

AUSTRALIAN GOVERNMENT
PRODUCTIVITY COMMISSION

INQUIRY INTO
DISABILITY CARE AND SUPPORT

SUPPLEMENTARY SUBMISSION
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BY

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1. Introduction

Pave the Way congratulates the Productivity Commission on a very thorough and comprehensive Draft Report on its Inquiry into Disability Care and Support.

This supplementary submission focuses on the following issues:

- (a) Importance of a positive vision for people with disability in proposed Scheme.
- (b) Role of personal planning in the proposed Scheme.
- (c) Funding of personal planning information, support and assistance in the proposed Scheme

2. A Positive Vision for people with Disability in Australia

Pave the Way is disappointed that the Draft Report contains no discussion of the importance of a vision for the National Disability Insurance Scheme (NDIS). There is much mention of the importance of the NDIS, and the National Disability Insurance Agency (NDIA), being efficient and accountable, both of which are important, but no reference to the need for a statement of vision to drive their focus and direction.

As we submitted in our original submission to the Inquiry, the NDIS will need a clear vision which supports people with disabilities to achieve a good, secure and meaningful life both now and in the future. (Original *Pave the Way* submission, Para 3). We wrote there: *“Without such a vision, it is likely that the Scheme will merely add to existing problems of bureaucratic wastage, obsolete service design and make little change to the lives of those people with disabilities it aims to support.”*

The discussion of service options in the Draft Report raises our worst fears. In the Report, unquestioning support is provided for the segregation and congregation of people with disabilities in “specialised” group homes, centre-based respite options “similar to a ‘group home’ structure”, and specialised employment services (Overview, page 21).

These options are contrary to the principle of participation and inclusion, set out in the UN Convention on the Rights of Persons with Disabilities which Australia has ratified.

Pave the Way presumes that the Commission justifies the inclusion of these options in the Scheme on the basis of choice. While freedom of choice is very important, there is a danger in giving choice a status beyond all else. As

Queensland Advocacy Incorporated noted in its book *“Include me In: Disability, Rights and the Law in Queensland* (Queensland Advocacy Incorporated, 1994):

“The elevation of freedom of choice to the status of a quasi-right which is preferred in most circumstances has had the effect of privatising social problems. In this way, individuals and society generally free themselves from the responsibility for others’ welfare when the apparent cause of those people’s predicament is an action “freely” chosen by themselves.” (page 13).

Pave the Way acknowledges that some families say they want group homes and centre-based respite. Yet these “choices” need to be seen in the context of the current limited options afforded people with disability and families and the lack of opportunities provided to support them to realise more inclusive alternatives.

The experience of *Pave the Way* is that when families are allowed the time to dream, to clarify their vision for what they really want for their family members with disability, and when people with disability themselves are given that opportunity, they do not seek segregated options. When given the chance to choose freely what they want, not to opt merely for what they think is possible, no individual, or family genuinely concerned for the welfare of their family member with disability, chooses a segregated option.

As the Commission notes in its Draft Report, the establishment of a NDIS will represent a fundamental change in the way supports and services are provided to people with disability in Australia for many years to come. This is a once in a generation opportunity.

It is the strong view of *Pave the Way* that the NDIS must be driven by a clear vision for the inclusion of all people with disability and a statement of goals aimed at achieving that vision for people with disability, as set out in the UN Convention on the Rights of Persons with Disabilities. We refer the Commission to our original submission.

3. Role of Personal Planning in proposed National Disability Insurance Scheme

Where will “personal planning” fit in the Scheme?

Pave the Way notes that “personal planning” is mentioned a number of times in the Draft Report. It is not clear to us whether people with disability will be expected to develop their personal plans without assistance, or, if they require assistance, who will be available under the NDIS to provide that assistance.

At page 21 of the Overview, planning does not rate a mention among the supports the NDIS would provide.

In Figure 5.2 at page 5.26, the outline of the suggested assessment process provides that the *“person (or their carer or family member) fills in a self report questionnaire (including an initial personal plan) or meets with the trained staff who fill in the form based on the person’s responses and views”*.

At page 6.24, in the discussion concerning self-directed funding, Step 2 requires: *“With the help of their family, friends or others strongly connected to them, the person would develop a personal plan and a funding proposal”*.

In Table 7.1, at page 7.6, one of the functions of the NDIA is to *“Facilitate personal planning”*. Yet Box 7.1, at page 7.14, in describing the roles of case managers in the NDIA, includes *“help them draw up spending plans”* when assessing someone’s capacity to use self-directed funding, but makes no mention of assisting people with personal planning.

At page 7.14, one of the roles of Disability Support Organisations (DSOs), as distinct from NDIA case managers, is stated to be *“Providing personal planning services”*.

It is not clear to us whether the Commission is intending to give the role of *“Providing personal planning services”* exclusively to DSOs or whether some sort of shared role between the NDIA and DSOs is contemplated. Is the Commission looking at contracting out to DSOs a NDIA function of facilitating personal planning? This lack of clarity suggests that the Commission has given little detailed consideration to the role of planning in the NDIS.

Personal planning needs to be “whole of life” and is not service planning

Further, while the Commission uses the term *“personal planning”*, the context of the Commission discussions around planning suggest that the Commission is focused on service planning, that is, planning focused on service delivery or funding allocations to pay for services and specialised supports and equipment. The Commission’s reference to *“spending plans”* under self-directed funding is an example of this limited notion of planning. We wrote in our initial submission:

“Pave the Way strongly believes that whole of life and succession planning is vastly different from service planning. This is planning for a safe, secure and meaningful life in which services may or may not play a role. This is “whole of life” planning. It is planning that families must drive and control. It is their family business.

Services might play a role in assisting individuals to achieve some goals, for example, those concerning home, work, recreation, communication and education, but are unlikely to play a role in many other aspects of the individual’s life, such as personal security, financial security, decision-

making, relationships and friendships, health, spirituality and developing individual passions. Services can assist people to have a good life; they do not constitute a life.

All services do some sort of planning with the people they support, such as “individual education plans”, or “individual program plans”, or “family support plans”, but that service planning is limited to what the service can do within its purview as a service provider. Service planning is very different from the whole of life planning relevant to planning for the future.”

Whole of life personal planning will benefit NDIS assessment process

The Commission might take the view that whole of life planning is beyond the scope of the NDIS. *Pave the Way’s* point is that without an individual and/or family looking at whole of life issues, it is impossible to give sensible consideration to where services, funded supports, and informal care and support fit. It is important to focus on whole of life in such planning, so that everything is not reduced to a service or funding response. Indeed, well facilitated whole of life personal planning is a very efficient process of determining the proper and appropriate role of funding and service delivery in an individual’s life. If only in the interests of efficiency and accountability, the Commission should be interested in how the NDIS can best assist individuals and families with whole of life personal planning.

Whole of life personal planning will also be important in assisting individuals, families and the NDIA assessors to determine the appropriate level of informal support provided to a particular individual. Only through this sort of planning process will there be a real opportunity for an individual to spell out whether he or she wants family (eg, parental) personal care support and how realistic it is for family members to continue to provide the level of personal care support they currently provide.

Table 1 (below) shows how strategies under different aspects of an individual’s life might be supported – some through informal support, some through government funding, and some through other financial support. For some aspects of an individual’s life, a combination of informal support, funding and other financial support might be required to meet a particular goal.

For example, taking the “home” aspect of life, an individual with disability may be supported to live in their rented home unit through a combination of government funded paid support workers (eg, 42 hours per week plus “sleepovers”), other financial contributions (eg, rent and household expenses paid from the individual’s pension; parents paying expensive electricity bills due to the need for high use of air-conditioning) and informal support (eg, other family members supplementing paid support to meet some direct care needs; a member of a

sporting club taking the individual to regular fixtures; a particular friend assisting the individual with weekly shopping).

Table 1 sets out how this combination of supports might support an individual, who does have considerable needs for support, to live in their own home.

| Table 1 - Planning Template | | | |
|---|----------------------------|---|--|
| Informal network (eg family, friends, club members) | Aspect of life | Govt Funding | Other financial support (eg pension, family) |
| Family members provide support as required during week, plus personal care on Sundays; member of Brisbane Lions Football Club takes individual to all local games; trusted friend assists with weekly food shopping; friends and neighbours invite individual for evening meal 2 nights a week. | Home | 42 hours per week paid support plus “sleepovers” (eg, 5 hours per day, Monday to Saturday, plus three 4 hour blocks of support during the week to allow individual to do things they enjoy in their local community, plus “sleepovers”) | Individual pays rent and basic living from pension; Family pays electricity bills. |
| | Work | | |
| | Relationships and friends | | |
| | Recreation, play, holidays | | |
| | Passions | | |
| | Education | | |
| | Spirituality | | |
| | Healthcare | | |
| | Financial security | | |
| | Decision – making | | |
| | Safety and security | | |

Without good planning, clarifying how such a combination of supports might be developed and sustained is unlikely to occur. The result can be that the individual

and or the family sees no alternative than for everything other than rent and basic living expenses to be covered by government funding.

Individuals and families need assistance with planning

It is the experience of *Pave the Way* that very few families are able to engage in such planning without assistance and the independent facilitation of structured planning sessions. This is not a typical every day activity. How many Productivity Commission staff, for example, have engaged in this sort of whole of life personal planning with the support of key others in their lives? Few, if any. This is because most in the community don't need this sort of planning (though we could all benefit from it) but those for whom the Commission is constructing the NDIS, and their families, will need such assistance if the Commission's aspirations for a consumer choice model, rather than "the current provider-centred approach" (Overview, page 30), is to be realised.

Planning assistance best provided independently of other DSO functions and service provision

For the reasons advanced in our original submission, *Pave the Way* believes that whole of life personal planning assistance is best provided independently of disability services. We also see considerable problems if this role is placed within DSOs which carry out the other roles suggested for DSOs, particularly service brokerage and administration of self-directed funding. These are roles which exist in the realm of service provision ("service business") which potentially conflict with whole of life personal planning ("family business"). We are also concerned by the suggestion that service providers could act as DSOs (Overview, page 31). This would lead to even greater potential for conflict of interest. Even with "Chinese walls" in place, the perception of conflict of interest can be as damaging as actual conflict of interest.

Presumably *Pave the Way* would fall within the description of a DSO. It is highly unlikely, however, that *Pave the Way* would be interested in taking on any functions other than personal planning assistance and we would be concerned if a myriad of other organisations attempted to do this alongside the other functions envisaged for DSOs of service providers.

Whole of life personal planning assistance not only for those under Tier 3

Pave the Way is concerned that the discussion of personal planning in the Draft Report appears to focus only on those individuals who will come under Tier 3. Whole of life personal planning support will assist those in Tier 2, and possibly even some in Tier 1.

If the expectation is that individuals and families will come to an assessment process with personal plans in place, many will need information and assistance

before that assessment process occurs. With some detailed thought and planning behind them, the process of assessment for funding under the NDIS (and entry into Tier 3) will be more focused, more relevant, and more efficient, than when an individual comes without giving the relevant issues any detailed consideration.

It might also be the case that, with facilitated planning, an individual or family concludes that they do not need to seek assessment for funding under Tier 3 at that time and that the supports they require are able to be found without funding. Investment in a broad range of whole of life personal planning information and supports could prove financially beneficial to the NDIS through assisting individuals to “select out” from seeking funding, at least until they determine, through considered planning, that their need for funding fits with their plan.

Pave the Way encourages and welcomes young families to participate in discussions and workshops on whole of life planning. Young families who begin thinking about these issues early are better placed to work out where the role of services and funded supports fit in their vision for their young family members. Encouraging young families to build networks of support sooner rather than later, to embrace financial planning strategies, to put in place wills and trusts, encourages them to take steps which minimise the impact of their family members’ disability on the individual, the family and the community. The more young families embark on future planning, the more appropriate and considered will be their later demands on the NDIS, with obvious benefits to the NDIS in reduced inappropriate and crisis driven demands. Much of this work with young families will fall within the Commission’s Tier 2 group in the community.

Much of the work of *Pave the Way* is in the form of “outreach” to families who have limited or no contact with disability service providers. Their only contact with a service might be with a local school and they have no need to seek specialist support beyond that provided in the school setting. We have learnt that offering to meet with families in their homes, throughout regional and rural Queensland, is a very potent strategy to provide them with information and assistance around future planning issues. Many families in regional centres or on remote farms and properties cannot always come to information sessions and workshops that *Pave the Way* provides in their local communities, which might be infrequently given the vast distances that we must cover in our work throughout Queensland. An offer to meet with families, in their homes, at times which suit their needs, gives them a greater chance to discuss ideas and information of relevance to them in their future planning.

Recently a *Pave the Way* team member travelled 2800km throughout south-west Queensland, visiting families as far west as Charleville, including a number on or from remote properties. In 15 days, this team member conducted 28 meetings with individual families, held 3 informal discussion groups attended by another 21 family members. There was only one cancellation and there are 5 additional

families on a waiting list for a further visit. Three families asked for specific follow-up with a facilitated planning session, all were provided with information relating to planning and their particular issues and others said they will follow-up with *Pave the Way* at a later date. The youngest family member with disability in the families visited was aged 4½ years and the oldest aged 55 years.

Pave the Way found this strategy to be costly but very effective in providing information and opportunities for discussion to many families who find difficulty in participating in more traditional information and discussion strategies.

Planning information and assistance can also benefit the broader community covered by Tier 1. *Pave the Way* is contacted by people in the general community who want information and assistance as a result of their involvement with a particular individual or family. Friends, acquaintances, neighbours and members of support circles set up to support an individual have contacted us for planning information and assistance. It is not clear to us that these people would fall within Tier 2.

Further, planning assists all of us. Many of the issues that we discuss with families have broad application and, if taken up by the whole community, could meet the NDIS goal of minimising the impact of disability.

For example, *Pave the Way* provides legal information relating to future planning, including information about guardianship and financial management issues, enduring powers of attorney, wills and trusts. A better informed community, in which more people have enduring powers of attorney and appropriate wills, minimises the impact on a wide range of agencies and services when people who lose capacity through illness or injury have not planned ahead for that possibility, or die without a will, causing inequitable distribution of estate assets, court applications and related disputes.

Despite the range of other services in the community which provide information on these topics, many provide specific information based on their area of expertise and/or carry “baggage” that results in many in the community refraining from consulting them (eg, State Trustee offices). The experience of *Pave the Way* is that there is a need for more opportunities for people to discuss these issues, often informally and confidentially without cost, with people who have experience and expertise around a broad range of disability issues.

4. Funding of personal planning information, support and assistance in the proposed Scheme

Tier 3

The issues discussed above raise the question of how such whole of life personal planning supports and services are to be funded under the NDIS. For *Pave the Way* (Mamre Association Inc) – Supplementary Submission to Productivity Commission Inquiry - Disability Care and Support – April 2011

some individuals who have received funding through the assessment process (Tier 3), payment for planning assistance from their funding package might be appropriate, so long as the package includes funds for that assistance. In our experience, funding for planning assistance would need to be quarantined or it will quickly be used for more immediate support needs. No matter how comprehensive a NDIS will be, many people will not receive the funding support they believe they need and, for many, paying for planning is likely to be a low priority.

We believe that part of the success of *Pave the Way* results from our being able to offer our assistance and support to families at no cost, with the exception of a contribution to live-in workshops. Indeed, many families only see the benefits of planning after some initial involvement with *Pave the Way*. They come to us worried about the future, wanting to do something, but not knowing what to do or how to make a start. Some come to a workshop to find out about legal issues, and leave with an understanding that future planning involves much more than sorting out their wills.

Pre-Tier 3; Tier 2; Tier 1

For all those seeking assessment for funding (pre-Tier 3), and those people in Tier 2 and Tier 1 who might benefit from planning information and assistance, there will be no funding package from which to pay for planning assistance.

If *Pave the Way* was expected to follow a user pays model, either those who do have funding would need to pay a premium to support all *Pave the Way*'s activities, or we would need to ask for payment from many people who do not have funding. We would need to seek payment at actual cost from those attending workshops and information seminars, for the use of our website, for all newsletters and Information Sheets, and for individual consultations and telephone information and advice. We could not answer a phone call seeking information without first taking down credit card details, or an address to which to send an invoice. Beyond the administrative costs associated with such a fee for service approach, we believe that many families would simply not approach us for information, advice and assistance. The additional costs associated with disability are high enough, and are likely to remain so even with a NDIS, for individuals and families to embrace such an all pervasive user pays model.

Preliminary analysis of the costs of our outreach "Road Trip" strategy suggests that the average cost per individual family would be in the vicinity of \$400, without including those who attended the small groups. If the NDIS were in existence now, a number of these families would be likely to have a funding package relating to their family member with disability. Nevertheless, as discussed above, unless sufficient funds were set aside to pay for planning consultations, it is unlikely that those families would have responded to an invitation to meet to discuss these issues, particularly if asked to pay the actual

costs incurred. Will funding packages take into account the additional costs of providing whole of life planning assistance to those in rural and regional areas?

Two of the small groups who met with the *Pave the Way* team member on the south west Queensland Road Trip were arranged by parents and would most likely not have occurred if families were asked to pay the actual cost involved. Some might have funding, some not, under the proposed NDIS. The other small group was arranged by Carers Qld. Whether such an organisation will have the financial capacity to pay for such a small group gathering under the proposed NDIS is unclear.

We refer the Commission to our original submission relating to other issues raised by working in regional and rural areas, about the concept of readiness, the challenges of working with indigenous families, families from a culturally and linguistically diverse background and people with mental illness. We cannot see how an organisation like *Pave the Way* could approach working with such families if funded on a user pays basis.

Importance of block funding

Pave the Way therefore believes there is a strong case for dedicated whole of life personal planning services to be block funded, at least substantially. Without specific block funding, the role of *Pave the Way*, and any similar organisation, would be reduced to an expensive user pays service, restricted largely to those who receive specific, quarantined, “personal planning” funding under the NDIS.

5. Other issues

Training of assessors

Those given the task of carrying out assessments under the Scheme will need to have a deep understanding of the place whole of life personal planning must play within the Scheme and the sensitivity to assist individuals and families to undertake such planning. Assessors will require thorough training and support to carry out their role appropriately and effectively. If they do not have this understanding, they are likely to direct individual’s plans towards a solution based on service responses and restricted options. The result will be not only poor outcomes for people with disability and their families, but increased costs to the NDIS.

Commencing the Scheme in one region of Australia

Pave the Way notes the Commission’s proposal that the Scheme commence in early 2014 “*in a particular region in Australia providing high quality services to many thousands of people*” (Overview, page 44). Our discussion above indicates

the importance of the Scheme commencing where there are well-resourced and experienced whole of life personal planning supports.

As we noted in our original submission, we know of no other agency such as *Pave the Way* throughout Australia. If the Scheme was to commence in Queensland, *Pave the Way* would be hard pressed to provide the support expected of it without additional block funding.

We believe that well-resourced planning supports will be crucial to the success of the Scheme and strongly recommend that the Commission includes in its final report, consideration of how that start-up transitional phase will be funded and supported.

Change, individual and family capacity building and advocacy under the NDIS

Real change in the disability sector in the last 50 years has occurred largely through the impetus of families and people with disability. Services and service providers have not driven change, unless those services are family governed or governed by individuals with disability. Occasionally, strong people oriented individuals working in services drive change but typically they will be acting as individuals, not on behalf of the organisation where they work. The change they might forge while they are working in the organisation is likely to fall away when they leave.

The “*new way of thinking*” envisioned by the Commission (Overview, page 39), the new “*consumer choice model*” (Overview, page 30), will require a change in the way of thinking on the part of individuals and families. When they embrace this new way of thinking, services, under the model put forward by the Commission, will change or not survive.

This new way of thinking requires capacity building, which is exactly where *Pave the Way* and similar approaches to whole of life personal planning give their focus. It is a new way of thinking which encourages and supports individuals and families to take control, to see this as in their realm, not part of the “service world”.

A consumer choice, market driven model will take people only so far without support and assistance. Just as in the open consumer market, everyone needs good quality, unbiased information and a regulated framework in which to exercise their freedom to choose. If the market alone was sufficient, we would not need the array of trade practices and consumer protection rules and regulation, nor the consumer organisations and websites which assist us to find our way through the maze of consumer choices.

The NDIS will operate in a small, largely contained area of specialised services, mostly disability specific. Currently the power imbalance in this world is extreme,

with many individuals and families facing limited or no choices (eg, in regional and rural areas) and out of their depth in attempting to challenge the status quo of current services. No doubt large disability service organisations are already looking at how best to restructure and position themselves to take advantage of the “new way of thinking”. They have the resources to do so; individuals with disability and families do not. Under the proposed NDIS, there is very little mention of advocacy and it is difficult to see how advocacy organisations will survive under the user pays model proposed. The advocacy community has put its case for the role of advocacy supports within the Scheme.

Pave the Way believes that the ideals of the Commission in proposing a consumer driven model are noble but unlikely to be realised without strategies to build capacity, provide advocacy support and provide the information people need to exercise their right to choose meaningfully.

Pave the Way sees its role as offering capacity building strategies to families. There is a need for similar approaches across Australia and for similar approaches which support individuals with disability who do not have supportive families in their lives.

6. Conclusion

Pave the Way thanks the Commission for this further opportunity to comment on the proposals in its Draft Report. For further information or clarification please contact either of the contact people below.