

AUSTRALIAN GOVERNMENT
PRODUCTIVITY COMMISSION

INQUIRY INTO
DISABILITY CARE AND SUPPORT

SUBMISSION

BY

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1. Introduction and Background

Pave the Way welcomes the opportunity to make a written submission to the Productivity Commission's Inquiry into Disability Care and Support.

1.1 Introduction to *Pave the Way*

Pave the Way is a team within Mamre Association in Queensland. Mamre Association is a family support community and service based in Brisbane. *Pave the Way* is funded to provide succession planning resources and support to families throughout Queensland who have a family member with a disability. *Pave the Way* began in September 2002 as a very small project funded by Mamre Association, before receiving funding from the Queensland Department of Community Services.

Pave the Way's vision is that people with a disability throughout Queensland will be supported and safeguarded by their family and important others to achieve a good, secure and meaningful life both now and in the future.

The aim of *Pave the Way* is to assist families with a family member with a disability to develop a vision for now and the future, to plan to implement that vision and to safeguard that vision and the individual with a disability in the long term. The focus of *Pave the Way* is on supporting families to take initiative to address their fears about "*What will happen when I'm gone?*"

The approach of *Pave the Way* has been to provide families with information and strategies around these issues and, where families have sought it, individual consultations and assistance. We offer 1 day workshops, as well as providing in depth opportunities for families to focus on future planning through 2 day and 6 day live-in workshops. *Pave the Way* assists families with planning and offering facilitated planning sessions on request. *Pave the Way* also believes that it is people who keep people safe and encourages families to develop networks of support, including support circles, around their family members. *Pave the Way* assists families to establish these networks and circles and is a resource for families to come back to when they need it.

Pave the Way also provides information and guidance in relation to legal issues relevant to planning and preparing for the future, including Special Disability Trusts. *Pave the Way* refers families to a panel of solicitors in Brisbane and throughout Queensland who are experienced in wills and trusts and with working with families who have a family member with a disability. We have a 1300 number for families outside Brisbane and offer an individual legal information service (one-on-one consultations with a lawyer) in person or by phone, so that families have the opportunity to discuss issues free of charge before consulting a solicitor.

Pave the Way is the only project in Queensland which offers a State-wide, comprehensive, vision driven, developmental approach to assisting families to plan for and safeguard the future. In our work throughout Queensland over the last 7½ years we have traveled to all major centres, sometimes on a number of occasions, and spoken with numerous families about planning for the future.

Pave the Way has visited and conducted workshops in Cairns, Atherton, Mareeba, Innisfail, Ingham, Mt Isa, Cloncurry, Normanton, Richmond, Townsville, Charters Towers, Ayr, Home Hill, Mackay, Dysart, Gladstone, Rockhampton, Emerald, Biloela, Longreach, Monto, Bundaberg, Gympie, Hervey Bay, Murgon, Esk, Sunshine Coast, Caboolture, Gold Coast, Beaudesert, Ipswich, Gatton, Boonah, Toowoomba, Warwick, Stanthorpe, Goondiwindi, Tara, Dalby, Miles, Roma, Chinchilla, Charleville and extensively throughout Brisbane.

Pave the Way now has a mailing list of 1300, including over 1150 families who have a family member with a disability. This submission is based on our experience working with many of these families. The work of *Pave the Way* is guided by a Reference Group including family members, committed allies of families in Queensland, and representatives of Mamre Association.

Pave the Way has a website with information and resources on planning for the future - www.pavetheway.org.au. Information and resources on the website are available to anyone throughout Australia (and elsewhere), though the legal information is largely Queensland based. Further information about *Pave the Way*, including a 2008 external evaluation report, can be found on this website.

2. Summary

2.1 Focus of submission

Pave the Way is focusing this submission on:

- 2.1.1 The vision for a Disability Care and Support Scheme (Scheme).
- 2.1.2 The target group of the Scheme.
- 2.1.3 Individualised funding.
- 2.1.4 Whole of life and succession planning within the Scheme.
- 2.1.5 Taxation relief when providing financial support to people with disability.
- 2.1.6 Issues and questions raised by the Commission when *Pave the Way* appeared at a public hearing in Brisbane on Thursday 15 July 2010.

2.2 Key points

The key points made in this submission are as follows:

- 2.2.1 The Scheme will need a clear vision which supports people with disabilities to achieve a good, secure and meaningful life both now and in the future. (3.0)
- 2.2.2 The Scheme should not exclude those described as having mild and moderate disabilities. (4.0)
- 2.2.3 The Scheme will need to support funding structures, service design and implementation which focus on flexible, individualised funding. (5.0)
- 2.2.4 The Scheme should include supporting and funding whole-of-life and succession planning initiatives in all states and territories, which:
 - differ from individual service planning
 - are directed towards families of all ages, not only “aging carers”
 - are located “arms length” from traditional services
 - take into account the individual differences of people with disabilities and families, including the specific issues facing elderly parents, and
 - take into account those people with disabilities who do not have supportive families in their lives. (6.0)
- 2.2.5 Payments of financial support for people with disabilities to meet the costs of their disability, whether made by family members or close friends, should be tax deductible. (7.0)

3. Vision

The Scheme will need a clear vision which supports people with disabilities to achieve a good, secure and meaningful life both now and in the future.

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.

As an appropriate statement of vision for the Scheme, we recommend adapting the statement of purpose and principles in the UN Convention on the Rights of Persons with Disabilities. We suggest the following draft vision for the Scheme:

The vision of the Scheme is that all persons with disabilities in Australia will experience full and equal enjoyment of all human rights and fundamental freedoms as set out in the UN Convention on the Rights of Persons with Disabilities, and that their inherent dignity will be respected.

In striving to achieve this vision, the Scheme will adhere to and promote the following principles from the UN Convention on the Rights of Persons with Disabilities:

- a. *Respect for inherent dignity; individual autonomy, including the freedom to make one's own choices, if necessary with support; and independence of persons;*
- b. *Non-discrimination;*
- c. *Full and effective participation and inclusion in society;*
- d. *Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;*
- e. *Equality of opportunity;*
- f. *Accessibility;*
- g. *Equality between men and women;*
- h. *Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*

4. Target Group – who should be eligible?

4.1 Inclusion on the basis of need

Pave the Way believes all people with disability should be eligible for assistance under the Scheme on the basis of their functional need. This will simplify assessment processes (so long as they meet a broad definition of “disability” they should be covered) and allow a proper focus on individuals: what are their needs depending on the specific nature of their disability and their specific circumstances?

Some people with a diagnosis of “mild intellectual disability” might require significant support throughout their lives (eg, with money, decision-making, diet, managing relationships), whereas someone with a diagnosis of “severe physical disability” might require substantial one-off support at certain times in their lives (eg, modifying a house, purchasing equipment, extra support costs when recovering from surgery), but might need only a small amount of ongoing assistance.

Some needs will best be determined by professional assessment (eg, the extent of necessary bathroom modifications), but most needs can best be determined through good planning support. With whole of life planning, the degree and nature of paid support, linked with informal, unpaid support, can be determined, reviewed and refined as necessary.

4.2 People with a disability and their families and carers

For most people with disabilities, their greatest support comes from family. It is families who are there in the long term, while services and paid service workers come and go. It is families who do the advocacy, who provide much of the unpaid support and who worry most about the individual's safety and security, particularly in the long term. Families have the knowledge, the history, the commitment, the love that services lack. Families keep people safe.

Issues faced by families keen to ensure that their family members have a continuing quality of life are faced by families of all ages. While older families feel an increased sense of urgency, their fundamental issues differ little from younger families. What sort of a life do they want for their family member? Who can assist them to achieve this? What is the role of services? What is the role of other family members?

Pave the Way believes the Scheme needs to allow for the full inclusion and participation of families in the lives of people with disabilities and to respect their role. Services need to be designed to welcome and involve families. Where individuals have a decision-making disability, family members are often informal decision-makers. The Scheme must be designed to encourage and support families to exercise that role, rather than encouraging or requiring services to demand that families seek formal appointment as guardians or financial administrators.

Where adults with disabilities have decision-making capacity, and do not want their families involved, that wish must be respected.

5. Who makes the decisions

5.1 Individualised funding

Pave the Way strongly supports the notion of individualised funding which allows individuals to, in effect, go into the market place with a set amount of funding and buy the support they need from the service provider that best suits their needs.

Pave the Way and Mamre Association describe individualised funding as funding assigned to a specific individual which is in the control of the individual or their family and which can be transferred between services at the direction of the individual or family.

Individualised funding does not mean non-accountability. There are numerous examples of families and individuals who control their own funding while remaining accountable for its proper use within funding guidelines. Mamre Association encourages all families it supports to take

more control over their funding, through its policy of *Family Managed Funds*. Under this policy, Mamre delegates the management of the funds for support directly to families by negotiating an agreed sum of money to provide an agreed level of support and then transferring the funds to the family. Mamre does this because it believes:

- Families typically do best when they can identify their own needs, and can plan and direct the services provided.
- Families have the best interests of their son/daughter and overall family at heart and can be trusted to use the money given to them to buy supports that are appropriate for them.
- The relationship between the Mamre Key Worker and the families ensures a high level of accountability without the need for excessive paperwork.
- Families are the experts in knowing their individual's needs and have the knowledge to provide most of the training in the individual's care.

Funds can be used for:

- in home care
- community support
- host family support
- support for the individual on a weekend or holiday away from the family
- support for the individual on a family holiday
- other strategies as negotiated with the Mamre Key Worker.

Currently, approximately 165 families from a total of 200 families supported by Mamre choose to manage their own funds. The maximum amount managed by an individual family is over \$100,000 per year.

[For further information, see the Mamre website: www.mamre.org.au and paragraph 3.8 of the Mamre Policy and Procedures, found on the website.]

5.2 Planning as a framework through which to make decisions

In its work with families throughout Queensland, and its limited contact with families in other States and Territories, *Pave the Way* has observed that many decisions made by, about and for people with disabilities are often driven by what a funding program allows and/or what a particular service chooses to offer.

People end up living in expensive and inappropriate group homes because funding agencies tell them, or their families, that there is no other

affordable option under available funding. In Queensland, there is now a practice of forced co-tenancy, whereby people are forced into sharing with strangers even where they are the lawful tenants of public housing. People spend their weekdays in segregated day services, often engaged in activities chosen by others, because they believe that is their lot. People do not aspire to real work because they think it is beyond their capacity.

The experience of *Pave the Way* is that, when given the time and space to reflect on what they really want, individuals and families rarely choose these limited options. Unsurprisingly, when given the opportunity, people choose what ordinary members of our society choose – their own home, living with people they choose, engaged in activities they enjoy, making contributions they value. Despite the claims of defenders of segregated, congregated group settings, that people must be offered a range of “choices”, few people actually choose those settings if a realistic alternative is presented to them. When they “choose” these settings, invariably it is because they believe there is no other option and they don’t want to ask for something they think is unrealistic or impossible.

Furthermore, *Pave the Way* believes that good planning assists families and individuals to use funding more efficiently. Rather than assuming they will need a certain amount of funding, often through assuming that paid support is the only option, a whole of life approach to planning encourages families to see that much can be achieved with less funding.

Through considered planning, and strategies aimed at building informal supports, families develop strategies to use supports already available in their communities. They draw on the many informal supports available through extended family and friends, to put funding agencies and services in their rightful place, as tools to achieving a good life, rather than the beginning and end of “a life”.

[For stories about planning, developing a support circle and independent living, see the Pave the Way website: www.pavetheway.org.au]

6. The Nature of Services in any new Scheme

6.1 Need to include Whole of Life and Succession Planning in a Scheme

Pave the Way believes that the Scheme will benefit greatly from the inclusion of funded succession and whole of life planning initiatives throughout Australia such as *Pave the Way*. Below, we draw on our experience in Queensland and set out some of the features of such planning initiatives.

6.2 Whole of life and succession planning is not service planning

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.

6.3 Location and staffing of planning options

Working with families to assist them with whole of life planning is very different from working with families around service planning. It requires not only clarity around the focus of the planning, but a state of mind that places the worker outside a typical “case worker” or “key worker” role. Workers who come from a service background might find this shift challenging. It requires a firm commitment to working with families, to support them in their family business.

Thus, locating planning projects within traditional services can be problematic. *Pave the Way* has been located within a family support service with strong values around community and working with families. Even so, *Pave the Way* has had to develop and maintain clarity around the way we work and distinguish that approach from the approach taken by other staff in Mamre Association who work more directly with families in key worker roles. In an attempt to address this issue, and following a recent external evaluation, *Pave the Way* has embarked on a review of its governance arrangements within Mamre Association.

Pave the Way has also found that many families respond very positively to staff who have direct family experience. Since its inception, at least 50% of full-time staff at *Pave the Way* have had experience as parents of sons and daughters with disability and one part-time consultant has similar experience. This is not to say that only parents or other family members can do this work. *Pave the Way* also has high quality staff and consultants who do not share this direct experience. However, evaluative feedback we

receive from families consistently confirms that they value working with staff with similar experiences to them.

6.4 Access to planning options and services and concept of readiness

In our work over the last 7½ years, *Pave the Way* has found that families need to be ready to embrace future planning strategies. Many of the ideas around planning for the future are challenging. If families are not ready to listen openly to the ideas and suggestions put to them, they will struggle to accept that they might be useful to them. For example, talking about wills requires thinking about our mortality and for many families with a family member with a disability, this thought can be terrifying. “*When I’m dead, who will be there for my son, daughter, sister?*”

One strategy that *Pave the Way* talks about is the idea of building a support network or circle, on the assumption that it is other people who keep vulnerable people with disabilities safe in the long term, rather than services, funding or government. Yet, unless and until families are ready to begin thinking about inviting other people into their lives and sharing important, intimate information with them, they will not embrace this idea.

Pave the Way has learnt that providing planning information and opportunities must take into account this concept of readiness. For this reason, we offer staged learning opportunities. We ask that families who are interested in our in-depth live-in workshops first attend a one day basic workshop on developing a vision, planning, including others in planning and how to incorporate important legal information into planning. We never talk about legal information without first talking about planning, because to be ready to address some of the legal issues requires that people first think about what they really want for their family member and who they want to ask to fill important roles, such as trustees.

Many families take years before they feel ready to do the challenging work on planning. It is not unusual for families to contact *Pave the Way* a number of years after they first attended one of our workshops, or first discussed planning ideas with us, and say: “*We now feel we are ready to make a real start on this.*”

Thus, *Pave the Way* believes that the concept of readiness has important implications for the choice and funding of planning options.

First, funders need to accept that this work takes time and funding needs to be recurrent. Short term, one-off, funding is of very limited use to families. It might allow an agency to fund some workshops, or produce some information, but when the family is really ready to do something with that information or act on the ideas put to them in a workshop, the time limited project may have come to an end. Even those families who are ready to do some work on planning at the outset of a short term funded

project will often want to come back to the project a number of times, perhaps indefinitely, for guidance and assistance to “get back on track”. Planning never stops, so projects that are serious about assisting and supporting families to plan need to be long term.

Second, funders need to accept that no two families are the same and few families will be ready to embrace planning at the same time. Future planning projects need to be funded with this in mind, so that project workers can respond to the differing needs of families with flexibility and individuality. Offering a series of workshops and nothing else might be useful to the families who are ready to come and listen and take on board the ideas put to them, but those who are not ready will miss out. Funding a service to provide planning assistance only to the families of the individuals the service supports, assumes that all of those relatively few families, or a significant number of them, will be ready to listen at the same time.

Third, funders need to support a range of different planning strategies, on the understanding that families will be ready for different strategies at different times. One family might not be ready to embark on an in-depth live-in workshop but might be ready to read and reflect on some written information. Some families will not be able to read a lot of material, or have access to the internet, but will be open to one-on-one conversations and discussions. Some will be open to starting a support circle and want some assistance to do so, while others will want assistance with planning but not circle or network development.

6.5 Queensland’s size, distances and sparse population

Queensland is a very large, decentralised State. While half the population lives in the south-east corner, there are many provincial towns and cities of considerable size. A flight from Brisbane to Cairns takes as long, and is usually more expensive, than flying from Brisbane to Melbourne. Flights to smaller regional centres are comparatively expensive. (eg, Brisbane to Roma - \$300 return; Brisbane to Charleville - \$500 return; Brisbane to Longreach \$500 return). Infrequent scheduling can mean that an additional overnight stay is sometimes required because there is no return flight to Brisbane on the day of a workshop or the only flight leaves too early in the afternoon. Often there is no direct flight, so a hire car is needed to travel to another town and those costs over two or three days often equate to the costs of flying into the region.

There are also many areas where the population is sparse and distances great. For example, on a recent trip to north Queensland, a staff member flew to Townsville, hired a 4-wheel drive and drove 6 hours to Richmond, spent one day involved in a family gathering organised by Disability Services, requiring two overnight stays, then drove back to Townsville the

following day and flew back to Brisbane. One day with the families required a lengthy three day trip.

Pave the Way experiences considerable challenges in providing supports and services to families in these areas. While we try to have a range of information and resources on our website, we know the limitations of relying on the internet and that many people in remote communities do not have reliable internet access. We try to arrange workshops and presentations in a wide variety of locations, knowing that only a small number of families are likely to attend.

Pave the Way believes in equity of access and puts considerable resources into events or visits that we know will involve only a few families. We are also conscious that some families cannot take advantage of our workshops, even when we do travel to their areas, as they might live on a property 2 hours from the local town and have difficulty leaving the property. We are currently looking at other possible ways to support these families, such as a “road trip” - hiring a campervan and making visits to individual families in isolated areas. This option would be expensive, especially if a 4-wheel drive vehicle is needed.

To date, *Pave the Way* has decided that the best approach to working across Queensland is to remain based in Brisbane and put resources into making regular visits throughout the State. We have determined that we can take a more flexible and focused approach by making regular visits to certain locations (eg, Far North Queensland and South West Queensland), rather than place part-time workers in different locations.

In its work throughout Queensland, *Pave the Way* has received considerable assistance and support from the Queensland Disability Sector Training Fund, Disability Services Local Area Coordinators, local service providers and local *Parent to Parent* coordinators. We are keen to continue these partnerships and believe that this work is best done in collaboration with others who have their own networks and local knowledge.

Nevertheless we continue to struggle with how best to meet the needs of families throughout Queensland. Ideally, other local projects with a more specific focus could be funded recurrently and we would be very happy to support and offer guidance to any such projects.

6.6 Working with indigenous families

Pave the Way has struggled with how best to support indigenous families faced with future planning issues and concerns. While we have been guided by local people with experience working with these families, we cannot claim great success. Cultural and community issues often stop families attending our workshops. We are currently looking at the “road

trip” option to visit some families in north-west Queensland. It may be that a specifically funded project aimed at working with these families would be the best approach.

6.7 Working with families from a non-English speaking background

Pave the Way has grappled with how best to work with and support families from a non-English speaking background. We obtained a specific grant to allow us to translate our booklet, “Planning for Now, Tomorrow and the Future”, into six languages, and to provide some basic information on our website in nine languages other than English. The total cost was \$22000.00 and now the booklet has been updated and we cannot afford to update the translated versions. We offer to assist families with interpreters on a one-off basis.

Pave the Way is mindful of the limitations of simply providing some translated information. We have had some contact with individual families who need interpreters (eg, Vietnamese) but know that we are not able to reach into many non-English speaking communities without additional funding. As with indigenous families, that work is likely to require a specifically funded project.

6.8 People with mental illness

Pave the Way also struggles to meet the needs of people with mental illness and their families. It is quite common for parents or other family members of people with a mental illness to attend our workshops or contact us for information and assistance. We are able to assist with legal information, and the strategies we suggest are all relevant to these families, but their implementation raises significant challenges.

For example, a number of these families have told us that the strategy of developing a support circle appeals to them in theory but the nature of their family member’s illness is that they find it very difficult to relate to others and maintain relationships, or they have no insight into their need for assistance and reject all such suggestions by their family.

Many of these families are also often overwhelmed by the struggles they face to keep their family member safe in the mental health service system and in the community. Often their planning focuses on attaining relevant services, safe accommodation and decent medical support.

Pave the Way has recently employed a new staff member with direct family experience of chronic mental illness and this addition to the team will build our capacity in this area.

6.9 “After the planning” – meeting “instrumental” needs

The work of *Pave the Way* is focused on assisting families to clarify their vision for the future of their family member, assisting them with planning, providing relevant information and referrals to professionals, and assisting them to develop safeguards around their family member, including support circles.

While we have developed a number of Information Sheets aimed at providing relevant information to assist families to implement their plans, we are conscious that some families require more support to implement their plans, to meet what are sometimes called “instrumental” needs.

The dilemma for *Pave the Way* is that we do not want families to become dependent on us, so that *Pave the Way* staff become de facto case workers, assisting families on a regular basis to work through the implementation of their planning. We do not see that it is our role to help families to find suitable housing, or to find a good local general practitioner who will take the health issues of their family member seriously, or to help them work out how best to support their family member with limited funding. We can assist families to develop a support circle, with the aim of that group assisting the family to work through these challenges, but support circles take time to develop and are not the answer for every family.

Some families simply need hands on assistance to meet these challenges. If they are involved with a good family support agency, they might have a key worker to assist them. But most families do not have that support. Indeed, *Pave the Way* meets many families that have no connection with any service.

Pave the Way continues to grapple with this issue and is developing additional workshops and resources aimed at assisting families to address these practical needs. However, there does appear to be a need for additional funded responses, other than planning options and services, to assist families to implement their plans.

6.10 Other States and Territories

We are not aware of State-wide planning options or services like *Pave the Way* in any other State or Territory. Perhaps the project working in ways most similar to *Pave the Way* is Personalised Lifestyle Assistance (PLA) in Melbourne but they have limited resources and work predominantly in metropolitan Melbourne. PLA's focus is on building “*capacity and knowledge predominantly in people with a disability and their families to enable them to have opportunities typical of other citizens in the community*”. (PLA website).

Personalised Individual Networks (P.I.N.) is an initiative in Perth which aims to assist families to address future planning issues but takes a very different approach to *Pave the Way*. While P.I.N. provides information and seminars on future planning, its main focus is directed to fee-paying life-members, assisting and supporting them with future planning and safeguarding strategies, particularly through the development of networks of support.

As in Queensland, there are agencies in other States and Territories with small projects aimed at addressing the future planning needs of families, but they are often located within services, might only have “one-off” funding, and typically focus exclusively on the families of the people to whom the service provides direct support.

Pave the Way has been asked to give a number of presentations to families outside Queensland. We have presented workshops in NSW [Tweed Heads, Doyalson, Sydney (twice)], ACT [Canberra], Victoria [Melbourne], Tasmania [Ulverston, Launceston, Hobart], and have a future request from the Newcastle area. We are not funded to do this work outside Queensland and need to charge full fees and accept invitations only when we have the capacity. Both government and non-government agencies have asked us to give interstate presentations.

We have found that the issues faced by families are similar wherever we go throughout Australia. Families everywhere are crying out for assistance and guidance in planning for the future. When presenting interstate, we provide simple legal information but cannot go into the depth that we might when presenting in Queensland, where our understanding of the relevant law and practice is deeper. On occasions we have presented with local legal practitioners.

Pave the Way would be happy to work with other initiatives interstate to assist them to establish similar projects to *Pave the Way*, but we would need additional funding to do so.

7. Financing Options

7.1 Taxation relief as a financing option

Many people with disability throughout Queensland receive no or little individualised funding. Our experience is that, throughout Queensland, approximately 5% - 10% of family members with disability are receiving individualised funding. To offset shortfalls in funding, families are contributing to direct support costs, supplementing rent and living expenses, purchasing real estate, buying equipment and paying for everyday expenses such as incontinence aids.

It would be of great assistance to families and other interested individuals if they could claim tax deductions for such contributions which assist with the extra costs of disability. In many cases these costs are very high and a huge drain on the resources of families who often have restricted earning capacity.

Pave the Way can cite a number of examples where extended family and close friends are providing financial support. For example, one support circle set up a bank account and individual members make contributions to cover the costs of private rental for a young man who has moved into his own flat. Others, particularly family and friends of young people, seek our advice about setting up a trust for the benefit of the young person with a disability, into which a number of people can contribute.

While there are schemes in all States and Territories that provide subsidies for some equipment items, they invariably do not cover the whole cost and inconsistencies exist from State to State. National incontinence aid funding is limited to \$500 per year, which for some people might cover 4 months supplies. In Queensland there is no support to assist families to purchase and modify vehicles, though in some other states there is limited support.

The cost of modifying a bathroom to make it accessible is likely to be between \$10,000 and \$20,000. The cost of modifications to a small van to make it wheelchair accessible could be \$28,000 (see, for example, www.fleetworks.com.au). The cost of installing a ramp which meets all safety and access regulations to a low set house is likely to be \$15,000. In Queensland, none of these costs attract any government subsidy. The cost of providing one hour of paid support per week for a year will be between \$1800 - \$2200. A family that wishes to pay for only 10 hours support a week, less than 2 hours per day, will be faced with paying between \$18000 and \$22,000 a year.

Families faced with these large financial commitments look at the tax system and see business tax deductions for equipment, vehicles, conferences, etc, and wonder why those often affordable business expenses are tax deductible and yet the high costs of providing necessary support and equipment for their sons and daughters are not.

The Australian Government has recognised the high costs faced by such families. A practical way of providing some additional assistance, and a “financing option” under the Scheme, would be to allow these expenses as tax deductions.

8. Specific Issues raised by Commission at Brisbane hearing

When representatives of *Pave the Way* appeared before the Commission at hearings in Brisbane on 15 July 2010, the Commission asked them to address a number of specific questions in this written submission.

These questions are:

- What examples does *Pave the Way* have relating to difficult situations concerning older parents and carers? (8.1)
- What examples does *Pave the Way* have relating to parents and carers who have no-one else in their lives? (8.2)
- What examples does *Pave the Way* have relating to people with disability who have no parents or carers? (8.3)
- What does it cost to provide a service like *Pave the Way*? (8.4)

8.1 Difficult situations concerning older parents and carers.

Pave the Way has had experience with many elderly parents of people with disability. We have worked with a number of parents who are retired, some in their 70s and 80s, who are working on many strategies to ensure good lives for their family members with disabilities and their long term safety and security. They are attending our workshops (including live-in workshops), inviting extended family and friends to join them in their planning, setting up support circles and some even joining with other families in developing small, family and community governed services.

For many this has been very difficult, and for some has come after they had thought they had put in place satisfactory arrangements to protect their family members, such as embracing a particular service, only to find that these arrangements were unsatisfactory. *Pave the Way* has had ongoing involvement with two families with parents aged in their seventies, who had to bring their family members with a disability home after they were subjected to staff abuse in residential settings. We have also been involved with families who have had to find alternative accommodation for their family members following unsatisfactory service responses to them. [See, for example, the story on *Pave the Way*'s website "Embracing Community Living" by Katatina Listopad.]

In some families, it is other adult children aged in their 50s, siblings of the family member with a disability, who have made the approach to *Pave the Way*, often bringing their elderly parents to our information sessions or workshops. On occasion we have had elderly grand-parents attend workshops, because they have taken over the direct care role of a grand-child. In one situation, a friend of the family came to a workshop and then asked *Pave the Way* to assist her to set up a support circle around the person with a disability.

Despite the challenges they face, we have had many positive experiences working with elderly family members. Our experience is that the information and strategies we offer is relevant to families of all ages. It is never too early to plan and it is also never too late.

While older families feel an increased sense of urgency, their fundamental issues differ little from younger families. What sort of a life do they want for their family member? Who can assist them to achieve this? What is the role of services? What is the role of other family members?

Our experience is that a mix of ages works well in workshops and information sessions. Younger families learn from older families and older families can be energized by the presence of younger families. The least successful information sessions and workshops that we have held were those where the majority of those attending were elderly.

Thus, while there is an issue of how best to assist older family members to plan, *Pave the Way* does not take a different approach with such families. If their age has resulted in the need for urgent action, or led to a situation of crisis, *Pave the Way* will be unable to assist because that is not the focus of our work. But if they have the time to work on clarifying their vision and to do some planning, we have found that our approach is as useful as it is to younger families. There is a pressing need also to assist younger families to grapple with the challenges of the future, so that they are not faced with these issues in old age, like many current older families.

8.2 Parents and carers with no-one in their lives.

When we talk to families about the strategies of inviting others to join them in planning and building networks of support, some say that they have no-one in their lives, or that their families and close friends live a long way away. For example, families who have moved from Victoria to work in the mines in Central Queensland often say that they can only make short term friends in mining communities because many people come and go from those communities every two or three years.

This is a significant issue for many families. Where families say they have no-one in their lives, that their families and friends have drifted away, and they want to address this issue, *Pave the Way* offers to sit down with them and talk through how they might build new connections. Usually families can think of one or two people that might form the beginning of a network and we help them look at ways of building from there.

Where families have family and friends but they live far away, *Pave the Way* talks to them about how they might take intentional steps to give more structure to those networks by using the internet and email, and taking advantage of annual gatherings such as at Christmas. *Pave the Way* also offers to assist with facilitated planning sessions to help them

make difficult decisions, such as whether to leave their work communities and return to live closer to family, or to make a long term commitment to those work communities than originally intended.

Pave the Way has yet to find a family regardless of their circumstances who, if they want to embrace future planning, cannot move forward with support and assistance.

8.3 People with disability without supportive families

An ongoing issue for *Pave the Way* is that we work only with families and, through them, only with people with disabilities who have supportive families. This focus arose partly from our being located within a family support agency, Mamre Association, and partly due to the initial focus on “succession” planning. The question “*Who will be there when I’m gone?*” is typically asked by parents and other directly involved family members and *Pave the Way*’s initial focus was to respond to family members who want to plan for their succession.

This focus also arose from a concern for those most vulnerable people with disability who need assistance to make some or many of their own decisions. We were not aiming to assist people with disability who are capable of making their own decisions, or their families, though they are very welcome to use our information if it is of assistance to them.

Pave the Way has also taken a developmental, resource based approach to supporting families, in the sense that we do not offer to support families in the long term or to act as ongoing case workers or key workers. We offer families information, ideas, opportunities to develop their vision and plans, assistance with beginning or strengthening network development and support circles, and finally, a resource which they can return to for assistance when they need to do so.

If we were to attempt to work with people with disabilities who do not have supportive networks, we would need to engage in the more intensive work of developing and supporting networks around those individuals. This is fundamentally different to the work we do and would require different skills with a more resource intensive approach. There are projects elsewhere which do focus on such individuals, such as the *Circles Initiative*, part of the Community Living Project in Adelaide.

Pave the Way has been contacted by service workers asking for assistance with planning for such individuals and has had to decline those requests, though information that might be helpful to such service workers is available on our website.

We have also been contacted by a number of individuals with disability who are capable of making their own decisions and who want assistance with planning and/or developing networks of support. In some cases

providing written information has been sufficient. In a few situations, we have agreed to work with the individuals on the basis that they have a supportive family or network, and our approach to clarifying a vision, planning, and building life-long safeguards through networks of support, is what they are seeking assistance with. The only significant difference is that they themselves have made the first approach to us.

Many services working with people with disability will claim to take “person centred” planning approaches, but that typically will be service planning. We do not know of any organisation in Queensland that offers specific planning assistance directly to people with disability who do not have, or want, their families involved. Some advocacy groups and the Queensland Disability Network might offer some assistance, but planning is not their primary focus.

There is clearly a great need for this sort of support to vulnerable individuals with disability who have no supportive family or friends.

8.4 The cost of providing a service like *Pave the Way*.

Pave the Way estimates the current annual cost of providing a state-wide service such as *Pave the Way* in each State or Territory would be between \$200,000 (ACT; NT), \$300,000 (TAS), \$400,000 (SA) and \$600,000 (QLD; NSW; VIC; WA), or approximately \$3,500,000 recurrently across Australia.

These are broad estimates only, based on the current budget of *Pave the Way* which includes funding for 4-5 staff, part-time consultants, extensive travel and live-in workshops. As noted above, the costs of doing this work across a decentralised state such as Queensland is considerable. We have assumed that similar costs would be involved in doing this work in NSW, Western Australia and Victoria. We have assumed lesser costs for the smaller States and Territories but there may be specific expenses unique to all other States and Territories of which we are unaware.

As noted above, there is also a need to address the specific needs of particular groups, such as the Aboriginal and Torres Strait Islander community, people from a non-English speaking background, and people with mental illness. Our cost estimates do not include the additional costs of funding specific projects to address the future planning needs of people in these groups.

9. Conclusion

Pave the Way supports the development of a long-term Disability Care and Support Scheme (Scheme) in Australia, so long as that Scheme has a clearly articulated vision and statement of purpose. Without a clear vision, a new Scheme is likely to effect no real change for people with disabilities and families,

regardless of new funding “models”. It is likely simply to entrench existing bureaucracies and service systems, widely seen as failing to meet the real needs and wishes of people with disability and families throughout Australia.

Pave the Way supports, within a new Scheme, the development of a range of funded planning options and services throughout Australia. Our experience is that families everywhere are looking for assistance with planning. Most families do not want others to do their planning for them, but they do want information, ideas, guidance, and opportunities to do the work on planning away from the challenges of their everyday lives. We have highlighted what we see to be the key issues above.

Pave the Way was developed to meet the needs of families in Queensland. Whether similar projects would meet the needs of families in other parts of Australia is for others to judge, though we do believe families everywhere face similar issues and challenges. With additional funding, we would be very happy to assist in the development of other initiatives aimed at developing similar planning responses to *Pave the Way*.