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SUBMISSION TO THE PRODUCTIVITY COMMISSION INVESTIGATION RELATING TO DISABILITY SUPPORT AND CARE

Recent reports on disability, namely the Consultation Report from the National Disability Strategy - SHUT OUT: The Experience of People with Disabilities and their Families in Australia and the report of the Disability Investment Group, The Way Forward, A New Disability Policy Framework for Australia demonstrate that the current policy setting and operating systems present a multiplicity of barriers for people with disabilities and their families to negotiate. The Centre for Cerebral Palsy's (TCCP) discussions with some of its client families endorse this view, making a strong case for an overhaul of the system.

In recent years all tiers of Government have pushed for directional change to enable people with disabilities to live in the community and for person-centred planning. However, service provision has lagged behind this directional push because of the lack of sufficient services to fulfil these objectives, and the lack of certainty in long term funding and support. The Shut Out Report states that 'Services were characterised as unavailable or unaffordable or of such poor quality as to be of little benefit. Many submissions said that there is little or no choice in services provided...that the system is characterised by a one-size-fits-all approach in which there is very little choice or flexibility. Programs and systems are built around organisational and system needs rather than the needs of the clients'.

UNMET & UNDER-MET DEMAND

Unmet and under-met demand can be defined as persons needing more services than they are currently getting but who are unable to access them for a variety of services and people who are not getting any services despite having similar level of disability as those receiving services.

Quantifying unmet and under-met demand in monetary demands is complex for a variety of reasons even for experts. Instead experts such as the Disability Investment Group have attempted to quantify unmet demand in terms of broad service areas such as the accommodation and respite services (23,800 people) and community access services (3,700). This figures were for 2005 and since then, unmet demand for specialist disability services is said to have risen considerably, with recent trends indicating a 7.5 per cent growth each year in real terms. The DIG Group that work undertaken by Pricewaterhouse Coopers estimated that unmet need for people requiring constant support would grow from 1 per cent of what they require in 2004 to 49 per cent by 2031. Also that unmet need for persons requiring regular support will grow from 25 per cent in 2004 to a projected 48 per cent in 2031; and for those requiring lower support, unmet need will grow from 77 per cent in 2004 to a projected 90 per cent by 2031. what all these figures show is

that unmet and under-met demand for services in disability services is real and needs to be addressed urgently.

Unmet and under-met services

While acknowledging that there is an unmet and under-met demand for a variety of services, including early intervention, the client families interviewed for the purpose of this submission stated that the recent push for early intervention programs has meant that unmet and under-met demand is greater in programs relating to critical transition points. These are programs relating to school commencement, transition from primary to high school and transition from school to employment or alternatives to employment and independent living options.

Mental health was another area identified as an area where there is a considerable unmet demand. Accessibility to available mental health services and support was identified as a major concern. Respite was also identified as a key area of unmet demand.

It was also evident that there was considerable unmet demand for aids and equipment which are required by people with disabilities for basic living. Although they are by no means luxury items, costs prohibit some families from accessing them to assist the person with disabilities. This can result in intensifying the disability, loss of independence and in the long term, in additional costs.

In addressing the issue of unmet and under-met services it is important to consider the viability of service providers for without a sustainable structure of service provision, the extent of unmet services will increase.

Hidden unmet demand: the needs of families and carers

In determining the feasibility of the National Disability Insurance Scheme, TCCP urges the Productivity Commission to consider the impact of the hidden or invisible unmet demand, that of family and informal carers and families of children and adults with disabilities. It is well known that family members, primarily as informal carers have been the rock upon which the entire disability sector has been and continues to be built, with a majority of them providing more than 100 hours of care a week. Access Economics estimated that the replacement value of informal care in Australia would be in the vicinity of \$30.5 billion. Their struggle to survive financially and to care for their family members is well documented. The Disability Investment Group (DIG) Report claims that a large proportion of primary carers were likely to be in the poorest two fifths of all households and that a majority of them receive income support as their main source of income. Due to their care obligations many of them are not engaged in paid employment and with time become unfit for work. The Report on the Nature and Impact of Caring for Family members with a Disability in Australia states that 'It is clear that many carers had stopped working since commencing caring and when asked why, a large majority said that it was because of their caring responsibilities'. As a result many of them suffered greater financial hardship than the general population, experiencing difficulty in paying the usual bills of gas, electricity, water and telephone that Australian families are expected to pay. About twice as many carers are in poor health when compared to other Australians and many of them as well as other family members suffer from mental illness and are unable to obtain services to address this need.

In addition, the cost in opportunity of carers not participating in activities of choice due to their caring role is colossal primarily in terms of each individual carer, their families and the community at large. Inevitably all of this also impacts on other members of the family, including children. While some families are more resilient than others, it is likely that many of them experience difficulties in family functioning, frequently having to deal with conflict and family breakdown. For a variety of reasons the reliance on carers to carry the system is becoming less and less sustainable.

It is critical for the sustainability of any new disability strategy to take account of the entitlement to support for families and carers of people/children with disabilities.

Unmet demand and indigenous people in rural and remote communities

TCCP is very aware of the limited services available to Aboriginal people, particularly those residing in rural and remote areas. The incidence of disability in the Indigenous community of Western Australia is consistently higher than for the non-Indigenous population. Despite Indigenous people comprising 3.8 per cent of the State's population, Aboriginal children made up 8.4 per cent of children born with cerebral palsy between 1980 and 1999. It is also suggested that Aboriginal people were twice as likely as their non-Indigenous counterparts to require assistance with a core activity. For a variety of reasons Aboriginal people are often unwilling and distrustful to approach and engage with non-Aboriginal service providers. Due to the inadequacy of services in rural and remote areas, often Aboriginal people with disabilities either have to put up with services available in those locations even if they do not realistically fulfil their need, or be referred to an urban centre with which they have little familiarity. Their situation in terms of these referrals is compounded by their inability to communicate effectively in English and the lack of understanding of this inability by mainstream service providers. A National Disability Insurance Scheme (NDIS) will assist Aboriginal families in rural and remote areas to support family members with disabilities. In an environment of competition which an NDIS is likely to create, there will be greater scope for Aboriginal individuals and families to have choice relating to services. It is also likely to prompt mainstream service providers to appreciate more the need to be sensitive to the cultural needs of Aboriginal clients.

As part of any future long term care and support scheme, it is particularly important for the Commission to encourage the establishment of Aboriginal specific services in rural and remote areas so that Aboriginal people with disabilities residing in those areas are able to receive services in their own environment.

Proposed eligibility for a new scheme

The unmet demand relates to both people as well as services. TCCP is aware of clients/families who receive funding support that only covers a small part of the costs of the care requirements of a family member with disabilities. With families having to cover the bulk of the cost of caring for a family member with disabilities, these families struggle to achieve a basic quality of life for the whole family.

Families were sceptical about current eligibility assessment mechanisms. They felt that families needed to reach crisis point before support is provided. They stated that current assessment processes force them to portray the worst case scenario regarding the person with disabilities to ensure funding. It was their belief that

schools too were forced to adopt such a process to ensure continued funding. They were concerned that this disallows dignity for the person with disabilities and prevents celebration of their achievements, a goal that families, service providers and funding bodies are attempting to achieve.

As stated previously, TCCP strongly advocates for any new scheme to be underpinned by the principles of equity, self-determination and sustainability. The Disability Investment Group (DIG) recommended a NDIS scheme to be restricted to ‘...to meet existing, unmet and future needs of people with severe or profound disability for life, where disability is acquired before age 65’. TCCP believes that an artificial age criterion is particularly meaningless in the context of the Federal Government’s push for social inclusion when improved technology and therapies are enabling people with disabilities to live longer. To enable the principles of equity, self-determination and sustainability to underpin the scheme, TCCP recommends that similar to entitlements relating to unemployment benefits, all people with disabilities be entitled to an automatic entitlement and a simple, fair and flexible assessment be applied thereafter to enable additional support. Currently, people with similar disabilities get varying levels of support depending on the way they acquired the disability, making the current system inequitable and unfair.

TCCP supports the position that all types of disability be treated equitably. Equally the cause of a disability should be considered irrelevant to eligibility. The gap that needs to be nullified is not between one person with a disability and another but between people with disabilities and other members of this society. This approach will also prevent situations where a single service provider is forced to provide services to people with identical disabilities but with vastly different funding packages.

Currently in Australia there are about 4 million people with disabilities. If the DIG group recommendation is adopted about one quarter of the people with disabilities will be eligible for NDIS. Whilst the under-met demand for this proportion will then be addressed, the unmet demand relating to a majority of people with disabilities will not be addressed. It is critical that any new scheme not replace one set of inequalities with another set.

TCCP’s clients were of the view that there was too much paperwork for families to deal with and little understanding of disabilities in relation to the questions in the proformas they were requested to fill out annually to obtain funding. They felt that the policy makers and other bureaucratic decision makers should have a greater understanding and appreciation of particular types of disabilities and their intensities so that duplication and repetition relating to paperwork can be removed.

SELF-DETERMINATION THROUGH PERSON-CENTRED PLANNING

Person-centred option is the central tool upon which independent living is based. Elements of person-centred planning are that the person is at the centre of the planning and is consulted throughout the planning process. In keeping with this pivotal feature, the person chooses who to involve in the process with family members and friends as partners in the plan; the person chooses the setting and timings of meetings and the plan reflects what is important to the person, their capacities and the support they require; there is shared understanding amongst all people involved that the person is the expert and that the plan results in action about life, not just services; It reflects what is possible rather than what is available.

The process as well as the product is owned by the client and cuts across the traditional methods of case management.

In addition to the person with disabilities and/or the family having control, the person centred care option plans for the whole person, in the short, intermediate and long terms with transparency and flexibility in funding. The person with disabilities and their families will know how much funding is received, have genuine control of it, and can purchase services on the basis of the plan. The control over funding gives people the flexibility to change the plan as they see fit.

While TCCP strongly supports person-centred planning and individualised funding, the organisation understands that a gradual, step-by-step approach must be adopted in their implementation. It was clear that families of clients interviewed for contributing to this submission did not have sufficient information relating to these mechanisms to be totally supportive. The families were happy to have an agency like TCCP which specialised in the disability of their family member. The organisation enabled them to have a channel through which they could associate with other families who have family members with cerebral palsy and to have a sense of belonging. They also said that the organisation assisted them to work through the maze of available services. They said the sector is full of services but that on their own they would not know which service would be the most appropriate for their family member.

In relation to individualised funding they seemed uncertain about how it will work. They said that while some families would welcome individualised funding, many will not be equipped to make choices. Some may even misuse the funding to the detriment of their loved one. While they welcomed the option of being able to set priorities, they would welcome an agency like TCCP to be available to guide them through these processes. They also felt that there should be flexibility in any scheme to take account of the different needs that exist in families that have a member with disabilities.

TCCP recognises that a considerable investment would need to be made in information, resources and advocacy to ensure that individuals, carers and families have the capacity to make informed choices. TCCP also recognises that all families are not the same, and that some would require more assistance than others prior to being able to make choices.

LONG TERM CARE AND SUSTAINABILITY THROUGH A NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

TCCP strongly supports the establishment of a NDIS, a social insurance scheme to replace an outmoded, fragmented crisis-driven, welfare-based approach. It also has the potential to be a streamlined model whereby the billions being spent by the various tiers of Government can be channelled through a single scheme.

TCCP strongly supports a National Disability Insurance Scheme which would:

- address current unmet and under-met demand which people with disabilities experience;
- enable people with disability to have certainty relating to the future and for the individual to be at the core of service planning and provision;

- enable individuals with disabilities to move away from a medical model of care to a holistic model of care whereby they can manage their own lives, become more independent and participate in the community;
- enable individuals and families to have real choice through which they will be empowered to make decisions and participate more fully in community life;
- enable service standards to be nationally driven. Due to the differing eligibility criteria currently prevailing between states and between States and the Federal system, the mobility of families between States is discouraged, reducing their freedom of movement.

TCCP supports the NDIS providing funding for essential care, support, therapy, aids and equipment, home modification, and access to the community, education and training. It supports the DIG group's recommendation that income support, accommodation and employment be separate, although the NDIS is likely to provide the impetus for greater integration in all services.

It is TCCP preference that the proposed NDIS be funded through a Medicare type levy or through general revenue. TCCP supports the views of clients who believe that disability is a social issue and not a purely individual one. Disability must be considered a risk that can strike anyone at any time and which needs to be addressed by the whole society. As such contribution to disability should be made by all Australians. However, client families were keen for the marketing of such a model to be done extremely sensitively to prevent a backlash against people with disabilities and their families.

It should be noted that there is limited understanding of even the broad elements of a NDIS among client families. There is a concern that the NDIS might be a welfare scheme like Centrelink or a purely medical/health related scheme like Medicare.

It is also important for any new scheme to develop innovative strategies to support families financially. Families with a member with disabilities carry a heavier financial burden due to care needs than other Australian families. As a result their tax burden is also heavier than for other families. While acknowledging HST exemption for some aids, equipment home modification and furniture that are specifically designed for people with disabilities, there are still a range of equipment items that could be made GST exempt. TCCP strongly urges the Commission to explore the option of removing tax on essential goods and services required by people with disabilities, carers and families and introduce a disability support tax rebate to recognise costs associated with disability.

While acknowledging the positive changes made to trusts families are able to establish for their members with disabilities, TCCP urges the Commission to explore additional incentives for families to establish these trusts.

Organisational issues

With the increased demand for services that any NDIS scheme will generate, TCCP is concerned with the impact of this upon:

- The level and quality of the workforce within the disability sector. With the current underpay within the disability sector it is difficult to attract and retain direct care and health professional staff. Appropriate remuneration, training, organisational governance and management are essential if quality services and choices are to be available for individuals and families;

- The possible structural realignment within the sector. With increased funding will come demand for services. It is realistic to expect 'For Profits' to enter the sector. This is not in itself detrimental to delivery of outcomes, but could be if they drive the small and more responsive mission based organisations out of operation;
- Regional service delivery. Any future cost structure needs to reflect the costs incurred in providing services within a jurisdiction the size of Western Australia; and
- Quest for productivity. There is productivity to be gained from this scheme, but it is at the macro society level as opposed to within individual organisations. The disability sector has been grossly under funded for decades and has struggled to provide viable quality services. In many cases this sustainability has occurred as a direct result of organisational fundraising. Government contracts have in reality been partial grants and not full cost for services. This Scheme will not produce organisational productivity. However it will provide productivity through the impact of earlier and increased therapeutic treatment, increased aids and equipment, and increased accommodation has on the reduction of costs associated with less acute medical, hospital, mental illness, social isolation as well as increased open employment.

Conclusion

In 2008 Australia ratified the United Nations Convention on the Rights of Persons with Disabilities. By doing so the government was endorsing the enjoyment of human rights, freedom and respect for people with disabilities as for all other people. The government was also agreeing to facilitate for people with disabilities the enjoyment of individual autonomy, independence, full and effective participation, non-discrimination, equality of opportunity, accessibility and respect for difference. This process would enable the government to fulfil its commitment. Tinkering at the edges will not constitute fulfilment – the system has to be overhauled to enable it to meet current and future needs in a sustainable manner that is fair to all people with disability. The establishment of a NDIS is both essential and inevitable.

References

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