DISABILITY CARE AND SUPPORT INQUIRY

Geelong Parent Network
Submission to Productivity Commission

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WHO WE ARE

The Geelong Parent Network is an informal group made up of members who are family carers of people with intellectual disabilities in the Geelong Region. The Network provides a forum, support and friendship, as well as a voice for family carers. Most members have provided or continue to provide direct care to their family member. Some members provide care indirectly through others such as where their family member lives in a community residential or other form of accommodation. The Network is independent of service providers.

Ministers Macklin and Shorten (2008) describe the disability system "hamstrung for years by buck-passing and a culture of reactive crisis management, to the detriment of those it is meant to support." Our members are directly impacted by this system and live everyday with the thought of "What will happen to my son/daughter when I am unable to care for him/her?"

SUMMARY

Introduction

- Unmet need in accommodation that provides appropriate support for people with intellectual disability continues to be a major concern for families. It largely underpins our thinking in making this submission. (See p.3)

Who should be eligible?

- We want to see a clear distinction between a disability care and support scheme and the health system. (p.3)
- Intellectual disability, for example, should not seen as a health issue per se. Historically such treatment has disadvantaged people with intellectual disability and perpetuated them as subjects of a medical model. (p.3)

How should carers' needs be factored into eligibility?

- We believe that care and support needs, together with person's functional limitations, should be the basis for determining levels of assistance. (p.4)

Natural ageing?

- We support the position of the DIG that, on balance, "people who acquire disability over the age of 65 years are better treated in the aged care and health systems." (p.4)

Comprehensive v narrow coverage

- We support a narrow or selective approach that will target those people who are most in need. (p.4)

- We believe that a new Scheme should apply to people with existing disabilities and not to just new cases. (p.4)
- A wide coverage is more likely to continue significant issues of concern to lifelong carers of people with intellectual disability. These concerns are encapsulated in the question of ‘What will happen to my son or daughter when I die or can no longer do the caring?”. (p.4)
- Eligibility should not be reassessed where there is permanent disability. (p.5)

Should eligibility take account of people’s income or assets?

- We support the transformational shift from a welfare to an investment model as proposed by DIG in their ‘three pillar’ policy. This should incorporate a ‘strong’ income support system adequate for people with a disability who cannot support themselves through work. (p.5)
- An expectation with DIG’s third pillar of persons with a disability and families making additional private provision needs to be tempered by DIG’s own research that “Primary carers are likely to be in the poorest two-fifths of all households and 55 percent receive income support as their main source of cash income.” (p.5)

Who makes the decisions?

- We believe that people with a disability and where appropriate their family carers be supported to have control over their lives. (p.6)
- Accountability is of the utmost importance to genuine empowerment of “end users”. This accountability must be two-way between all elements of the scheme. Governments and their departments, service providers and end users all have a part. (p.6)

How should people’s needs be assessed?

- In defining ‘needs’ account should be taken of carers and not just be ‘functional limitations’. (p.6)
- In addition to a focus on validity and reliability, construction of an assessment tool needs to be transparent, critically and independently reviewed at regular intervals, and have these findings made public. (p.6)

Sources of funding

- We support development of strong incentives for families and other private sources to contribute to meeting future costs of people with a disability. (p.7)

Consolidation of funding

- We support consolidation of funding through a single financing point under a National Disability Insurance Scheme. Within this, we believe that Disability Support Pensions should be maintained. We would also want to see explicit fund identifiers such as ‘Disability Support Pension’, ‘Mobility Allowance’, ‘Rent Assistance’, etc used. (p.7)
- In constructing a new disability policy framework based on investment is an opportunity to promote a consciousness of moving people with a disability beyond ‘a charity model’ and being ‘burdens’ to society. Recipients of Medicare support for example are not stigmatised in this way. (p.7)

INTRODUCTION

The work of the Disability Investment Group (2009) in its *The Way Forward* has given us hope for a more optimistic future. We have not experienced such hope since the early 1980's when *New Directions* was developed at a Federal level. This put a spotlight on 'disabling conditions' that limited opportunities for people with intellectual, physical and sensory impairments. Now, a generation later, we look with hope to A New Disability Policy Framework for Australia. The DIG (2009) statement that a National Disability Investment Scheme "is not beyond Australia's capacity to deliver. ... (and furthermore) it would be a net saving on government expenditure through a more effective service system" (p.4) is heartening. Supporting people to plan with more certainty across a life course and be in a position to more effectively participate in, and contribute to, Australian community life is most welcome.

Unmet need in accommodation that provides appropriate support for people with intellectual disability continues to be a major concern for families. It largely underpins our thinking in making this submission. There remain concerns too with the mantra of independence that can cloud more complex understandings of a necessary interdependence with support for a circle of caring relationships.

We support the 'three pillar policy' proposed by DIG (2009), namely:

- A new and comprehensive National Disability Insurance Scheme,
- A strong income support system, and
- Increased private support.

Our submission that follows responds to questions posed in the Productivity Commission Issues Paper describing our position on what these pillars might mean.

WHO SHOULD BE ELIGIBLE?

The Productivity Commission Issues Paper (2010) asks "Who should be eligible?" (p.16) From our long experience with disability issues generally but particularly with intellectual disability, we would want to ensure that intellectual disability is not seen as a health issue per se.

Historically such treatment has disadvantaged people with intellectual disability and perpetuated them as subjects of a medical model. For this reason, we would wish to see "illness-related" conditions separated and funded through the health system. Where the health treatment phase is concluded and determination should be made as to whether the person with a significant ongoing impairment is eligible for a disability care and support scheme.

Treatment of people with intellectual disability under Australia's Immigration legislation and practices still perpetuates intellectual disability as an illness although this is currently being reviewed by the Federal Joint Standing Committee on Migration in their inquiry *Enabling Australia: Migration Treatment of Disability*.

HOW SHOULD CARERS' NEEDS BE FACTORED INTO ELIGIBITY?

Most of our members' sons and daughters are not able to live independently, but nevertheless value their independence while being supported in their living arrangements and community access.

We believe that care and support, albeit linked to a person's functional limitations, should be the basis for determining levels of assistance. This will then take account of physical limitations, self-care limitations and behavioural issues, but incorporate them with immediate care limitations. It makes a difference, for example, where there is a single aged family carer rather than multiple family members providing care and support. Another example is where care limitations relate to rural/regional factors involving perhaps respite, transport or access to other formal and informal care.

NATURAL AGEING?

Members of the Geelong Parent Network support the position of the DIG (2009) that, on balance, "people who acquire disability over the age of 65 years are better treated in the aged care and health systems." (p.20)

COMPREHENSIVE V NARROW COVERAGE

Members of the Geelong Parent Network support a narrow or selective approach that will target those people who are most in need. In stating this, we believe that a new Scheme should apply to people with existing disabilities and not to just new cases.

- This is at base a matter of fairness. Those people with a disability and their informal carers who, like many of our members, have invested their personal energies and financial supports over many many years must not be bypassed here. This care has been done with love and compassion that is so often hidden to a wider community, but nevertheless should not be taken for granted.
- Our view is that a wide coverage is more likely to continue significant issues of concern to the lifelong carers of people with intellectual disability. These concerns are encapsulated in the question of 'What will happen to my son or daughter when I die or can no longer do the caring?".
- There is a difference between assessing a person's needs and assessing a person's care needs. The former may not change but the circumstances of

the latter may change significantly with a family's circumstances e.g. divorce, loss of income for main provider etc.

- Eligibility should not be reassessed where there is a permanent disability. However, support needs may change and these should be subject to review. A proforma review might be completed annually, with updates as relevant, while a face-to-face review might be every 5 years.

SHOULD ELIGIBILITY TAKE ACCOUNT OF PEOPLE'S INCOME OR ASSETS?

People with lifelong disabilities such as profound intellectual disability are unlikely themselves to have a capacity for employment and hence to access superannuation provisions. Even many of the people with less severe intellectual disability who do get employment finish at low skill and less secure levels that make capital accumulation more usually expected through workforce participation less likely.

Most people with intellectual disability fall back on their families then for financial support and security beyond that usually confronting other families in the community. The providers in these families not only contribute through taxes, but also through their informal caring and meeting the costs that are beyond their family member with a disability. The gaps between the income of a person on a DSP even with supplements such as rent assistance, mobility allowance and continence aids is significant and continues to grow. For example, the mobility allowance that 10 years ago covered the cost of transport to day programs in regional Geelong now falls short by approximately 20 percent for a person attending daily.

Our members are not objecting to income or assets test, nor to copayments. Members support the transformational shift from a welfare to an investment model as proposed by DIG (2009) in their 'three pillar' policy. This is based on a 'strong' income support system adequate for people with a disability who cannot support themselves through work (DIG, p.3). In going beyond the welfare model, the Scheme will "be person-centred, have a genuine whole –of-life focus and maximise independence and participation (DIG, p.2). But an expectation with the third pillar of persons with a disability and families making additional private provision (DIG, p22) needs to be tempered by DIG's own research that "Primary carers are likely to be in the poorest two-fifths of all households and 55 percent receive income support as their main source of cash income. Most primary carers (71 per cent) are women. Nearly two thirds of primary carers were not employed." (p.12) Additionally, many of these primary carers we know from our own experience are financially supporting their family member with a disability from their own very limited means.

WHO MAKES THE DECISIONS?

We believe that people with a disability and where appropriate their family carers be supported to have control over their lives. This will involve control over funding (in some cases this might be delegated to a responsible agent), decision making power to move services, and capacity to ensure accountability of service providers. Of the utmost importance to genuine empowerment of “end users”, for whom the scheme exists, is the notion of accountability.

Accountability must be two-way between all elements of the scheme. For example those who determine eligibility must be open to account to people with disabilities and their families through transparencies in meeting defined criteria, assessment tools and independent scrutiny. People with disabilities and their families will be accountable through reviews, providing evidence for expenses (perhaps through a broker or agreement with a service provider) etc. Governments and their departments, service providers and end users all have a part.

The PC Issues Paper (2010) states that while individualised funding and personalised care might be the dominant basis for decision making in a new scheme, inevitably service providers and governments will continue to play a major role (determining who is eligible, funding rules, promoting innovation, quality assurance and so on) (p.24). We understand the major role involved but we believe the dominant basis for decision making must always be as close as possible to those ‘the system’ proposes to empower.

HOW SHOULD PEOPLE’S NEEDS BE ASSESSED?

As noted under Comprehensive v Narrow Coverage above, we believe that it is necessary but insufficient to an effective Scheme to consider ‘needs’ as only ‘functional limitations’. Account must be taken of ‘carer needs’ as well. Given the importance of informal care throughout the lives of people with severe and profound disabilities, accounting for its variabilities will make a difference to how the person with a disability is able to maximise their potential. Carer needs or circumstances (e.g. single or married, employed or unemployed, older etc.) have an impact.

While an assessment tool needs to satisfy validity and reliability criteria, if it is to have the confidence of those affected by it, its construction needs to be transparent, it needs to critically and independently reviewed at regular intervals and the findings made public. In 1992 the Victorian Department of Human Services constructed an assessment tool to determine levels of support for people with intellectual disability attending day programs. This tool was heavily weighted mobility factors in comparison to behavioural factors. The Department insisted over years on the validity of the tool in spite of the lack of confidence in it of practitioners. The assessment tool was a bulwark to containing funding but lacked credibility for its proper function. Weighting of mobility over the care associated with challenging behaviour was disappointingly not made transparent. We believe that transparency, independent and critical review, together with public reporting are essential elements of a tool that is used accountably.

SOURCES OF FUNDING

We support development of strong incentives for families and other private sources to contribute to meeting future costs of people with a disability, as DIG (2009) notes "in the same way as extra voluntary superannuation contributions are today adding to future retirement incomes." Importantly though, there must be "a certain and reliable stream of ongoing essential care and support" (DIG, p.22) for all of those in the Scheme.

FUNDING CONSOLIDATION?

We support consolidation of funding (cf. PC Issues Paper, 2010, p.37) through a single financing point under a National Disability Insurance Scheme. Within this, we believe that Disability Support Pensions should be maintained. We would also want to see fund identifiers such as 'Disability Support Pension', 'Mobility Allowance', 'Rent Assistance', etc made explicit.

Currently all levels of government provide some funding for disability services. As users of services, we support our accountability for services received but are overwhelmed by the increasing level of their requirements of us, their duplications, our difficulties in keeping up with their changes, and the level of control they can have on our lives.

We are hopeful that in the construction of a new disability policy framework, there is a consciousness of moving people with a disability beyond 'a charity model'. A significant barrier to the participation of people with a disability, particularly a profound disability, is the perception of being a 'burden' on society. Yet other sectors of society are able to access Medicare services, have access to funded superannuation guarantee payments without such branding.

CONCLUSION

As parent carers of people with disabilities, we welcomed the initiative of the Federal Government in establishing the Disability Investment Group and its report, The Way Forward. Now we welcome this Productivity Commission Inquiry. We are hopeful that these provide the foundation for a genuine transformational shift from an inadequate welfare system to one that recognises people's rights, opens life opportunities and helps put an end to the stigmatising of people with disabilities.

REFERENCES

Disability Investment Group (2009) *The Way Forward: A new disability policy framework for Australia.* Canberra: Commonwealth of Australia.

Macklin, J. & Shorten, B. (2008) *Supporting people with disability, their families and carers.* Media Release, May.

Productivity Commission (2010) *Disability care and support.* Productivity Commission Issues Paper, May.