

Submission
No 107

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY
THE DEPARTMENT OF AGEING, DISABILITY AND
HOME CARE**

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THE DISABILITY
TRUST

Submission: Social Issues Committee

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...creating an inclusive world

Introduction

The Disability Trust welcomes the opportunity to provide this information.

In order to frame our response our organisation would, at the outset, like to acknowledge the current sense of optimism within our sector for the future of disability services in NSW. The sustained efforts by the Department of Ageing Disability and Home Care and NSW government through the roll out of Stronger Together over recent years has led to genuine outcomes for people with a disability and their families, people we at The Disability Trust come into contact with on a daily basis. Although unmet and under-met need remain as the most significant key challenges for the future, as a sector and a service system we are now well set to “do more” and “do better”.

The Disability Trust appreciates the strong sense of partnership that is emerging with our funding body. This is built on a shared sense of purpose around creating a service system that is flexible, person centred and of the highest possible quality. With the impact of increased funding being felt at the front end of service delivery, we now have for the first time the opportunity to move from reactive and crisis driven responses to an environment that supports critical consideration of the design of models of funding and care. We believe that ongoing collaboration between people with disabilities and their families, service providers and government is the key to getting the architecture of our service system right. There is a lot of work to be done and many challenges to meet.

The Disability Trust

The Disability Trust was formed in 1974 by people with physical disabilities and by parents of people with intellectual disabilities. We have very much an advocacy and rights based perspective that has continued informing our values as we have grown into the major service provider we are today. We have as our underpinning mission to – *create an inclusive world*.

In the 2009-2010 year the Trust provided services to over 2,300 people with disabilities. We had a turnover of 20,600,000 comprising of \$12,300,000 from State Funding, \$ 2,300,000 from Commonwealth funding \$ 6,000,000 from other sources. These figures include one-off funding for capital acquisitions and/or care in advance.

In the last financial year the Trust's NSW government funded programs provided 515,949 hours of care to 1,087 clients (475 hrs per client per year). This involved 85,432 episodes of care (an average of 6 hours per episode). In terms of respite and in-home care services alone (excluding residential respite) we provided 83,188 hours of care to 362 clients (230 hours per client per year). This involved 27,628 episodes of care at an average of 3.2 hours per episode. The Trust also delivered over 10,000 hours of training to direct care staff. The Trust's state government funded service types broadly include supported accommodation, independent living, attendant care, flexible respite, centre based respite and day programs and sport and recreation services.

The Trust has an effective internal quality assurance system and annually surveys its clients and stakeholder base as one way of determining areas for quality improvement. We are interested also in service design and operate a number of internal Committees to try to drive best practice. These include an Access and Equity Committee, Training and Workforce Development Committee, Image and Identity Committee, Clinical Services Committee, Quality Assurance Committee, Business and Regional

Development Committee, Office Management and IT Committee and various Committees based on best practice in service types e.g. Supported Accommodation.

The Trust has successfully taken a social entrepreneurial approach to developing alternate incomes through business activity. This provides opportunities to value-add to the service system by allowing us to self fund a specialist clinical services wing internally. We employ a registered Psychologist and Clinical Nurse Specialist through these sources. We also have a more modest income resulting from fundraising allowing us to offer access to subsidised aids and equipment to families of children with disabilities.

Key Challenges for the Service System

Industrial Relations Policy Alignment

Contrasting government policy is something that needs to be addressed and better understood to deliver the most effective and efficient service provision. The central policy drivers for contemporary disability services are person centeredness, flexibility and choice in service provision. This is at odds with contemporary Industrial Relations policy which is far less flexible in its current format. This misalignment is something we feel that needs to be addressed.

With new industrial relations (IR) requirements in place service organisations must work within increasingly inflexible work practices with respect to their staffing of shifts. For instance changes to the relevant modern award require direct care workers to have a 10 hour break between shifts and complete their hours for a broken shift within a 12 hour span. These changes have presented a real challenge. Considering the highest level of demand for personal care support is predominantly clustered in the mornings and evenings with little demand during the day, the changes to the Award have often made it difficult to maintain flexibility of staffing and meet client preferences in their choice of staffing. For an organisation that places a firm emphasis on addressing individual needs, as The Disability Trust strives to do, this new context has added cost and complexity to our rostering.

Issues related to work practices make it particularly hard to administer models that maximise client choice and control over services such as in the NSW Attendant Care Scheme. Clients need to be fully up to speed on the nature of work practices in order to manage their own care services within the system without adding additional costs to their care packages. When a care worker is working with several people with a disability, a client that makes a last minute change to their service schedule will not only impact on their own service provision but may also have a negative impact on the cost of another person's care services later that day.

Demands for choice, spontaneity and flexibility of service arrangements require service provision to be disaggregated into smaller individualised units. Under modern Award conditions this necessitates an increasing casualised workforce. This is an issue in terms of the protection of the rights of direct care workers within the sector but also leads to challenges in creating sustainability and genuine workforce development. For the most effective delivery of quality services that recognises each unique individual, there needs to be a rethink in IR policy with regard to disability services. As we move further toward a system that encourages full and active participation from people with disabilities and their families, we feel that this is a vital hurdle to overcome.

Accountability

The Disability Services sector can be highly regulated with mandatory external and internal accountability demanded by various jurisdictions. In addition to the general corporate regulations, IR, taxation, OH&S, Privacy Act provisions, charitable fundraising compliance, and financial audit requirements, there are a range of specific standards and accreditation processes that may be required by providers in the sector. Some that are pertinent to the Trust include; NSW Disability Services Standards, measureable in previous years through the Integrated Monitoring Framework; Commonwealth Disability standards with external Quality Assurance audits; Home and Community Care Standards; Attendant Care Industry accreditation, also externally measured; Office of the Children's Guardian registration; and Statutory Out of Home Care compliance. *Accountability is further demonstrated through regular quarterly data returns, external scrutiny through a community visitors' scheme and end of year financial acquittals. Additionally the Expression of Interest process for new funding requires evidence of an organisation's capacity to deliver the quality and outputs of services that are subject to tendering.*

These overlaying accountabilities can divert energy and resources from the most important part of the care system, that is, the interface with clients

and families. While The Disability Trust is proud of our achievements within an audit and compliance framework we believe that significant work needs to be done so that State and Commonwealth are not duplicating their efforts in measuring the performance of funded organisations in similar key domains in analogous ways. Importantly organisations could benefit from a streamlined approach that does not require assembling the large volumes of data and supporting evidence to respond to the same questions from different parts of government. The Disability Trust believes that rationalisation of accountability requirements and serious efforts at red tape reduction will create a better and more efficient service system.

Creating Efficiency and Integrated Management Systems

The Disability Trust is a significant provider of flexible services. Person centeredness requires the capacity for people with disabilities to have their care in locations of their choice, with staffing to suit their needs and at times that are amenable to their lifestyle. Old block funded programs simply opened their doors, booked people in for “their care” well in advance and were inflexible to amendment. New person centred approaches need to be built on the expectation of regular change and require frequent last minute re-rostering to take into account the whole of life needs of individuals and their families. As indicated previously The Disability Trust last year delivered 83,188 hours of respite and in-home care services. These hours were at irregular times, across various staffing shifts with associated penalties and were of varying durations in a wide range of settings. This requires a mobile and fluid approach to resource management. It would be impossible to deliver these outcomes without heavy investment in new technology and the back up provided by integrated management systems that support rostering, payroll and financial management and generate the corresponding data returns for government.

The Disability Trust believes that there is a strong role for government in assisting the sector to create the “back office” efficiencies to deliver real differences in the nature and timing of services. The move from standard hours of operation to a very high number of short episodes of care constructed around client choice necessitates sophisticated IT systems and a change in the culture of organisational management.

Organisations that have traditionally worked with block grants could well need assistance to develop the complex management systems required for support of individual packages where the nature and hours of care change on a daily basis.

Sustaining Infrastructure

The move to individualised funding can create inefficiencies unless there is work around capacity building of the service system. Applying individual funding models to accommodation services presents challenges in building service infrastructure including maintaining quality and efficiency that were previously built into traditional grant funding. Put simply, group living arrangements are very cost effective and many people with disabilities and their families choose this model of service. Where people are individually funded we cannot presuppose that there will already be infrastructure and accommodation in place that they can access. Without an established referral system possibly linked to the case management facility it is likely that service providers would be reluctant to build this infrastructure and meet the cost of developing group accommodation.

The challenge in creating opportunities for group living is exacerbated in regional and rural areas where low volume of potential referrals could see people with disabilities needing to move out of area to find something that better suits their needs. This is particularly pertinent to regional organisations like The Disability Trust, who want to ensure clients can receive the best services at a local level. Of course this is an issue with block funding also, but these issues can be more readily examined and infrastructure developed to overcome regional or rural disadvantage.

For group living arrangements to be most effective, a system for preplanning, placement and vacancy management systems need to be in place. This system needs to be sophisticated enough and responsive enough to deal with issues of resident compatibility both socially and in terms of staffing requirements and also needs to be able to take into account location of services in communities where residents can maintain existing social and family networks.

Supporting a Healthy Community Sector

Governments rely on the community sector to deliver their strategies for social innovation, social inclusion, and community wellbeing. It is vital that the not for profit sector is recognised and valued for our capacity to deliver important social outcomes. Many not-for-profit disability organisations value-add to the service system through their ability to leverage additional income from fundraising or corporate sponsorships or through their motivation to facilitate personalised community networks for clients that support inclusion.

The importance of a healthy and vibrant not for profit sector was recognised in The Productivity Commission' 2010 Research Report *Contribution of the Not-for-Profit Sector (NFP)*:

"NFP activities may generate benefits that go beyond the recipients of services and the direct impacts of their outcomes. For example, involving families and the local community in the delivery of disability services can generate broader community benefits (spill overs), such as greater understanding and acceptance of all people with disabilities thereby enhancing social inclusion. Smaller community-based bodies can play an especially important role in generating community connections and strengthening civil society".

As it is unlikely that the funded service system can meet absolute levels of demand, new systems and models need to look at ways to value-add to the strengths of the current service system. It is heartening to see that funding

bodies recognise the important role of community services in combating social exclusion and enhancing the economic, social, cultural and environmental wellbeing of society.

Important issues for a sample Client Group - Summary of Results of TDT Survey

The Disability Trust recently surveyed its membership base and received 297 responses back from people with disabilities and their families. This survey was constructed around the Lifetime Care Inquiry currently being undertaken by the Commonwealth Productivity Commission. The Disability Trust believes however that the results may have some wider value in understanding what our client group see as the most essential features of a service delivery system.

It should be noted that the views expressed by respondents were quite diverse and The Disability Trust cannot assure that our response is representative of the full range of opinion. Respondents represented people with a wide range of different disabilities and of various ages. Families also had opportunities to have their say through the survey process particularly in terms of the needs of their younger children. Respondents had variable levels of support needs and used a wide variety of disability service types, some through The Trust's service provision and some through other providers. The largest percentage of respondents (almost 50%) were utilising some form of respite care. This is quite high considering that a further 18% were accessing independent living services, 20% were accessing attendant care services and 4% were living in residential services.

In forming our response The Disability Trust has utilised our existing knowledge of the disability service system and our ongoing contact with and feedback from people and families utilising disability services. We have highlighted information attained through the survey where there have been clear trends in responses and we have attempted to integrate these into our overall submission.

Assurance of Service

An analysis of our survey results suggests that overwhelmingly the most highly ranked feature that clients and families would like to see under the proposed model is that there is a guarantee of a minimum level of service. Many people with disabilities and their families added comments to support their high ranking of this as a desirable element of a new scheme. These comments suggest that their biggest fears were for their future. The lack of surety of services and supports clearly causes many people to experience a high degree of uncertainty about their long term options. This was raised as an issue even for family and clients that currently receive the services that they need but who nevertheless feel vulnerable to changes in government policies and funding levels. The Trust would add that there should also be a mechanism for reassessment of levels of service support for people as their needs change due to personal circumstances, ageing or the possible impact of degenerative conditions.

The issue of service guarantee is a vexed one in terms of political policy but The Trust believes that certainly people with significant ongoing support needs should feel some certainty regarding their current and future support.

Service Responsiveness and Flexibility

The second most highly ranked feature of the new scheme was service responsiveness and flexibility. This fits with The Disability Trust's general perception that people with disabilities and families are increasingly requiring services that are built around their personal needs and preferences; able to be easily rearranged so as to afford spontaneity and choice in day to day life; and are variable to meet changing needs over time. Some funding models within NSW already allow a high degree of flexibility and choice including the Attendant Care Scheme and flexible respite models. The Disability Trust believes however that in other models of service, both state and federally funded, the tied nature of grants and funding arrangements to a fixed range of predetermined outcomes can, at

times, hamper a more fluid approach to changing needs. The nature of contracts can create a silo effect in the service delivery system that is limiting to providers as well as the people using services.

Key features of the Attendant Care Scheme that are more universally desirable include, capacity to “bank” hours of service; choice of service provider or self managed care models; choice in when and how services are delivered; capacity to change the timing and nature of services at short notice; and incorporation in the funding model of a wide range of supports including assistance with tasks of daily living. The latter holistic approach overcomes problems associated with adherence to overly prescriptive services that may for instance be independently offering personal care, domestic assistance, meal preparation, or community access.

Given this trend in demand for improved responsiveness to needs, it was interesting to note that 75% percent of respondents indicated that the services they currently receive were responsive or highly responsive to their needs. While this is encouraging The Disability Trust believes that the disability sector can significantly improve upon these figures by overcoming some of the systemic barriers to service responsiveness that are tied into current funding arrangements.

Quality of Care

Maintaining quality of care was ranked third highest by our client group after surety of services and service flexibility. The Disability Trust annually checks for service quality through a range of surveys and by having other systems for quality feedback and improvement.

The Disability Trust believes that quality of care as an outcome can best be addressed through the creation of a set of minimum standards applicable to both direct service providers and to case management arrangements should they be built into the scheme.

Access to Information and Assistance in Tailoring Care

The high ranking given to this feature by respondents to The Disability Trust's survey was somewhat surprising. However it is possible that while contemporary policy has been driving changes in flexibility and responsiveness in service provision, the resourcing of people with disabilities and families to understand and best utilise these systems and make them work for them has not always kept pace. The fragmented nature of funding going to each individual from a variety of sources also contributes. Several comments suggested that while increased availability of services was welcomed, it is hard to stay up to date with the various eligibility requirements in terms of geography, service type and levels of care available from each provider.

Increased Range of Service Options

An increased range of service options was identified as an area requiring further attention. Transport needs were specifically cited as problematic by some respondents. Although there were other comments offering examples of gaps in the service system these were predominantly in relation to a specific individual need and no clear pattern emerged suggesting a role for new service types to be built into the scheme. The Disability Trust again believes that allowing the provision of care to be holistic and individually tailored may meet demand for specific support not currently offered as a funded service type.

Rural and Remote Areas

A number of respondents identified the need for a scheme to offer a better coverage of the needs of people living in remote and rural areas. The Disability Trust believes that while there are demands for person centred arrangements, individualised funding may be insufficient to build infrastructure and choice of services in areas of low demand. There may be further challenges inherent in developing infrastructure around accommodation models in rural communities.

Portability of Funding and Individualised Packages

Portability of services through individual funding packages was seen as highly desirable by most respondents. Again this reflects trends towards increased demand for choice and flexibility in services.

Options for Self Managed Care

While overall this was not ranked as highly as a number of other features, it was clearly identified as a preference by a number of respondents. The option was also highlighted in comments offered by several respondents suggesting that, for some people, it is an area of choice that is vitally important.