

STATE DISABILITY PLAN--CONTINUING THE JOURNEY--A PERSONAL AND BOARD PERSPECTIVE¹

The timing and subject of this Conference, “Continuing the Journey”, could not be more appropriate. We are now half way through the State Disability Plan’s 10 year horizon from 2002 to 2012² and so the conference theme provides the opportunity both to reflect and to look forward.

As a parent and as a Director of several organisations providing services to people with disabilities, the State Disability Plan gives me confidence because it is based on equal rights, equal opportunities, choices and the full inclusion of people with disabilities in the community.

It is a Vision of a civil society which has the potential to support and embrace some of the most disadvantaged and marginalised in our community today, to lift the well-being of all people with disabilities and to enrich us all through the full inclusion of people with disabilities in our society. It is also a Vision that has been widely embraced by people with disabilities, their families and the disability sector.

The State Government has underwritten the early years of the State Plan through very significant increases in its spending on disability. Between 1998/99 and 2005/06, the latest year for which we have actual data, expenditures by the Victorian Government on disability services nearly doubled to \$1 billion³. In real terms, i.e. after adjusting for the effects of inflation, the increase in disability expenditures was nearly 50% and within this total, Grants and Payments to Service Providers in the Disability Sector rose by 63% in real terms.

Over the past seven years we have therefore seen both a very significant increase in disability spending and an unprecedented commitment by the Victorian Government to bolster services through disability organisations, like Yooralla and the many other organisations represented here tonight. The Government should therefore be congratulated for the confidence it has demonstrated in the quality, efficiency and capacity of community-based disability organisations to meet the Plan’s targets.

¹ Presentation to State Disability Forum, 5 September, 2007

² Victorian State Disability Plan 2002-2012

³ Department of Human Services Annual Report 2005-06 and previous years

However, as a director of organisations which are deeply committed to providing high quality services that meet the needs of all people with disabilities, I feel an enormous sense of frustration and disappointment that there are still many people with disabilities and their families we cannot help, because of insufficient resources.

In August last year, the Coalition for Disability Rights published a "Call to political parties", highlighting the needs for very significant additional investments in early intervention programs, community living and accommodation, respite services, aids and equipment and inclusion in the community. In total it suggested that additional recurrent expenditures of \$320 million per annum and capital expenditures of \$500 million over the next 4 years are urgently needed⁴.

As a director of Yooralla I regularly visit our services, so that I can meet clients and families and hear about their perception of our services and hopes. On a recent visit to one of our Early Intervention Centres, I spoke to the mother of a young boy with autism. Her question was: I know that early intervention is critical to my son's future, but why can't I get more support?

I explained the funding system, which does not differentiate between different disabilities or needs, but I was left feeling that I was failing her, her son and the many families needing tailored early intervention services. I also spoke to the staff. Their positive attitude, dedication to the needs of our clients and creativity was terrific. Their way of meeting unmet needs is to take more clients than their strict quota by factoring in an allowance for children's likely illnesses. Then, if everyone attends, they work unpaid overtime. However, I was also left feeling uneasy about the strains the current system places on Yooralla staff and others working in the disability sector.

Hearing these stories also brought memories flooding back to me from when my oldest son, Michael, was in pre-school and my wife and I wanted to obtain the best early intervention services for him, 20 years ago. I also found, as is often the case when I visit a Yooralla site, that my resolve to improve services for all people with disabilities was refuelled.

⁴ Coalition for Disability Rights, Call to Political Parties 2006 Victorian State Election

I am sure we have all felt this way at times and so, as leaders in the disability sector we need to ask ourselves: Why is there such a continuing gap between the aspirations of the State Disability Plan and today's reality; a gap between what you and I believe is right and fair and what we as a community do today to assist people with disabilities and their families.

In seeking answers to this question, it is important to recognise that there has been widespread acceptance of the principles of the Plan in the broader community and very significant increases in spending by the Victorian Government on disability services since the late 1990s.

However, the resources needed to give the Disability State Plan full life for all people with disabilities and their families are not sufficiently understood. There has also been only very limited discussion and no agreement on the responsibilities of people with disabilities to help themselves, the responsibilities of families to provide informal care and support, the rights of people with disabilities and how the balance of these rights and responsibilities should be shared given different disabilities.

In my view these are discussions and debates that we need to have as a community. The conversation needs to include people with disabilities, their families, the Commonwealth and State Governments and disability sector leaders. Moreover, as leaders of the disability sector it is part of our responsibilities to persuade the broader community that this is a matter of national importance.

In the time remaining I would like to focus on 3 key steps on the journey that I believe are needed to address the unmet and under-met needs of today and turn the State Disability Plan's vision into reality for all.

First, we need a commitment to planning across the State based on high quality data and the full analysis of this data in order to provide clear forecasts of future service and resource needs.

We need to start with children born with disabilities. According to the Birth Defects Register which is the principal source of information on 28 specific disabilities evident before the age of 15, the prevalence of disabilities has risen from 3.7% in the 5 years from 1990 to 1994 to 4.4% in 2000 to 2004⁵.

Amongst disabilities not included in the Register, there are about 2 children per 1000 born each year with cerebral palsy, the most common form of severe physical disability. There are also about 10 to 16 children in every 1000 being diagnosed with autism and the increases in the recorded incidence seems to reflect higher rates of occurrence, not just better identification methods. Amongst very low birth weight babies, those weighing less than 1.0 kilogram, the incidence of developmental disabilities such as motor, cognitive and behavioural impairments is as high as 50%.

The failure to include all disabilities and especially a number of severe disabilities limits the Birth Defects Register's use as a planning tool. It has also lead to some significant omissions. For example, the disabilities not included in the Register were not fully considered in last year's landmark publication, The state of Victoria's children report, 2006, undermining the Report's aspirational tag line "every child every chance"⁶.

We are also not using predictive tools that are now readily available that would enable future service demands for children with disabilities to be mapped well in advance of their needs. For example, for children whose disabilities become apparent in early childhood, it is now possible to predict adult mobility levels based on the milestones reached at two years of age⁷. Medical experts know how many are likely to be able to manage to walk with a walking aid and how many are likely to be confined to wheelchairs, but this is not part of our planning for either mobility equipment or access needs.

Services for adults with disabilities could also be planned much better. The Coalition for Disability Rights estimates that there are approximately 2600 people with disabilities waiting for accommodation, including 1600 people whose need are classified as urgent or

⁵ Birth Defects in Victoria 2003-2004.

⁶ The state of Victoria's children report 2006

⁷ CanChild Centre for Childhood Disability Research, July 2002. Ontario Motor Growth Study Project Report

high priority and 500 living with a carer aged 75 or over. A more recent study by the Australian Institute of Health and Welfare would suggest that in excess of 5000 people with disabilities have an unmet need for accommodation in this State⁸. Not to know the current and prospective demand for housing for people with disabilities is not acceptable.

More also needs to be done to differentiate between different disabilities, to gauge the needs for different specialist services and to map the current and future needs for services by location, because “one size does not fit all” and integration into local communities is an integral plank of the State Disability Plan.

Planning for disability services also needs to take account of expected social, demographic and economic changes, many of which can be predicted with a high degree of certainty. Foremost amongst these will be the erosion of current informal care arrangements.

We are already seeing that young families have less capacity to provide informal care than earlier generations, because both parents have to work and families today are more often located a long way from grandparents or other family networks. The trend towards more two income families seems set to continue, as for example housing affordability declines, further reducing the capacity of younger families to offer informal care.

Current informal arrangements amongst older carers are also set to be eroded as many people who are currently caring for a relative become too old or infirm to continue to shoulder these responsibilities. The Australian Institute of Health and Welfare estimates that there are nearly 30,000 people in Australia aged in their 60’s providing primary care. Amongst this group, 40% do not have a fallback informal carer, 69% of those being cared for could not manage independently for a few days and 20% need further assistance⁹.

The National Centre for Social and Economic Modelling has produced projections of the need for and supply of informal care for older people with disabilities over the period 2001 to 2031. While projections over such a long time period need to be treated with

⁸ Australian Institute of Health and Welfare, Disability Series, Current and future demand for specialist disability services, June 2007

⁹ Ibid.

caution, the trend is very clear. The number of principal carers for every 100 older persons needing informal care is projected to fall from 57 in 2001 to 35 in 2031¹⁰. According to Access Economics, in a 2005 Report for Carers Australia, the replacement value of informal care, Australia wide, would be \$30.5 billion annually¹¹.

In an economy which is already very close to full employment, finding paid carers will be a major issue for the aged care and disability sectors. Policies designed to attract and retain workers who are empathetic and supportive in assisting people with disabilities to make choices and access the community will therefore be a critical challenge and needs to be incorporated into the planning framework for the sector.

In addition, outside the traditional disability sector, the ageing of the population is going to lead to very significant increases in disability. Currently there are approximately one million people with a disability living in Victoria, which is around 20% of the State's population. Over the next 15 years Victoria's population is projected to increase by around 750,000 people, of whom approximately 350,000 will be disabled¹². Such growth in disability is unprecedented. It is equivalent to almost 1 in every 2 additions to the population and will place huge pressures on the aged care sector, while the disability sector will need to play a key supporting role.

We also need to fully incorporate access for people with disabilities into the design of our communities, as part of our planning. It is extraordinary that at a time when Victorians are ageing and acquiring disabilities at an unprecedented rate, almost all new houses being built today are not fully accessible, new public buildings are frequently difficult to access and the new public transport ticketing system, myki, will not be accessible even though the Transport Ticketing Authority has been advised by the Public Transport Access Committee. Full access for people with disabilities needs to become a part of universal design, as a matter of priority, if we as a community are to avoid the very large and unnecessary expenditures required to adapt more and more places so that they are accessible as the number of people with disabilities grows.

¹⁰ NATSEM(National Centre for Social and Economic Modelling) 2004. Who's going to care? Informal care and an ageing population. Report prepared for Carers Australia

¹¹ Access Economics Pty Limited August 2005. The Economic Value of Informal Care. Report prepared for Carers Australia

¹² Estimates calculated based on ABS Disability Australia, 2003, ABS Disability, Ageing and Carers, Australia, 2003, ABS Population Projections, 2004 to 2101

In the face of such far reaching changes confronting our community in general and the disability sector, in particular, obtaining the best estimates of future demand for services should be imperative, the responsibility of Government, widely available and one of the foundations on which the State Disability Plan is built.

The second step that I believe needs to be taken in the State Disability Plan journey is a re-examination and reform of the relationship between the Victorian Government and the Department of Human Services, on the one hand, and the disability sector, on the other.

The first urgent reform relates to funding because, over recent years while Grants and Payments to Service Providers have increased sharply, organisational capacities have actually been eroded. These declines in capacity reflect the Government's funding formulae, which do not fully index administration costs or provide for depreciation of capital. As a result, the physical infrastructure of disability organisations is being stretched and essential capital equipment, for example vans and buses to transport clients, are not being replaced.

There has also been unprecedented growth in the reporting requirements and regulation of the disability sector by the State Government. As an example, the recent introduction of the Disability Act, while leading to important improvements in the rights of people with disabilities, will cost Yooralla \$500,000 per annum in additional administration costs. This represents about 1% of the funding that Yooralla receives from the Victorian Government and for which Yooralla will receive no additional funding.

The shift to individualised funding is also creating benefits and unfunded costs. Individualised funding models are positive because they help to empower people with disabilities. However, they also weaken the capacity of disability organisations to deliver services because the funding does not compensate agencies for the risks that they may offer services that are not purchased. Agencies also lose some of their cash reserves and interest earnings as they no longer receive funds from government in advance of service delivery.

For-profit organisations are also cherry picking services where a commercial return can be made on the capital employed. From the perspective of people with disabilities this competition is healthy. However, to the extent that disability organisations are using their profitable services to cross subsidise services where the full costs cannot be recouped, this development also erodes capacity.

The State Government has recognised the significance of some of these trends and so has commissioned a Review of Not-For-Profit Regulation, set up a Strengthening Community Organisations Project and promised to review some of its formulae for funding disability organisations.

I welcome these inquiries as they are very timely and have the potential to have far-reaching positive effects. However, as with all inquiries and reports, they will only make a difference if the current deficiencies are fully recognised and quick and decisive actions follow. For the disability sector, it is imperative that the current shortfalls in funding are corrected to rebuild the sector's capacity and excessive regulation and reporting are eliminated.

A second aspect of reform lies in a review of the current relationship between the Department of Human Services and the disability sector. DHS has a dominant position. It provides in excess of 50% of the funding of many organisations, creates competition between agencies through its tender processes, monitors agencies' performances and in some areas is a service provider itself, creating an obvious conflict of interest.

At times, to win DHS contracts, agencies do not fully recoup their costs when bidding for services, reducing their capacities in the medium term. At other times, the unequal relationship between DHS and community organisations makes it difficult to give feedback that would improve resource allocation or facilitate innovation and program development.

Untangling the causes and effects in the current arrangements is complicated but the solution would appear to lie in more outsourcing of services, a further shift in funding to individuals and the development of more partner type models, based on evidence based innovation, investment and best-practice models of service delivery.

Possible specific measures include:

- A clearing house to fund and review innovation and ensure that the results are disseminated and widely adopted across the sector;
- A clear recognition that many disability services are an investment and not just a cost. This is particularly the case in early intervention where there is strong evidence that support in the early years leads to much better and less costly long term outcomes. An example with which I am very familiar is some recent research undertaken by Solve! At the RCH and Uncle Bobs Early Intervention Centre that shows that supporting children with autism through a short weekly visit by a special education teacher at home for a year leads to significant and sustained cognitive and behavioural benefits two years later¹³. Currently, recurrent funding for this new service is not available, even though the investment payback is enormous.
- The appointment of Facilitating Partners with responsibility to provide leadership in service delivery and account to Government on disability services in specific areas. This approach has been used by the Commonwealth Government in its Communities for Children program and has led to better services, based on stronger cooperation and collaboration between agencies.
- Further outsourcing of services which are currently directly provided by Government could generate major efficiency gains. For example, the Productivity Commission estimates that the costs per person of shared supported accommodation provided by community organisations is 40% lower than in Government provided services¹⁴. The transfer of these services to community organisations would save up to \$100 million and represents the largest potential cost saving in the sector, as well as removing one of the current conflicts of interest between DHS's partnering and direct service roles.

All of the measures I have suggested would lead to significant long term benefits.

¹³ Anne Rickards, Janet Walstab, Roslyn Wright-Rossi, Jacqui Simpson and Dinah Reddihough August 2007. A Randomized, Controlled Trial of a Home-Based Intervention Program for Children with Autism and Developmental Delay

¹⁴ Productivity Commission 2007. Report on Government Services, Services for People with a Disability

The third step that I believe is required on the journey to fulfill the State Disability Plan is the recognition that the full rights of people with disabilities will only be achieved through a coordinated approach between the State and Commonwealth Governments.

The need for a more co-ordinated approach to service delivery is clear from the gaps in the current system. For example, people with disabilities in day services are funded by the State Government, while those in employment services are funded at the Commonwealth level. It is therefore difficult to work part-time and also access day services. Accommodation for people with disabilities is a State responsibility, while aged care is a Commonwealth responsibility. As a result, older people with disabilities are still being required to go to day placements, because many Community Residential Units are not staffed during the day, when these older people really should be able to stay at home.

Two months ago, when negotiations over the Commonwealth, States and Territories Disability Agreement broke down, the Commonwealth announced new funding for accommodation for people with disabilities living at home with a parent aged over age 65. While this new funding source is very welcome and is targeted at an area of enormous need, it is yet another example of the current fragmented approach to disability services.

One approach to better coordination would be to seek a clear delineation and allocation of responsibilities for people with disabilities and their families between the States and the Commonwealth. A better approach would be systemic reform based on the principles of universal insurance.

Currently, for people with disabilities from birth, where there is no evidence of medical negligence, there is no automatic support. In contrast if there has been medical negligence then compensation can be provided by the courts. In some cases there have been multi-million dollar pay-outs, while a child with an unsourced disability in the next hospital bed receives nothing, even though their disability and needs may be greater.

There are similar gaps in the support structures for people with acquired brain injuries and this problem has recently been highlighted in the case of James Macready-Bryan¹⁵, an

¹⁵ James Macready-Bryan Foundation, www.macready-bryan.com

innocent victim of a street bashing. He has received no compensation, in contrast to road accident victims or someone who sustained similar head injuries as a result of a workplace fall.

These anomalies and injustices have been recognised in some government, medical, insurance and disability circles and some work has been undertaken on a national compensation or insurance scheme, which would mean that all people who acquire major injuries or are born with severe disabilities would be fully covered. There have been some consultations with the Commonwealth and all States and Territories and the initial focus of the research has been on the costs of extending motor vehicle, work place, public liability and medical indemnity insurances to provide no-fault long term care for the catastrophically injured¹⁶.

In Victoria, the Transport Accident Commission and Workcover already provide no fault long term care. The aim is to persuade the other States and Territories to bring their insurance arrangements into line and then reform public liability and medical indemnity insurances. Then the provision of no-fault long term care for people born with disabilities would be the next step in the development of a national compensation scheme for all people with significant disabilities irrespective of the cause of the disability.

With such a scheme people with disabilities would be in control and able to make choices consistent with the goals of the State Disability Plan, while their families would be able to better balance their lives, in the certain knowledge that the long term care needs of their disabled family member would be provided.

The contrast between this vision and today's reality could not be more stark. For most families with young children with disabilities, the challenges are enormous. While grappling with their grief and anger that their child is disabled, these families must juggle work and care, including the care of other children. They must then decide whether the two incomes that they were planning, to provide an adequate standard of living, are essential or care full-time for their disabled child, while also facing higher costs than if

¹⁶ John Walsh, Anna Dayton, Chris Cuff and Peter Martin March 2005. Long Term Care Actuarial Analysis on Long-Term Care for the Catastrophically Injured

their child had been able-bodied. These choices are not choices; the joint demands of work and care for disabled loved ones are irreconcilable.

In many cases the tensions and stresses created by caring for a disabled family member leads to family breakdown. In other cases, perhaps even more tragically, the families relinquish their disabled child, not because they do not love that child, but simply because they can no longer cope in an environment in which they are receiving insufficient support. Amongst ageing parents with a disabled adult son or daughter living at home there is the fear of what will happen to their child when they are no longer able to continue to provide the care.

Obviously, more services would help to alleviate these family pressures. However, to fully solve these problems it is imperative that there is a complete overhaul of the support mechanisms for people with disabilities, based on the principles of national insurance and after consultations with all stakeholders.

As leaders of the disability sector, our role is to lead public discussion, as well as our own organisations, to influence community attitudes, to explain the critical next steps required to meet the objectives of the State Disability Plan and to seek a fairer outcome for all people with disabilities.

I will know we have completed the journey mapped in the State Disability Plan when:

- People with disabilities have the rights, and if needed facilitation, to choose from a range of service options, free from stigma, ideology or prejudice;
- There are no more waiting lists for essential communication devices, mobility equipment, car modifications, hoists or accommodation;
- Families with children with disabilities no longer experience far higher rates of family breakdown than in the broader community and families that love their disabled children no longer relinquish them out of despair;
- Parents have confidence that their children with disabilities will be well cared for, when they are no longer able to provide the care themselves, without reliance on another family member; and,

- The community respects, protects and promotes the rights of people with disabilities and our actions are fully inclusive.

Thank you.

Bruce Bonyhady¹⁷

5 September, 2007

¹⁷ Bruce Bonyhady is Chairman of Yooralla, President of Philanthropy Australia, Chairman of the Advisory Panel to Solve! At the RCH and a Director of the Disability Housing Trust. He has 3 children, 2 of whom are disabled.