

**SENATE COMMUNITY AFFAIRS REFERENCES
COMMITTEE**

**INQUIRY INTO
PLANNING OPTIONS AND SERVICES FOR
PEOPLE AGING WITH A DISABILITY**

SUBMISSION

BY

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1. Introduction and background

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 Disability and Community Care Services in the Queensland Department of Community Services.

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, including 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 acts as a resource for families who want to come back for further assistance 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 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 1450, including over 1300 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* can be found on this website.

2. Summary

The key points made in this submission relating to the planning options and services relevant to this Inquiry are as follows:

- 2.1 *Pave the Way* is the only project in Queensland which focuses on whole of life planning on a State wide basis. (1.1)
- 2.2 It is important to distinguish between individual service planning and whole of life planning. (3.1)
- 2.3 Planning options and services are best directed towards families of all ages, not exclusively “aging carers”. (3.2)
- 2.4 Planning options and services are best located outside traditional services. Families respond positively to staff with direct experience as family members. (3.3)
- 2.5 Policies and procedures of planning options and services need to take into account the concept of readiness. (3.4)
- 2.6 The funders of planning options and services need to:

- Provide funding on a recurrent basis
 - take into account the concept of readiness
 - take into account the individual differences of all families, and
 - support the provision of a range of different planning strategies. (3.4)
- 2.7 The Queensland Government provides significant State funding but more is needed. The Commonwealth Government has funded some small, mainly “one-off”, projects in Queensland, as have some non-government trusts and foundations. [3.5(a) & (b); 1.1]
- 2.8 Queensland’s size, distances and sparse population creates challenges for assisting families across the State. [3.5(c)]
- 2.9 Assisting indigenous families, and families from a non-English speaking background, present significant challenges and might require specific, focused funding. [3.5(d) & (e)]
- 2.10 In Queensland, there is a lack of planning options and services for people with disability who do not have supportive families. [3.5(f)]
- 2.11 Assisting families with a family member with mental illness present particular challenges. [3.5(g)]
- 2.12 Assisting families with the practical implementation of their plans raises significant challenges. Other than some family support services, there are no agencies doing this work in Queensland. [3.5(h)]
- 2.13 There appear to be few planning options and services in other States and Territories and none that *Pave the Way* is aware of that offers a State-wide service. *Pave the Way* has been asked to present workshops in four other States and Territories and can only do so on a full fee paying basis and subject to our capacity. (3.6)

3. Terms of Reference

The Terms of Reference set by the Senate state that the Committee is to inquire into and report on:

Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

3.1 Concept of planning “for people with a disability to ensure their continued quality of life as they and their carers age”

Pave the Way strongly believes that planning in the context of parents or other important family members aging 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 planning that families must drive and control. This is “whole of life” planning and is in the realm of family business, not service business.

Direct support services can 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. Even where services do play a role, they are unlikely to be the only factor in assisting an individual to achieve a particular goal. For example, supporting a young person with disability to live in their own home might involve a mix of paid support, unpaid support and financial contributions by the individual and/or their family. 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.

Pave the Way believes that, in its consideration of whether people with disability have access to “*planning options and services*”, and in its inquiry to “*identify any inadequacies in the choice and funding of planning options currently available*”, the Senate Committee must focus on whole of life planning which takes place outside the service context.

3.2 People aging with a disability and their carers

Pave the Way works with families of all ages who have family members with a disability. Most family members who attend our workshops, or contact us for information and assistance, are parents. However, at times brothers and sisters, grandparents and cousins, and even close family friends, are the main contact within a family.

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?

Our experience is that a mix of age 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 see the questions raised by the Terms of Reference to this Inquiry as being relevant only to people aging with a disability and their carers. 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.

3.3 Location and staffing of “planning options and services”

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 to do this work 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. Three of the current five full-time staff at *Pave the Way* have 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, feedback we receive from families consistently confirms that they value working with staff with similar experience to them.

3.4 Access to planning options and services and the 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 disability, this thought is 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 disability 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 in 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.

- a) 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 provide some workshops, or produce some information resources, 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, 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.

- b) 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. Providing short term funding to a service to provide planning assistance to the families of the individuals the service supports, assumes that all of those families, or a significant number of them, will be ready to listen at the same time.
- c) 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 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.

3.5 Issues in Queensland

a) State Funding

Pave the Way was funded under the Queensland Government’s 2005-2006 Succession Planning Initiative, which provided recurrent funding to three projects. The two other projects were *Parent to Parent* and *Homes West Association*.

Parent to Parent provides structured planning opportunities for families using tools such as Planning for Alternative Tomorrows with Hope (PATH).

Homes West used its funding initially to provide workshops for families wanting to learn about the experiences of this small, family governed accommodation support agency and to write a book, “The Homes West Experience”. The small grant to *Homes West* was later

transferred to the *Community Resource Unit* which continues to work with groups of families interested in the development of small family governed services.

Since that 2005-2006 funding round, the Queensland Government has not provided additional funding for succession or future planning options or services, though the original recurrent grants continue, subject to contractual requirements being met.

b) Other Funding

From contact *Pave the Way* has had with other agencies, we are aware that some other agencies have established small future planning projects, some funded through Commonwealth funding, some through grants from non-government trusts or foundations. These projects typically focus on the families of people supported by a particular service, or families in a particular geographical location, and seem mostly to be time limited. None of these projects offer State wide services.

c) Queensland's size, distances and sparse population

Queensland is a very large, decentralized State. While half the population lives in the south-east corner, there are many provincial towns and cities of considerable size and a flight 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 flights.

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 alone and also that many people in remote communities do not have reliable internet access.

Pave the Way believes in equity of access to families. We put considerable resources into events in a wide variety of locations, knowing that some will attract 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.

d) 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.

e) 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. We have offered 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, this work is likely to require a specifically funded project.

f) People with disabilities 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 families and *Pave the Way*’s initial focus was to respond to families 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 capable of making their own decisions, or their families.

Pave the Way’s focus raises the question of what happens about those people with disability who need support but who do not have a supportive family. Who keeps them safe? There are projects elsewhere which focus on such individuals, such as the Circles Initiative in the *Community Living Program* 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. We have also been contacted by a number of individuals with disability who are capable of making their own decisions but who want assistance with planning. We have offered them our written information and held brief discussions, but otherwise have had to decline their requests.

Many services working with people with disability will claim to take “person centred” planning approaches, but they are involved in 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.

g) 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 such that they find it very difficult to relate to others and maintain relationships, or they have no insight into their need for assistance and so reject all suggestions by their family.

Many of these families are also 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.

h) Issues relating to “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, there is nevertheless an issue of how best to support families in the implementation of their plans – to assist them “after the planning” 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 with strategies to assist them to implement goals, such as developing 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 work out how to implement their goals. Aging parents in particular need this assistance. 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, many families that *Pave the Way* come across 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.

3.6 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. Of those initiatives we are aware of, 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 usually located within services and typically focus on the families of the people to whom they provide direct support services.

Pave the Way has been asked by some of these services to give presentations to families. *Pave the Way* has presented workshops in NSW (Tweed Heads, Doyalson, Sydney), ACT (Canberra), Victoria (Melbourne), Tasmania (Ulverston, Launceston, Hobart), and has future requests to present workshops in Newcastle and Sydney. 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.

4. Conclusion

Pave the Way supports 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 in the summary 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 any other initiatives aimed at developing similar planning responses to *Pave the Way*.

Pave the Way has welcomed the opportunity to make a submission to this Senate Community Affairs References Committee Inquiry. We would also welcome the opportunity to appear before a public hearing. If the Committee feels it would assist in its deliberations, *Pave the Way* could arrange for families with experience in these issues to attend a public hearing.

Further Contact:

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