>lt;sup>5</sup> Australian Institute of Health and Welfare *Unmet Need for Disability Services: Effectiveness of funding and remaining shortfalls* July 2002, <u>http://www.aihw.gov.au/publications/dis/unds-efrs/unds-efrs.pdf</u>

The AIHW study did not consider under-met need or needs being inappropriately met: for example, younger adults with disability inappropriately placed in aged care residential facilities. In February 2006, COAG agreed to commit \$244 million over five years to reduce the number of younger people in residential aged care. While this will certainly assist, it will not be sufficient.

In 2003, according to the Australian Bureau of Statistics (ABS), of the 957,000 people of all ages with disability and needing assistance, 35% reported that their needs were only partly being met and 5% (48,000 people) that their needs were not met at all.<sup>6</sup> The AIHW has estimated the potential population of those who may at some time need access to specialist disability services to be around 900,000 across Australia.<sup>7</sup>

In Victoria – which exceeds the national average in its provision of disability accommodation services – the waiting list for shared accommodation and inhome and community support is almost 4,500.<sup>8</sup>

There are strong indicators around Australia that the unmet need for services is great and that substantially increased funding is required. When completed, an updated AIHW unmet needs study should help ascertain the quantum of funding required. Through the next CSTDA governments should resolve this problem as a matter of high priority.

#### Funding commitments based on realistic projections of demand growth

During the course of the next CSTDA, demand growth is likely to exceed population growth. Among the factors accelerating demand for services are:-

- population ageing (because the prevalence of disability increases with age and people with lifelong disabilities are living longer);<sup>9</sup>
- a decline in the supply of informal carers because of increasing workforce participation by women and the ageing of the current cohort of carers; and
- changing social attitudes to disability, with younger parents less willing than their predecessors to spend a lifetime caring for a son or daughter with a disability<sup>10</sup>

Funding commitments in the next CSTDA should reflect analysis of the factors driving demand, such as these.

<sup>8</sup> Department of Human Services Victoria, Service Needs Register at http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/sectionone/supports\_people?open

<sup>&</sup>lt;sup>6</sup> ABS, *Disability, Ageing and Carers: Summary of Findings*, Australia 2003 (cat.no.4430.0)

<sup>&</sup>lt;sup>7</sup> The estimate is at June 2003. Potential population is not the same as the population needing services at a particular time, or the population choosing to access services.

<sup>&</sup>lt;sup>9</sup> For a discussion of the complex relationship between disability and age, see AIHW, *Disability and Disability Services in Australia*, January 2006, pp 6-10.

<sup>&</sup>lt;sup>10</sup> Methods to Address Requirements for Changes in Funding Disability Services Brought About by *External Change* Bruce Bradbury, Social Policy Research Centre University of New South Wales. Report presented to the Department of Human Services for the National Disability Administrators, April 2002

Under the CSTDA governments provide annual minimum funding commitments.<sup>11</sup> These commitments are based largely on history rather than on need and demand growth. Schedule A of the Agreement, which specifies funding commitments, is retrospectively updated, but not systematically reviewed during the course of the Agreement. It should be subject to annual review.

## Indexation that reflects the unavoidable cost increases incurred in delivering services

Indexation that fails to keep pace with unavoidable cost increases is effectively an annual funding cut. The impact of the Australian Government's indexation rate, which is particularly inadequate, is felt – to varying degrees – by all services funded through the CSTDA.

Under the current CSTDA, Commonwealth indexation is determined by Wage Cost Index 2, composed of 90% wage costs based on the safety net adjustment and 10% non-wage costs.

The indexation increase applied by the Australian Government in 2006-07 is a mere 1.8%, which falls well short of the cost increases borne by service providers. Western Australia, which has adopted a more realistic indexation formula, applied an increase of 3.0%.

A 2002 Social Policy Research Centre (SPRC) study for the National Disability Administrators<sup>12</sup> recommended that the Commonwealth revise its method of indexing disability grants and use an alternative method based on the ABS Wage Cost Index with a small CPI component.

In human services, wage costs account for most of an organisation's expenditure, so the heavy weighting in the Commonwealth indexation formula on wage costs is appropriate. However, as the SPRC argues, the Commonwealth's Wage Cost Index 2 "implies assumptions about productivity growth that are not in accord with generally accepted economic principles." The formula assumes that productivity gains will compensate for wage increases that exceed the safety net adjustment. This may be a reasonable assumption in, say, the mining or manufacturing sectors where replacing human labour with technology can produce substantial productivity gains; but not in sectors, such as disability services, where social interaction is at their core. Most wage growth in disability services in excess of Safety Net increases cannot be offset by efficiency or productivity gains.

The problem of inadequate indexation is exacerbated by the current difficulty experienced by service providers in recruiting and retaining staff. This workforce shortage inevitably places upward pressure on wages.

<sup>&</sup>lt;sup>11</sup> Clause 8(8)

<sup>&</sup>lt;sup>12</sup> Ibid

It is likely that, with the Australian Fair Pay Commission now setting the Federal minimum wage, the minimum wage will rise at a slower rate than in the past. If so, and if the Commonwealth pegs indexation to the minimum wage, indexation increases will become even less adequate.

The SPRC recommends a new indexation formula based on the Australian Bureau of Statistics *Wage Cost Index* (ABS Cat. No. 6345.0), which includes data on health and community services. This index has typically increased at a faster rate than the Department of Finance Wage Cost Index 2.

All governments should apply an annual indexation formula (or provide equivalent supplementation) that reflects the unavoidable cost increases incurred by service providers. The SPRC's study for the NDA sets out a rational method of doing this.

### Public reporting of expenditure that is transparent, detailed and comparable

A 2003 Access Economics report criticized some State governments for a lack of transparency in their expenditure on disability.<sup>13</sup>

In addition, cross-state comparisons are marred by a lack common 'counting rules'. In its Report on Government Services, the Productivity Commission provides figures on the proportion of total disability expenditure allocated to administration, but notes that these are not comparable across jurisdictions because governments employ different methods to apportion administrative costs.<sup>14</sup>

The ANAO criticized this inconsistency of 'counting rules' across jurisdictions in relation to financial expenditure and performance reporting. It said that the FaCSIA Services Portfolio Budget Statements and annual report also lacked transparency.

To aid public accountability, the next CSTDA should deliver public financial and performance reporting that is transparent, detailed and enables meaningful comparisons across jurisdictions

#### Relative funding efforts that are equitable

Under the current CSTDA there is a wide disparity of funding effort by States, leading to widely varying levels of access to services by Australians with disabilities. In 2003-04 per capita expenditure in Victoria (\$5,114) was almost twice that of Queensland (\$2,609) and the Northern Territory (\$2,615).

The Australian Government's contributions to States also vary markedly and, in effect, reward poor performance by giving proportionately more money to

<sup>&</sup>lt;sup>13</sup> *Transparency of State and Territory Budgets*, Report prepared by Access Economics for the Commonwealth Department of Family and Community Services, March 2003. In terms of financial transparency, Tasmania and NSW were the poorest performing States.

<sup>&</sup>lt;sup>14</sup> Steering Committee for the Review of Government Service Provision, Op cit Vol 2, 13.50

low-funding States. In 2003-04, the Victorian Government contributed 86.4% of the CSTDA funds spent in Victoria and the Commonwealth contributed only 13.6%. In South Australia, by contrast, the State Government contributed 69.2% and the Commonwealth contributed 30.8%.

This situation is inequitable and should not be allowed to continue under the new Agreement.

#### Joint funding

For governments, funding is clearly a contentious issue. In the past, negotiations have been marred by suspicions of cost-shifting and accusations from each level of government that the other provides less than its fair share of funding for State-administered services.

While, overall, the Commonwealth's funding effort relative to the States has not declined during the course of the current CSTDA, much of its new funding has gone into disability employment services, which it directly administers. This reflects the Commonwealth's view that:-

- implementing the ambitious raft of disability employment service reforms required additional spending on those services;
- States are insufficiently accountable for the expenditure of funds they receive from the Commonwealth;
- State-administered services are principally the responsibility of the States; and
- higher-than-expected GST revenue should reduce the States' call on Commonwealth specific-purpose transfers.

From ACROD's perspective, *both* levels of government have the capacity and the responsibility to increase substantially their funding of State-administered disability services.

The Commonwealth is right to claim that the GST is a windfall for the States. In 2006-07 the States collectively will receive about \$1.9 billion more in GST revenue than the Guaranteed Minimum Amount (GMA) – with net benefits ranging from \$60.6 M in the ACT to \$664.9 M in Queensland. <sup>15</sup> State Governments are free to spend this revenue according to their own priorities and disability services ought to be one of those priorities.

At the same time, there can be no doubt that - with the Federal Budget reporting an underlying cash surplus of \$10.8 billion - the Australian Government also has ample capacity to increase its funding of disability services - both to the services it directly administers and to State-administered services.

<sup>&</sup>lt;sup>15</sup> 2006-07 Budget Paper Number 3, Federal Financial Relations. The GMA is an estimate of the funding each State would have received had the Australian Government not implemented tax reform six years ago. It takes into account several factors, including lost revenue from the abolition of State taxes.

The current CSTDA makes clear that funding of State-administered services is a *joint* responsibility and this stipulation should continue.

# Stronger public accountability, in return for more Commonwealth funding to the States

In return for significantly increasing its transfers to the States, the Commonwealth should insist that the CSTDA contains a stronger performance management framework that ensures that all jurisdictions are publicly accountable for delivering the outcomes that the CSTDA promises.

The publication in recent years of an annual CSTDA report has increased public accountability, but there is significant scope to improve public reporting.

## An increased proportion of State-administered disability services delivered by non-government organizations

Based on service usage, government operates 40% of State-administered disability services. The Productivity Commission has shown that government-delivered disability services are substantially more costly for tax-payers when compared to non-government service provision (the cost to tax-payers for each resident averages around \$40,000 a year more in a government-operated group home).<sup>16</sup> In addition, non-government service providers are typically more responsive to local conditions, less encumbered by bureaucracy and more mission-driven. While State governments continue to retain such a large role as service providers, public funds are not being as efficiently or effectively spent as they could be.

In increasing its funding to the States, the Commonwealth should require a progressive increase in the proportion of State-administered disability services delivered by non-government organisations.

#### A well-developed planning framework, based on improved data

In their bid to Treasuries for public funds, disability services and the departments that administer them are significantly disadvantaged by the lack of sound and systematic data to guide budgetary and service planning.

An update of the AIHW Study into unmet need will assist, as will the ABS's inclusion of questions on disability ('need for assistance') in the 2006 Population Census. Further research is required to project demand growth over the life of the next CSTDA.

During the course of the current Agreement the National Minimum Data Set (NMDS) has been redeveloped. <sup>17</sup> However, there remain problems in making

<sup>&</sup>lt;sup>16</sup> In 2003-04 State and Territory governments spent an average of \$98,289 to support a person in a government-operated group home. These same governments paid non-government providers of group homes an average of only \$59,213 per person. Steering Committee for the Review of Government Service Provision, op cit. Table 13A.25.

<sup>&</sup>lt;sup>17</sup> http://www.aihw.gov.au/disability/csda\_public/index.cfm

meaningful comparisons across jurisdictions. For example, 2003-04 data suggest that community access expenditure per client varies from \$18,002 in NSW to \$2,004 in Western Australia. At least some of this difference reflects variations in the response rates between the States, the inclusion of disparate service models in the community access category and varying hours of service per client.

The relevance of the NMDS collection to the non-government disability sector could also be enhanced. At present it contains no way of identifying organisations, only service outlets, and thus does not capture data on the average size or range of sizes of organizations (which may be pertinent to sector viability), or the number of multi-service organizations compared with single service organizations.

The ANAO noted that the CSTDA failed to provide a framework that would allow a focus on the changing and future needs of people with disability, comparable to the National Strategy for an Ageing Australia. Such a framework would provide data more useful for planning than is currently the case.<sup>18</sup>

The CSTDA should provide a planning framework for the provision of disability services across Australia, one that takes into account demographic changes, future service needs, the changing expectations of service users and carers, the capacity of service providers and other relevant factors. This planning framework will require an improvement in the quantity and quality of data collected.

The CSTDA should include a commitment by governments to ensure that disability data collections are consistent with the International Classification of Functioning Disability and Health, endorsed by the World Health Organization.<sup>19</sup>

#### Higher investment in research and more engagement with stakeholders

The CSTDA Research and Development Program exists to investigate the need for new services or enhancement of existing services; innovations in planning and service delivery; and the measurement of outcomes for people with disability using these services.<sup>20</sup> The small commitment of funds to research – amounting to 0.012% of annual CSTDA expenditure - fails to reflect the importance of these subjects.

<sup>&</sup>lt;sup>18</sup> Aged Care in Australia, Department of Health and Ageing, August 2003. The National Strategy for an Ageing Australia provides a framework to address current issues facing older people and to prepare for future demographic changes as Australia's population ages over the next 50 years. It also highlights that the ageing of Australia's population is an issue for all Australians – governments, business, community organisations, and individuals.

<sup>&</sup>lt;sup>19</sup> ICF (International Classification of Functioning, Disability and Health), World Health Organization, http://www3.who.int/icf/icftemplate.cfm

<sup>&</sup>lt;sup>20</sup> Clause 10(5)

The ANAO found that the NDA does not engage sufficiently with the nongovernment disability sector to develop and carry out its research program. Without this engagement, the NDA's research agenda won't reflect issues of concern to the industry, service users, carers and university researchers.

Governments should substantially boost their investment in CSTDA research. In planning and developing future research programs, the NDA should engage in a greater level of consultation with relevant non-government stakeholders; and provide them with full access to the results of research. Reference groups overseeing research projects should include non-government as well as government representatives.

#### National benchmarks and annual targets

Much of the argument between governments about CSTDA funding is about maintaining or increasing 'relative funding effort'. Missing from the debate is an objective reference point - a benchmark to guide budgetary planning and against which the performance of governments can be gauged.

How much more funding is really needed? What level of services would be acceptable? How long should governments have to achieve these levels? How should their progress or regress be assessed and with what consequences? To these questions, the current CSTDA has no answers.

Aged Care uses a needs-based planning framework that seeks to achieve and maintain a national provision level of 108<sup>21</sup> residential places and Community Aged Care Packages (CACPs) for every 1,000 of the population aged 70 years and over. While there is some debate about the formula, its aim is to ensure that the growth in the number of aged care places is in line with growth in the aged population and that there is a balance of services. including services for people in rural and remote areas.<sup>22</sup>

The disability sector has nothing similar to guide the provision of residential and community care places to people with disability. We know that only 48 of every thousand persons in the comparable population (broadly, people under 65 years with a severe or profound core activity restriction) receive a CSTDAfunded disability accommodation support service.<sup>23</sup> But we don't know how far below a reasonable level of service provision this sits.

ACROD believes that the next CSTDA should set national benchmarks for the provision of disability services. These could be framed as proportion of service users per 1,000 'potential population' for each principal service type. In determining an appropriate target, account should be taken of current levels of service provision, unmet demand for services, and anticipated growth in demand.

<sup>&</sup>lt;sup>21</sup> Review of Pricing Arrangements in Residential Aged Care, Final Report WP Hogan, 2004 <sup>22</sup> Aged Care in Australia, Department of Health and Ageing, August 2003, see

http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-about-agedaus1.htm- $\frac{\text{copy2}}{23}$ 

Disability Support Services 2003-04, AIHW, Table A1.5

Because the cost of different service models (group home compared to inhome support, for example) can vary considerably, work would be required to ensure that performance comparisons across States were meaningful. At present, interstate comparisons of some service levels (community access, for example) are problematic because the broad category covers diverse services and hours of support. Nevertheless, with appropriate weightings and refinements, a firm basis for comparison could be established.

ACROD accepts that in most States, the need for disability services is so great that a reasonable level of service provision could not be achieved in one budget, but would require a staged approach over several years. What is important is to establish benchmarks and annual targets based on objective comparable data. Financial incentives and penalties should be linked to performance against these targets.

#### Coordination of a national assistive technology strategy

By enabling greater personal independence, the provision of assistive technology (aids and equipment) can improve the lives of people with disabilities and reduce the demand for more costly personal assistance.

Although both the Commonwealth (through the Departments of Health and Ageing, Veterans Affairs and Employment and Workplace Relations) and State and Territory governments administer schemes that provide cost-free or low-cost aids and equipment to people with disabilities, assistive technology is excluded from the CSTDA.

Overall, the existing network of schemes is under-resourced and contains significant gaps. In its 2003 study of aids and equipment AIHW found there to be "a limited range of equipment, problems with cost, availability and shortage of referral services in remote areas of Australia, and a decline in equipment supply from traditional dispensing units such as hospitals. Systems for the provision of equipment appear to be nationally fragmented."<sup>24</sup>

These findings are reinforced by a NSW report that focused on the equipment needs of children. It found that the processes of equipment provision are slow and inefficient and that children do without prescribed items for long periods. Because of the high costs associated with some equipment, families often need to seek external support to purchase items.<sup>25</sup>

Other schemes are fragmented by Commonwealth-State divisions and undersupply. An example is the Continence Aids Assistance Scheme, which the Federal Department of Health and Ageing funds for people 16 to 65 years but not for people over 65 years unless they are in paid employment.

<sup>&</sup>lt;sup>24</sup> Disability: the use of aids and the role of the environment, AIHW, August 2003, p.16

<sup>&</sup>lt;sup>25</sup> Lyn Dowling, *Children Who Live with Equipment: Report to Department of Ageing and Disability and Home Care* (DADHC) – Issues Paper February 2002.

A national study into the unmet need for, and the benefits of, assistive technology and therapy is currently underway ('community support services', which includes therapy, were excluded from AIHW's 2002 study of unmet need).<sup>26</sup>

Investment in improving the provision of aids and equipment would reduce the need for other forms of assistance that are labour-intensive and more expensive. A well-developed assistive technology strategy for frail older Australians and people with disabilities would reduce the demand on hospital, residential and community care services.

In 1996, as part of the evaluation of the Commonwealth State Disability Agreement, Ernst and Young recommended the development of a National Equipment Strategy that improved the range and timeliness of equipment provision and lowered the cost of maintenance and repairs.<sup>27</sup> The need for such a strategy is now pressing. The CSTDA would be the appropriate multilateral framework under which to coordinate such a strategy.

#### A stronger focus on early intervention

Early intervention means providing assistance before a problem escalates into a crisis. It also means providing support and therapy early in life to enable a child or young person to develop well and fulfill their potential. CSTDA policy directions should underline the value of early intervention

Many children and young people with disability lack adequate access to programs that would encourage their optimum development. The support available is often ad hoc.

Early intervention assists children and young people to grow, learn and achieve and it can prevent the development of secondary disabilities. All family members benefit from the improvements in the life of the child or young person.

Services should be family-centred, trans-disciplinary, evidence-based, socioecological and developmental. A child with autism ideally should receive structured intervention in the pre-school years for a minimum of 15 hours per week if the family is to develop resilience and the child is to acquire behaviours that address individualized developmental needs.<sup>28</sup>

As part of its new focus on human capital, the Council of Australian Governments (COAG) has flagged increased investment in early childhood development to lift the proportion of children entering school with basic skills for life and learning. It also wants school-leavers to make a smoother transition to work or further education. It is imperative that such investment addresses the needs of children and young people with disability.

<sup>&</sup>lt;sup>26</sup> The Study of Therapy and Equipment Needs is being conducted by AIHW and CP Australia.

<sup>&</sup>lt;sup>27</sup> Commonwealth/State Disability Agreement Evaluation: The Equipment Study, Supporting Paper 5, Ernst & Young, January 1996

<sup>&</sup>lt;sup>28</sup> Autism Spectrum Australia, communication with ACROD, April 2006

Included in the next CSTDA should be a policy principle that underlines the value of early intervention programs to assist children and young people and links the CSTDA to COAG's initiatives to invest in early childhood.

# A robust consistent approach to service quality and a reduced compliance burden for providers

The CSTDA requires that the Australian and State/Territory governments work towards continuous improvement in services and in quality assurance processes and systems. It is meant to provide a nationally consistent approach to quality.

Progress in this area has been uneven. A nationally consistent approach to quality has not been achieved and quality monitoring in some States is not independent and transparent.

National inconsistency imposes a compliance burden on service providers. Multi-service organizations often have to comply with multiple quality systems. An organization that provides a disability employment service, a State-funded disability service, a HACC service, and an aged care service may be audited against four different quality assurance systems. This reduces the financial and human resources available for service delivery. If governments are serious about reducing red tape - and FaCSIA has a project specifically aimed at cutting red tape – they should act to reduce the compliance burden in this area.

Governments should agree on the essential features of a robust approach to quality assurance. Third-party accreditation (independent of both provider and funder) is one such feature. Some governments (such as the Commonwealth and Queensland) have built this principle into their quality monitoring systems; others (such as NSW) have yet to do so. In general the approach to monitoring quality should be compatible with generic systems (ISO) and contain transparent rules (KPIs, evidence questions, appeals process etc).

In consultation with the disability sector, governments should agree on the essential elements of a robust approach to monitoring service quality, and work to achieve compatibility and cross-recognition of quality systems. They should recognise the cost of compliance in their service funding formulae.

#### Measurement of quality of life outcomes

Quality monitoring has focused more on processes and systems than on quality-of-life outcomes for service users. This should change.

Commentators distinguish between quality of care and quality of life, arguing that efficient, well-documented quality systems within an organization don't necessarily produce a better quality of life for people with disability.<sup>29</sup>

<sup>&</sup>lt;sup>29</sup> Quality of care/quality of life, Barrie O'Connor, 'Disparity', ACROD, Spring 2005

In the quality of care approach, people with disability are seen as 'consumers' or 'clients' of a care system rather than citizens of a society. The emphasis is on impairment, categorisation, homogenous grouping, health and safety, and control. In contrast, quality of life approaches focus on all of a person's life domains  $^{30}$ 

Several instruments for measuring quality of life outcomes have been developed and evaluated. Some are currently being piloted and/or used in Tasmania and Victoria (see the Attachment).<sup>31</sup> There is no one definition of quality of life, but basic to the approach is asking the question: what individualized supports are required to enable this person to achieve his or her goals and participate in community life?

While measuring quality of life outcomes for service users poses challenges (and invites scepticism from some commentators), there are several existing designs which claim to do it well. Measurement systems should include subjective and objective dimensions, be administratively simple for governments and service providers and closely involve service users. Because a person's quality of life is affected by factors beyond the control of service providers, a measurement system should not penalize service providers for an outcome beyond their control.

The NDA has added a review of the National Disability Services Standards to its work plan. This should be linked to an investigation of quality of life outcome measures.

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.

#### A national workforce planning strategy to underpin service quality

The quality of services provided to people with disability relies heavily on the quality of staff.

Across the disability sector, service providers face increasing difficulty recruiting and retaining staff. In recognition of this, the NDA has commissioned research into workforce planning. A scoping study concluded that the skills shortage would become a crisis unless action was taken. Because wages and conditions are generally poorer in non-government disability services, recruitment and retention difficulties there are even worse than in the government sector.

<sup>&</sup>lt;sup>30</sup> *Quality of Life Versus Quality of Care: Implications for People and Programs*, Isabel De Waele et al, 'Journal of Policy and Practice in Intellectual Disabilities' Vol.2 No.3/4, pp. 229-239, September/December 2005

<sup>&</sup>lt;sup>31</sup> *Review of Evaluation Process State Disability Services Tasmania DHHS, A Report by the Centre for Developmental Disability Studies, April 2005* 

While comprehensive data are lacking for the disability workforce, researchers<sup>32</sup> have found that (at 27%) the annual rate of staff turnover in disability open employment services was almost double the general workforce average. The cost of staff turnover is high: Disability Services Queensland estimates that the average total cost for replacing an intellectual disability service worker is 61.7% of annual salary.

There is no single solution to the looming workforce crisis. A nationallycoordinated strategy would include raising public awareness about careers in disability services; increasing investment in training; addressing the disparity in wages and conditions between the government and non-government disability sectors; and strategies to boost job satisfaction among direct support workers.

A number of disability workforce projects and initiatives are under way around Australia. These include initiatives by State Governments – in particular Western Australian and Queensland – by Federal Departments (such as DEST's project to increase the number of school-based apprenticeships in disability services); by the Health and Community Services Industry Training Council; and research by the Health and Community Services Ministerial Advisory Council. These various initiatives need to be linked to a nationallycoordinated plan.

As part of improving service quality, the CSTDA should include a commitment to develop - in consultation with the non-government sector and relevant sections of government - a nationally-coordinated workforce planning strategy.

#### A whole-of-government approach led by the heads of government

The CSTDA promises to strengthen inter- and intra-governmental linkages. It aims to:

- foster a whole-of-government approach to maximise the opportunity for people with disabilities to participate socially and economically in the community; and
- improve collaboration and coordination across programs and governments to ensure that people with disabilities have fair opportunities to access and transition between services at all stages of their lives.

These goals are consistent with the (albeit more modest) goal of the Commonwealth Disability Strategy<sup>33</sup>, to remove barriers in Commonwealth policies, programs and services for people with disabilities. Subsequent reviews of the Strategy have identified few achievements in breaking down barriers across government departments.

Several States also have commitments to whole of government approaches, but, again, in practice, departments and programs outside of Disability

 <sup>&</sup>lt;sup>32</sup> Keeping Quality People Engaged: Workforce Satisfaction Within the Disability Employment Industry, Associate Professor Joe Graffam, Deakin University, 2005
<sup>33</sup> http://www.facs.gov.au/disability/cds/index.htm

typically do not see responding to the needs of people with disability as a priority.

In its review of the CSTDA, the ANAO found that there is *immediate potential* for FaCSIA to enhance its CSTDA leadership/coordination role in relation to Australian Government agencies responsible for aged care, health, housing, education, multicultural and indigenous affairs, transport and veterans' programs and policy. The same criticism could justly be made in relation to State and Territory disability departments.

Governments are hierarchical entities. If a whole of government approach is to be effective it needs to become a priority of central government agencies and, ultimately, requires leadership by the heads of government.

#### Improved interface between the aged care and disability service systems

Exemplifying the urgent need to enhance coordination across programs, departments and levels of government is the interface between disability and aged care. Despite CSTDA bilateral agreements that specifically identify the need to improve linkages between aged care and disability services, those linkages remain poor.

This interface is of growing importance because of population ageing, which increases the general prevalence of disability and also the proportion of people with lifelong disabilities who are growing old. The effects of old age often arise earlier in people with lifelong disabilities – with Down Syndrome, for example.<sup>34</sup>

The needs that arise from ageing do not displace the needs associated with a long-term disability: they are additional. Yet the existing funding arrangements and policy rules mostly deny a person simultaneous access to services from the aged care and disability service systems.<sup>35</sup>

Group home residents, for example, are denied community nursing, palliative care, dementia support and allied services, because these services are administered by different levels of government. Effectively these people are denied the right to 'age in place', a right that the broader community expects. The Federal review of Community Care (which resulted in 'The Way Forward Strategy'<sup>36</sup>) overlooked this issue.

One positive way forward is indicated by the Department of Health and Ageing's 2002-03 Innovative Pool pilots. By allowing the use of

<sup>&</sup>lt;sup>34</sup> Ageing in Place: Good Practice Sourcebook Angela Dew and Tim Griffin, (Eds.) Centre for Developmental Disability Studies and Bernard Judd Foundation, May 2002

<sup>&</sup>lt;sup>35</sup> Submission to the Senate Community Affairs References Committee Inquiry into Aged Care, ACROD, July 2004

<sup>&</sup>lt;sup>36</sup> A New Strategy for Community Care – The Way Forward Department of Health and Ageing, 2004, outlines the next steps the Government will progress from 2004-05 to reshape and improve the community care system, including the adoption of common arrangements, see 'About The Way Forward', online, May 2006

Commonwealth Aged Care funds to top up State Disability Services funding the pilots aim to prevent the premature admission of people with disabilities into nursing homes. The Innovative Pool pilots are based on the recognition that people with lifelong disabilities develop additional needs as they age. AIHW has conducted an evaluation of the pilots, which is due to published shortly. At this stage, the Federal Department of Health and Ageing has agreed to continue to fund clients already in the pilots, but not to admit new entrants or to expand the pilots into a program.

The COAG initiative (agreed in February 2006) to reduce the number of younger people in residential aged care is also likely to identify innovative service models. To enable young people inappropriately accommodated in residential aged care to move to the community and to enable people with disability housed in the community to age in place will require joint funding by both levels of government and involve ongoing commitments by Aged Care and Disability Services programs.

The Commonwealth State and Territory Strategy on Healthy Ageing provides a mechanism for positive ageing that coordinates activity between governments on community attitudes, health and wellbeing, work and community participation, sustainable resourcing, inclusive communities, appropriate care and support, and research and information. A similar approach that enhances the positive inclusion in the community of people with disability is needed across government departments.

Between disability programs, the interface can also problematic. Retirement is very uncertain territory for supported employees; the transition to work for clients in post-school option programs can be equally uncertain. Even for people seeking to move from supported to open employment the transition is fraught wit risk (now that the splitting of responsibility for disability employment services between two Federal Government departments has abolished 'dual funding'). Again, pilot programs and research show that most of these problems are not insurmountable.<sup>37</sup>

Ageing residents in State-administered group homes should have access to Commonwealth community care services, to enable them to age in place.

The principle of 'top up' funding (with clients of disability service programs entitled to attract Commonwealth Aged Care funding) should be more widely applied in recognition of the fact that the needs that arise from ageing are additional to those associated with a long-term disability.

<sup>&</sup>lt;sup>37</sup> See ACROD SA, *Transition to Supported Employment for Students with a Disability*, December 2003. A second ACROD SA project on retirement from supported employment is currently under way. The NSW Government funds a successful Retirement Options Program in the Illawarra region that assists people who wish to retire from a Disability Business Service. In a study on transition to employment programs, the NSW Department of Disability, Ageing and Home Care has identified service structures and approaches which appear to affect the rate of transition of clients into employment.

### Governments' purchasing power used to increase the employment of people with disability

The record of all governments around Australia in employing people with disability is poor and generally worsening. The employment rate of people with disability in the Australian Public Service has fallen from almost 6% in the mid 1990s to 3.8% in 2004.<sup>38</sup> The Commonwealth heads of department (Management Advisory Committee) have instigated an inquiry into this.

Among the causes of the decline is the disappearance of lower-skill positions from the public service. Some of the functions performed by these positions have been outsourced.

All governments should seek to increase the employment rate of people with disability in the public service. In addition, governments should use their considerable purchasing power to increase the employment rate of people with disability in the community. The Javits-Wagner-O'Day program in the USA provides a clear guide to what can be achieved.

In the USA the Federal Government is required by law – under the Javits-Wagner-O'Day program – to purchase specified goods and services from organisations that employ people with severe disability. As well as the US Federal initiative, over 30 US States have complementary programs of preferential purchasing.

The Javits-Wagner-O'Day program has checks to ensure that the supported employment organisations that secure Federal Government contracts have the capacity to deliver the goods and services at the required standard and that other businesses are not significantly disadvantaged. The program requires little public expenditure to administer, but delivers significant net savings in terms of income support and taxes paid. Moreover, it helps enable the not-for-profit organisations which have secured Federal government contracts through the program to employ 48,000 people with disability. The program commands bipartisan support.<sup>39</sup>

Australian State and Federal governments should adopt similar programs. While the US program is targeted at Disability Business Services, it could be broadened in Australia to include mainstream employers, as long as they employed a specified proportion of people with significant disability.

Given its welfare-to-work reform agenda and its responsibility for disability employment services under the CSTDA, the Commonwealth should embrace such a program. In doing so, it would need to expand the supply of disability employment assistance places. The benefits of such a program would be the growth of employment opportunities for people with disability, savings from

<sup>&</sup>lt;sup>38</sup> Human Rights and Equal Opportunity Commission, National Inquiry into Employment and Disability, Issues Paper No. 1, 2005.

<sup>&</sup>lt;sup>39</sup> Features of the Javits-Wager-O'Day program are summarized at <u>www.acrod.org.au/conferences/EF2006/presentations/Atkinson-GovtPurchasing.ppt</u>

decreased income support outlays and from increased taxes paid and a sustainable supported employment sector.

In adopting a similar program, each State government should insist that the Commonwealth guarantee the provision of sufficient employment assistance places to meet the increased demand in that State. An expanded disability employment sector would ease some pressure on State-administered community access services, while enhancing the economic and social participation of people with disability.

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#### About ACROD

ACROD is the national peak body for disability services. Its membership includes 550 non-government non-profit organisations that collectively operate several thousand services for Australians with all types of disabilities.

In seeking to achieve its purpose, ACROD provides a wide range of advice and information to the disability services sector through e-mail publications, a magazine, conferences and seminars. Its consultative structures include a system of issues-based National Committees and State Sub-Committees, forums and interest groups. ACROD's submissions to Government are developed in consultation with members.

ACROD provides advice to governments in relation to all significant disability matters. It is currently represented on almost 20 Commonwealth Government (or quasi-Government) reference groups, working parties and advisory groups, and on numerous State and Territory committees.

ACROD has a National Secretariat in Canberra and offices in every State and Territory. The organisation as a whole is governed by a national Board which includes the elected Chair from each State/Territory Division as well as representatives elected directly by members.

#### **ATTACHMENT**

	Quality of care focus	Quality of life focus
Perspective	Provider	Person in his or her natural network
Interest	Process	Outcomes
Content	Management of care systems	Support and its effects on a personal life
Typical criteria for evaluation	Efficiency, cost-effectiveness, planning, consumer satisfaction	Long-term value-based outcomes on inclusion, personal development, and self-determination
Structures	Actual care systems only need improvement	Support serves a person's case, even if this means that alternative structures have to be found

#### Differences between a Quality of Care and a Quality of Life focus<sup>40</sup>

The differences summarised above should not be construed to mean that safety and security needs are not critical. Care or support needs to be of good quality, but the question is whether a system of quality of care is enough to create a personal life of good quality. The dominance of the quality of care can lead to situations where control, health and safety, and impairment become central issues, without critical reflection on the context and the aim of long-term quality of life outcomes.

Quality of life domain	Monitoring variables	Outcome indicators
Emotional well-being	Increases safety, stable and predictable environments, positive feedback	Contentment, self-concept, lack of stress
Interpersonal relations	Foster friendships, encourage intimacy, support families	Interactions, relationships, supports received
Material wellbeing	Ownership, possessions, employment	Financial status, employment status, residential status
Personal development	Functional	Education status, personal

#### The quality assurance process in quality of life-focused organisations<sup>41</sup>

<sup>&</sup>lt;sup>40</sup> Quality of Life Versus Quality of Care: Implications for People and Programs Isabel De Waele et al, 'Journal of Policy and Practice in Intellectual Disabilities', Vol.2 No.3/4, pp.229-239, September/December 2005 <sup>41</sup> Ibid

	education/training, augmentative technology	competence, performance
Physical wellbeing	Health care, mobility, wellness, nutrition	Health status, activities of daily living, leisure, and recreation
Self-determination	Choices, personal control, decisions, personal goals	Autonomy, goals and personal values, choices
Social inclusion	Community role, community, activities, volunteerism	Community integration, community roles, social supports
Rights	Privacy, voting, due process, civic responsibilities	Human (eg, respect), legal rights (eg, access)

#### Examples of quality of life measurement tools

<u>Quality of Life Questionnaire (QOL-Q)<sup>42</sup></u> 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.

<u>Personal Outcomes Measures (POMs)</u>, developed and refined by The Council on Quality and Leadership in the USA<sup>43</sup>, 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; automony; 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.

<sup>&</sup>lt;sup>42</sup> http://www.acrod.org.au/divisions/vic/NACS/NACS2006/presentations/Schalock.ppt

<sup>&</sup>lt;sup>43</sup> <u>http://www.thecouncil.org/measuring\_performance</u>

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.

POMs is being implemented by Marillac House in Victoria and Tasmanian State Disability Services<sup>44</sup>.

<u>Supports Intensity Scale (SIS)</u><sup>45</sup>, 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.

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.

<sup>&</sup>lt;sup>44</sup> *Review of Evaluation Process State Disability Services Tasmania DHHS*, A Report by the Centre for Developmental Disability Studies, April 2005 <sup>45</sup> http://www.siawabiita.org/index.www.