

Report of the External Evaluation Team of the Evaluation of “Pave the Way”

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PAVE THE WAY BACKGROUND

Pave the Way (PTW) is a unique Brisbane based project auspiced by a local Brisbane family support agency called Mamre, that has been assisting families for several decades in a broader family support context (Please see Attachment C). Its focus throughout, from its initiation in 2002, has been on enabling families to become more effective in their ability to plan for their futures, such that their family member with a disability can enjoy the best possible life prospects. It began with financial support from Mamre Association until limited funding from the Disability Queensland Innovation Grants was received in December 2003. Early workshops with families were supported by a number of small agencies and the Queensland Disability Training Fund which continues to offer support for some regional work. Further funding was received from the DSQ Succession Planning Fund in early 2006.

This facilitation of families becoming more pro-active in engaging their futures, originally drew inspiration from the PLAN project of Vancouver, BC, Canada, (Planned Lifetime Advocacy Network www.plan.ca), and its emphasis upon independent future planning by families. The director of Pave the Way attended training events with PLAN in Western Australia early in the PTW process of evolution. Pave the Way differs from PLAN in significant ways, however, largely in that Pave the Way does not offer any ongoing service to families. Planning for Pave the Way has also been very much tied to planning for now as well as for the future rather than just to answer the question of families as to what will be in place after they die for their family member with a disability.

The current configuration of key features of PTW is that it remains an independent statewide planning assistance project, auspiced by Mamre, for families with a disabled family member that are voluntarily interested in becoming more pro-active in engaging and planning for their futures. It offers interested families and people in their networks a variety of workshops and information sessions extending from a matter of a few hours to some lasting for six days. These are supplemented by a variety of other supports including an extensive website that remains under continuous development, a newsletter, a professional panel, a reference group, addressing a variety of inquiries, short calls and consultations and for a few, some assistance with support circle development and facilitation. The project currently has a team leader, three development workers, one administration and support worker, one research assistant and a part-time consultant. It links with the Mamre internal staff structures through the project's director sitting on the Mamre staff leadership team.

A PREVIOUS EXTERNAL EVALUATION OF PAVE THE WAY COMPLETED IN EARLY 2006

An initial external evaluation of Pave the Way was completed in March of 2006 by a four member team lead by Leslie Chenoweth, PhD. It relied on interviews with key people in and around Pave the Way, focus groups and an extensive survey questionnaire. This same questionnaire served as the initial starting point for Pave the Way to formulate its own survey questionnaire as part of its external evaluation in 2008. The review made eleven major recommendations and commented on a variety of subjects including follow-up, governance, leadership development, relationships with persons with disabilities, circles development, safeguards and sustainability and individual and family centeredness.

THE OCTOBER 2008 EXTERNAL EVALUATION

This evaluation was led by Michael J. Kendrick PhD of Kendrick Consulting Intl with a team consisting of four parents of persons with disabilities as well as a sister of a person with a disability. (Please see Attachment B). The team was brought together in October of 2008 to respond to the questions raised in the terms of reference prepared by Pave the Way for the evaluation. (Please see Attachment A). In conjunction with the evaluation, but prior to it, a survey questionnaire was circulated by Pave the Way asking families and others who had had contact with Pave the Way about their experience with Pave the Way. The final report on the results of the survey was compiled by Pave the Way in the publication, "Pave the Way: Survey Of Stakeholders Results, October 2008" available through Pave the Way. This report was made available to the team as well as the completed questionnaires.

The evaluation consisted of several key parts in addition to reviewing the survey results. The first was telephone interviews with over forty families concerning their experiences with Pave the Way. Also interviewed were the staff of Pave the Way, the reference group for Pave the Way, the Mamre Staff Leadership team, DSQ contact people for Pave the Way, representatives of allied agencies, involved solicitors, a selection of circle facilitators and some circle members. This was followed by the team's compilation of its findings and the sharing of these initial findings and recommendations of the evaluation team in a verbal debrief. This report is the written summary to this initial preliminary verbal debrief by the team.

A Brief Summary of Some of the More Notable Strengths of The Pave the Way Initiative

- **Success in Enabling and Supporting Families to Plan for their Future**

Pave the Way had set as a key reason for its existence its belief that families can play a key lifelong role as key catalysts and safeguards for the well being of their family member with a disability through efforts at consciously clarifying a strong and positive vision for their life as the basis for working with others to plan and shape their futures. (Please see Attachment E). This original vision of planning was shaped by the reality that there had to be in place a strong vision and plans shared with others for when the parents were no longer there to act as a key support for their family member due either to death or other causes. An additional difficulty was to enable families to see that the resources that are already in their own networks could be usefully drawn upon in terms of shaping positive future possibilities.

"Family directed planning" in this regard refers to the plans that families actively make for themselves to address what they believe, at a given point, will be their future circumstances. "Family directed planning" in this context also means that the development and clarification of a strong and positive vision for the life of the person with a disability needs to be the basis of any planning.

Since such anticipations of the future can change, planning is seen as an ongoing and repeated exercise rather than a single discreet event. It is noteworthy that there co-exists other forms of futures planning that are largely generated and controlled by service systems and agencies, though done in the name of people with disabilities and their families which seek their involvement. These efforts at planning are distinct from that promoted by Pave the Way insofar as Pave the Way urges families to recognize that they can ultimately make their own choices, or at least to preserve this independent "family directed" option at all costs.

This initial insight, that conscious family and network based planning might play an empowering and preventive role, was later enriched by the idea that planning could be valuable at any point in the lifecycle of a family, simply because it helped families manage their futures proactively at all stages of the lifecycle of the family. It presumed that families had a vested interest in the future and would have a "natural" stake in shaping their futures. These assumptions were upheld in practice, as was witnessed by the large numbers of families that stepped forward to show an interest in planning by attending Pave the Way educational events, accessing Pave the Way resources and maintaining contact with Pave the Way. It would not be excessive to say that Pave the Way has, in a relatively very short period of time, helped stimulate an unprecedented interest and engagement by families in planning for a positive future for themselves and their family members. It also had the effect of reducing family isolation and offered them the opportunity to connect with other families and community resources. Perhaps most importantly, it encouraged families to have hope and to hold onto their dreams for their family member and themselves.

- **The Perception that Pro-Family Values Drive the Work of Pave the Way**

Pave the Way has not only promoted families becoming more proactive in planning for their futures, it has also helped affirm the positive roles that families do and can play to ensure that their family member with a disability and themselves are enabled to have full and rich lives. In this respect, Pave the Way offers families the opportunity to become more visionary about what is possible for not only the lives of people with disabilities, but also their families. It recognizes the huge contributions families can make to such ends as well as crediting families with the many ways in which their presence can be a crucial and constructive safeguard through their planning, independent advocacy, vision, hope and values. This generous and encouraging view of the potential role of families was also, in its way challenging and disturbing, insofar as it helped point out that many families had raised their expectations for themselves and their family member with a disability and subsequently demonstrated that these higher expectations were viable. This has meant that PTW has been both a catalyst for more proactive family planning, as well as an agent for change in terms of the vision and possibilities that might guide families. The motive and mission of Pave the Way for pursuing these linked challenges has been the eventual achievement of better lives for both people with disabilities and their families. It is the belief that life could be much better that both inspires and challenges those who have had contact with Pave the Way.

- **Consistently Positive Overall Family Experience with Pave the Way**

Though a small number of families had occasional complaints about Pave the Way, these were hugely overshadowed by the positive experience they typically had with Pave the Way. These included Pave the Way's ability to "think differently", their knowledge, their ability to clarify issues, their supportive and respectful manner, their ability to open one's mind to new possibilities, their resources, their website, their networks and so on. Additionally, their consistent affirmation of the worth of families and the fact that they were unfailingly responsive to families' questions and needs was much appreciated. Many remarked on Pave the Way's professionalism, conscientiousness, their ability to win trust and inspire confidence, their respect for families and their capacity to strengthen family's belief in themselves and their own capacities as being admirable assets of the Pave the Way team.

The Pave the Way project was frequently mentioned as a dependable source of the kind of high quality information and explanation that families were seeking. This information was conveyed through multiple means including newsletters, the Pave the Way website, the many workshops, meetings and phone calls and the promptness that Pave the Way showed in getting back to people. What was also appreciated by

participating families was the modest, thoughtful and intentional way that Pave the Way went about its work. As many families said, they were very glad to know that Pave the Way existed and was “there for them”.

- **Pave the Way has been Successfully Designed and Launched**

The challenges involved in the creation and full scale implementation of an innovative project of this scale and complexity should not be underestimated. Pave the Way is an entirely “made in Queensland” initiative that essentially had to be put together “from scratch” with nothing initially to go on other than the examples of PLAN in Vancouver and the very nascent work of PIN in Western Australia. In this task, Pave the Way decided to shape an initiative that differed strikingly from PLAN, yet was largely consistent with the aims PLAN had for families. It set out to be a statewide project as opposed to being a more local one. Further, it selected the option of focusing only on indirectly encouraging and supporting the family futures planning process rather than being directly instrumental in it themselves. While it alerted families to circle development as an aid to planning, it largely avoided providing direct circle development supports itself except in a very few instances, given the total number s of families attracted to planning by Pave the Way. It also chose not to be the source for ongoing advocacy for families, but rather encouraged families to develop and pursue whatever advocacy assistance options they might be able to enlist. Finally, it saw planning as being conducted and directed by families themselves with Pave the Way’s role being principally a support to these processes and not one that would be necessarily ongoing or require Pave the Way’s presence in order to succeed. Each of these design decisions meant that Pave the Way had selected its own approach to supporting families through establishing a largely educational initiative and catalyst that would encourage proactive family planning, but not have individual families become dependent upon Pave the Way so much as on their own marshalling of the resources they had at hand.

Pave the Way and its key collaborator Mamre, moved past the design phase of its work to establish the means by which the work of Pave the Way would be achieved. This included initially finding ways to support its work with families and as time passed, to expand this work on a resource permitting basis. In this regard, they forged a key partnership with Disability Services Queensland both through its innovation and succession planning funds and later through support from the Disability Sector Training Fund and a number of small agencies. This partnership has made Pave the Way viable as an expanded educational program and catalyst and allowed it to offer more for families. Pave the Way went on to develop a specialized website, a newsletter and a variety of workshops and information sessions. It picked and supported very credible people to deliver on these many initiatives such that Pave the Way quickly obtained and upheld a solid reputation within Queensland and elsewhere. This ability of Pave the Way to design and deliver on an effective, innovative and unprecedented program “from scratch” is a notable accomplishment and a tribute to the leadership of both Pave the Way and Mamre for setting out and tackling the many challenges involved notwithstanding the many uncertainties and risks that had to be faced and overcome. It is an example of the role of leadership in being able to create and leave something in place that has the potential to do much good. Pave the Way is deservedly seen as having provided important leadership on an important issue of systemic significance not only in Queensland but elsewhere. Further, Pave the Way has done this with a level of quality and relevance to their work that has been appreciated not only by families but also by many well informed professionals, academics and civil servants in Queensland and elsewhere.

Pave the Way is also notable because the precise role it has undertaken is unique to Queensland and offers families and others a type of support that had not heretofore been present as a practical matter on the scene. It was certainly true that various systems of personal and family planning predate the launch of Pave the Way, but these were largely standardized personal planning system packages or tools. Pave the Way has largely left such tools in the hands of others. It has instead focused upon the broader role of supporting and

educating families to the actual task and potential of planning itself as a desirable activity for families to pursue. In this regard, it has carved out for itself a principally educational and catalyst role at a statewide level. In doing so it has complemented many of the other efforts to assist families such as direct person centered planning, family support, crisis support efforts, direct "hard" services such as residential and day programs and various voluntary family support initiatives. It has also attempted to generate a presence for itself in the various regions of Queensland. Additionally, its successful efforts to draw in suitable professionals in legal and financial matters to be a further resource for families has begun and will likely expand in coming years.

The Evaluation Team's Response to the Key Evaluative Questions Posed by Pave the Way

Prior to the evaluation beginning, Pave the Way's staff and board met and decided upon various key evaluative questions. What follows are the responses the evaluation team had in regard to these questions.

1. Question One: Pave the Way's vision is that "people with 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".

How effective is Pave the Way in contributing to the achievement of this vision?

Given that Pave the Way has charted for itself the quite explicit and focused role of being an educational catalyst to support families in their role as key planners and safeguards in relation to their family member with a disability, there is ample evidence that the families that took advantage of the offerings of Pave the Way subsequently believed that these opportunities were for the most part hugely helpful to them. They rated Pave the Way very highly both in the survey that was completed and in personal interviews given to the Pave the Way evaluation team. This result is distinct, of course, from whether these families actually proceeded with the kind of overall planning that PTW encouraged. There was no way for the evaluation team to independently verify either the extent or quality of any planning that was stimulated by Pave the Way. Nonetheless, Pave the Way was able to attract, interest and engage significant numbers of families around the question of planning entirely based on voluntary family interest in the subject. This is a significant accomplishment, particularly given the relatively small number of years Pave the Way has been in existence. What is not known, at this point in time, are the precise reasons why other families who did not join into Pave the Way's programs did so? Given that there has not been a specific effort, thus far, to systematically reach out to these uninvolved families, any conclusion would only be speculative. It would also be mistaken to prematurely conclude that Pave the Way has, or has not been, effective with these (as yet uninvolved) families, as it might presume reasons for involvement or not, that remain to be identified.

Recommendation One: Pave the Way should randomly interview a small sample of families who have thus far taken advantage of Pave the Way's offerings, to ascertain what progress and difficulties they have made with planning for their families and its precise relationship to what Pave the Way has offered (or not) by way of assistance.

Recommendation Two: Pave the Way should randomly interview families that have not opted to take advantage of Pave the Way's offerings for insight as to what their reasons for doing so might be.

2. In working towards this vision, the aim of Pave the Way is to "work with families throughout Queensland to clarify their vision and to plan for a good life and a secure future for their relatives with a disability."

(a) How effective is the work of Pave the Way in meeting this aim?

Pave the Way has been identified by many families as being a transformational influence upon their thinking and vision as to the life possibilities for both themselves and their family member. Those that were less effusive were nonetheless quite generous in their praise for Pave the Way. More specifically, families reported that they had their vision strengthened as to what could be possible for them if they became more visionary. In this regard, Pave the Way became a key link, amongst others available to families, to better practices and thinking both in Queensland and elsewhere. Many families reported that what Pave the Way had demonstrated to them was both mind and eye opening and that they were very grateful to have had such opportunities to better explore what might someday be possible for them and their family member. A second area where Pave the Way has been effective appears to be the extent to which many families had become engaged in planning for the future. The precise nature of the various types of engagements in planning by families have not as yet been documented, but all of the families interviewed and surveyed indicated that they were more engaged than had been the case prior to their exposure to Pave the Way. Perhaps more significantly, the families overall reported that they were largely more hopeful and encouraged after their experience with Pave the Way and felt much more educated and had greater depth in regards to taking charge of planning for their future. These positive outcomes were not without some exceptions "here and there", but even these exceptions to the rule were comparatively small as a proportion of the whole.

Recommendation Three: Given Pave the Way's success so far in inspiring families in the role of taking charge of their planning for the future, it should continue to experiment with new ways in which it reaches out to families, so as to build upon and surpass its success with families in regards to this issue and to expand, evolve and evaluate on an ongoing basis, its repertoire of offerings.

(b) What have families done as a result of contact with Pave the Way?

Not surprisingly, families responded quite individually to the influence of Pave the Way according to their own needs and priorities at the time. A range of specific action responses were reported. These included various examples of families exploring or developing more individualized, "person centered" and independent living support arrangements. Other families focused on clarifying and addressing the legal issues that they faced as a family. Various families showed interest in exploring or developing different kinds of circles of support. Some families took action to invite people into their lives to play supportive roles either informally or as part of ongoing circle of support initiatives. In some instances families took the time to rethink the role and relationship of their family member with a disability in regards to their personal and family lives. In some instances, this resulted in families changing long held patterns of family life. Some families were brought to a decision on various matters and decided to become more proactive. Some families consciously deferred immediate action, but did come to the decision to take up various planning issues at a later date. Many families were stimulated to pursue information and possibilities that had captured their interest. Many reported that the work of Pave the Way had given them a lot to consider and think about and they were engaged

in a process of "digesting" what they had learned. Many families had connected with other families they had either met or heard about through Pave the Way. Some families pursued advocacy for their family member or themselves or sought new resources or funding including the use of new community resources they had not yet explored or used before. What seemed to be true for the families exposed to Pave the Way, was that Pave the Way had triggered in them an increased interest and commitment in regards to planning and acting in regards to shaping the future for their families. This is precisely the kind of result that Pave the Way was seeking in its catalyst role.

Recommendation Four: In conjunction with recommendation one, Pave the Way should document, through summaries of actual family stories in Queensland, the various ways that families have responded to the challenges they have encountered in managing a planning role in the short and long run. This will offer many other families both role models and insights into the variety of challenges and rewards that come with families taking on the planning role.

(c) How have families changed their thinking as a result of contact with Pave the Way?

It would seem from what the families have conveyed, the effect of Pave the Way on their thinking was many sided, but largely in the direction of a more empowered sense of the way that they could directly influence their futures. This strengthened sense of self-efficacy went well beyond the value of planning before one reaches old age. Families were enabled to recognize that they could improve their knowledge and apply it to their concrete concerns. They recognized that they had greater capacity to take matters into their own hands and impact upon their future possibilities. This left them feeling more hopeful and encouraged overall and more confident in sticking with their purposes and their willingness to "dream". They also gained a better sense that they were not alone with their difficulties and that they could locate and develop a variety of allies. They also tended to grow in terms of being able to see more of the potential of their family member to have a life of their own and on their own terms. In some instances, these realizations were akin to an epiphany and were radically transforming whereas in others, Pave the Way had the effect of being a positive reinforcement and affirmation. The net result seems to have been an inspiration to families to open up to possibilities for their lives and the life of their family member and to become more decisive and intentional in acting on their hopes and dreams.

Recommendations Five: In conjunction with Recommendation Three and Four, Pave the Way should build upon the demonstrated strengths mentioned here in its future work and offerings, with a special emphasis upon the ways in which Pave the Way has enabled families to "imagine better" as it relates to building vision for the life potentials of their family member with a disability as well as the life potential of their families overall.

3. The work of Pave the Way is grounded in the values of Mamre, which are set out on page 21 of the Mamre Policy and Procedures Book 2008. Mamre, and Pave the Way, values dignity, community, relationships, hospitality, service, fidelity, simplicity, justice and humility.

In its work with families, does Pave the Way embody these values?

Though not all of the families commented upon the values of Pave the Way, many did draw attention to their appreciation for them. In some instances, specific values were mentioned as notable such as Pave the Way's ability to listen, their respect for families, their responsiveness, conscientiousness and dependability in terms of being of service, their modesty and poise, their strength of conviction about the life possibilities of people with disabilities and their directness and professionalism. We have elsewhere also identified that these values, when clustered together, were perceived by families as being largely "pro family". Given that the families felt valued, supported and upheld in their role as families, this would resonate very well with Mamre's own long held commitment to the families it supports. In this regard, many families would not necessarily know of Mamre's role in creating and hosting Pave the Way, particularly those families from regional and country Queensland, so their source for information on the values of Pave the Way have come directly from their contact with Pave the Way. As a consequence, this tends to suggest that Pave the Way does embody the values cited by the families and are not benefiting for the most part from some sort of halo effect from Mamre itself. As such, Pave the Way is exhibiting the values that Mamre had hoped it would.

Recommendation Six: Even though Pave the Way has already notably distinguished itself as embodying many, if not most, of the values emphasized by Mamre, its future performance in regards to these values would be greatly assisted by Pave the Way becoming more explicit about how it wants these values to be reflected in its day to day work and what it sees as being ways to further self consciously strengthen its clarity and internalization of the values with special reference to those that families believe are particularly helpful to them as they take up strengthened roles with planning.

4. Pave the Way uses a number of strategies to achieve its aim. These include providing information (phone, written, website, email); presentations and workshops; individual family consultations; facilitating a planning session; or assisting a family to develop a network or support circle.

What do families find most useful/least useful in these strategies?

It would be difficult to single out only one communication or other strategy as being of more value to families than another because of the fact that families relied on all of them to a greater or lesser degree, given their needs at a particular moment. The newsletter was perhaps the resource most mentioned, but it was also the resource, other than workshops, that almost everyone would have had exposure to. What may be overlooked in focusing solely on these strategies is the fact that many families drew comfort and reassurance that Pave the Way was "out there" and could be accessed whenever it was needed. If you like, many families like the idea of Pave the Way being an ally they could call upon. As such, its presence was as important a factor as the means by which it operated. Obviously, the workshops were the principal means by which Pave the Way initially engaged families, so it would be hard to imagine their diminution given their central role. The support circle direct assistance strategy as well as the facilitation of planning sessions were used only in a comparatively very tiny number of instances, so their importance was minimal in the overall mix.

Recommendation Seven: Given the likely ongoing challenge to Pave the Way of using its scarce resources to maximum effect, it may possibly become necessary on occasion to eliminate or reduce some offerings to

families that have less overall impact than others, even if some families did find such offerings useful in their lives. Consequently, representative sample of families should be asked to list the relative value of the offerings to their family and to state why this is so. This would give Pave the Way the confidence that it is making the right decision should it have to curtail at least some of its offerings in the future.

5. Pave the Way aims to work developmentally with families by assisting them to find their own solutions to planning for the future, rather than offering them a solution.

Can families throughout Queensland achieve the sense of hope and confidence they want from this developmental approach?

It is certainly the case that families can be strengthened to develop their confidence to have and pursue their own vision for their future. The families in the survey, as well as the ones we spoke with, quite uniformly reported that contact with Pave the Way was strengthening for them in this regard. However, what may be true at a general level across many families may emerge in quite different ways one family at a time. This is because of the variability of the difficulties they may currently be facing, their own abilities and limitations, the degree and relevance of the support they are receiving or could be assisted to receive, the allies they presently have, their own history with being proactive, other competing factors at work in their lives and so on. Consequently, a crucial factor in whether families can make meaningful progress with this goal, will be whether they are well supported or not in the task. Many families might be favored in this regard and others might be at a disadvantage. Obviously, there are limits that Pave the Way has in being able to directly provide support to the many families it has contact with, as well as the question of whether the Pave the Way support is the exact support that is needed at a given moment. So, the goal is a feasible one, notwithstanding the limitations available to support families in this task.

Though it may seem unusual to some, there may be advantages for families that do not have the expectation that someone will invariably come to their aid in planning for the future, because it may enable them to conclude that they will have to manage the task principally by themselves. This will help them escape from the dependency of waiting and hoping that others will step forward, thereby relieving them of having to make the decision to act on their own. In such circumstances, whatever support is available will be better used by the concerned family because they have already in their own mind, become the key stewards of their own future. This self reliant attitude is clearly not widespread by any means, so it is clear that it may have to be further strengthened and engendered by Pave the Way in order to become more of a factor. It may also partially explain why some families are reluctant to engage the question of family directed planning. Like all worthwhile aims, the achievement of them in practice is rarely easy. This does not mean that the goal is invalid or lacks feasibility. Rather, it is best cast, as has Pave the Way, as being a developmental challenge for all families and that the optimal approach is to take up such challenges one family at a time, so as to best resolve their specific issues in their own terms and timing. In this regard, a major limitation of Pave the Way is its ability to directly provide instrumental assistance to families and thus the need for families to be the architect of their own sources of instrumental support. Even if Pave the Way could assist to some degree, there is always the danger that some families might transfer their dependence upon Pave the Way and Pave the Way may not always be there. Thus, this would leave such families at a brick wall unless they could begin to develop attitudes more along the line of self efficacy.

Recommendation Eight: Pave the Way has quite rightly emphasized family self reliance as a desirable foundation for families to proceed with self directed family planning so that families can potentially locate and draw upon many formal and informal community supports in the process. Given that many families will lack experience and confidence in pursuing these supports, Pave the Way could play a helpful role by continuing to directly address this challenge that many families still face and to look for any additional improvements in its work that might be a source of further strengthening of families in their role of locating and using supports that they may find helpful.

Recommendation Nine: Given that many families will not proceed with pro-active measures in regards to planning and drawing upon community supports if they lose hope or are deeply discouraged, Pave the Way may want to expand in its offerings on the question of what are sound bases for hope and why is this so. Given that many families have already indicated that Pave the Way has a message of hope, this message could possibly be further strengthened on a self conscious basis.

6. Pave the Way states that it cannot promise to be there for families indefinitely. One reason for this is that Pave the Way is funded by the Queensland Government and it cannot be assumed that any government funding will continue indefinitely.

What other responses are you aware of that may inform our practice around this issue?

Pave the Way is wise to assume that all sources of funding may have their limits, including those associated with governments. Obviously, the more diverse the sources of funding the better, should one source or another fail to deliver. In this regard, Pave the Way would be in a better position if it had a more diversified funding base which raises the questions of what might be other sources of funding. In this regard, there are several broad categories of possible sources of funds that might have relevance, though it is difficult to imagine them being sufficient enough to make up for the potential total loss of the present DSQ funds. These additional options would include any combination of philanthropic funds or foundations, private fundraising efforts, including the establishment of Pave the Way's own foundation that could receive donations/bequests from individuals or corporations, membership fees, special grants from other government sources, revenues obtained through the sale of materials, possibly some monies from selective consultations, "pay-as-you-go" fees for specific events and possibly some user charges. Pave the Way is well aware of PLAN's determined effort over many years to find sources of funding other than government and could conceivably borrow from this experience.

Recommendation Ten: Though Pave the Way may find that some of the time it may be unable to locate or tap into additional financial resources, pro-active efforts to locate and qualify for them should be part of its annual work plan so that this task is not taken up in the middle of a sudden crisis due to the loss of any of its present core operating funds.

7. In its work with individual families who want to set up a support circle, Pave the Way has been assisting some families in an open-ended, ongoing way. This has involved not only assisting the family to find a facilitator for the support circle, but sometimes paying and providing ongoing one-on-one supervision to facilitators. Three Pave the Way staff also provide ongoing facilitation to one support

circle each. Some of these “ongoing” commitments have been in place for 5½ years with no plans in place to bring them to an end.

This “ongoing” work is more like family support, whereas the remainder of Pave the Way’s work might best be described as providing resources to families. These resources include providing information, presentations and workshops, and time specific involvement with individual families such as individual consultations, assistance with one or two planning sessions and time limited assistance to establish a support circle.

The “ongoing” work has resource implications for Pave the Way, given the cost of paying facilitators and the staff time involved in facilitating circles and supervising other facilitators. However, the professional development benefits from this longer term involvement, both to individual staff and Pave the Way, are considerable.

If Pave the Way was to withdraw from this “ongoing” involvement, it would not mean that families were left without any resources to assist them to establish and sustain a support circle. Pave the Way could still offer to:

- Consult with individual families interested in setting up a support circle to help them to clarify if this is what they really want, the purpose of doing so and to discuss what is involved and how to start.
- Assist families to find facilitators (if requested).
- (Perhaps) offer one-off grants to help with payment of a facilitator where needed – perhaps \$1500 initially with max \$3000 – subject to funding.
- Attend the first meeting of a support circle (if requested).
- Be available to discuss any issues as they arise but not offer regular one-on-one supervision with facilitators.
- Be available for reviews of progress of support circles and facilitation of planning sessions.
- Convene regular meetings of facilitators to which all facilitators of support circles are invited.
- Offer training and information re facilitation.
- (Perhaps) support the development of an external “Circles Network” of people interested in support circles, by providing assistance with photocopying, mail-outs, meeting room.

(a) Should Pave the Way continue with its “ongoing” support circles work with some individual families, or should Pave the Way restructure that involvement so that all work with individual families wishing to set up a support circle is in the form of offering only to be a time limited resource?

The “ongoing” work with support circles work is not central to Pave the Way’s mission, as support circles are a means to an end and in any case, may not be necessary for many families. It is also an unsustainable and potentially very costly commitment for Pave the Way to take on without reimbursement. Further, it also is a serious distraction to Pave the Way’s main purpose, which is to support the emergence of “family directed planning” as described earlier (see “Success in Enabling

and Supporting Families to Plan for their Future”, paragraph 2, page 4). Even at present, Pave the Way has only been able to assist a very few families on an ongoing basis and scarcely more on an initial “get started” basis.

Overall, this has amounted to about 50 or so families that Pave the Way has had some staff role in regards to supporting support circles. Though as a portion of the total families supported otherwise by Pave the Way this number seems small, it is not a small matter in terms of the commitment of staff time. Though the original thinking behind this work was that Pave the Way staff needed to be actively involved in the establishment and even facilitation of circles of support to understand this important strategy and undoubtedly staff do gain many useful insights from it, it is a very costly way of obtaining these insights from the use of staff time point of view. This is not meant to say that such facilitation work is not needed by many families and that they might look to Pave the Way to provide it. Rather, it is to point out that Pave the Way should be very careful not to foster such expectations of staff time availability unless it has a realistic likelihood of living up to these expectations for the majority of the people who have taken advantage of Pave the Way’s offerings. This does not seem to be a probable prospect for the foreseeable future and Pave the Way has other priorities that should come first. Consequently, it is timely for Pave the Way to vacate this role as quickly and responsibly as possible. There do appear to be people available to take on such facilitator roles on both a paid and unpaid basis, so it would be better for Pave the Way to emphasize that families can pursue these other options should circle development or sustenance be central to a given family’s urgent concerns at a given moment. Undoubtedly, this will leave many families without a real alternative in the short run. Nonetheless, it does prepare the way for the consideration of other ways that families might get this kind of support that do not require scarce Pave the Way staff time as a routine matter.

Recommendation Eleven: Pave the Way should begin to disentangle itself from being the direct provider of support circle facilitation with these goals in mind:

- a) To support families who are currently reliant on Pave the Way’s assistance to develop alternative means to obtain this support.
- b) To communicate to families that this support might be available from other sources and that Pave the Way no longer believes it can offer this support.
- c) To do its part to continue to refer interested families to reliable sources of facilitation support.
- d) To educate families more generally about how to tap into natural networks for this kind of facilitation support.
- e) To help families share their learning about the many ways that they have managed to succeed with support circles.
- f) Does Pave the Way paying a facilitator weaken the long term sustainability of a family’s support circle, by encouraging “dependence” on Pave the Way?

(b) Does Pave the Way paying a facilitator weaken the long term sustainability of a family’s support circle, by encouraging “dependence” on Pave the Way?

As has been indicated, it is important for families to develop as strong a sense as possible of what they can directly control and develop in their own lives relative to family directed planning. While having some assistance from Pave the Way regarding support circle facilitation may not necessarily weaken the ability of families to create their own solutions, it does create a measure of dependence by families upon Pave the Way that is not sustainable by Pave the Way and it may, temporarily or otherwise, discourage them from pursuing other viable options. The same could be said for the sustainability of Pave the Way entering the role of being a nurturing body for the facilitation industry itself in whatever form or fashion that is advanced.

Recommendation Twelve: Pave the Way's role relative to support circles should be principally educational for families in terms of facets such as knowledge of support circles and how they work, acquainting families with published or other media resources, alerting to and informing families of each other's experience with support circles, advising families of potential sources of support for support circles that may be developed or tapped into, advising families of quality challenges with support circles and how they might be managed and other such educational and informational offerings.

8. There are a number of aspects to Pave the Way that make it different from what else is happening in Queensland and elsewhere in Australia. Pave the Way works across the State, yet is located within a family support community and service that operates only in the Brisbane area. Pave the Way is funded totally by the State Government (though there has been limited other income from consultation and presentation fees).

(a) What makes Pave the Way different from what else is happening, and not happening, for people with disability and families in Queensland?

Pave the Way is a largely family directed, independent, community controlled initiative that emphasizes lifelong and long term family controlled planning for their future. It is not a proponent of a particular planning method, but instead emphasizes a flexible approach to families that enables families to be person and family centred. Its major distinction from agency sponsored individual or family futures planning is that Pave the Way favours (entirely) family directed planning. Pave the Way's own role is one of being a catalyst and supporter, through principally educational means, of families to take up this role as autonomously as possible. No other group in Queensland does this explicitly on a state wide basis, though there are other family directed initiatives in the state that do some of this work on occasion.

Recommendation Thirteen: Pave the Way should continue with its role of emphasizing the potential of family directed planning with an emphasis on the potential variability of methods on a family-by-family basis depending upon their needs and capacities and continue to cooperate where practical with other organizations in Queensland that share Pave the Way's vision and who are themselves willing to cooperate with Pave the Way in referring potentially interested families to its educational and other resources.

(b) Where should Pave the Way be located? (i.e., within Mamre? If not, where?)

It is unlikely that Pave the Way could have existed without some initial support in getting it started. Mamre has stepped in to provide this support and has undoubtedly been a critical factor in Pave the Way being able to be as effective as it has been thus far. Pave the Way is now well through its start up phase and is in a quite different position from this earlier period. Pave the Way is now well enough established that it faces the question of whether or not it should move from its current status of being a hosted project to being independently incorporated as a “stand alone” mini-agency of its own. In between these two positions is the possibility of a more distinctively “arms length” hosted mini agency with its own governance board in distinction from its current reference board. There is no urgency to make this decision at present, but it is timely for Pave the Way to come to a decision as to whether it wants to alter its status from its “hosted project” status to either an arms length internal hosted mini agency status or to being entirely separate from Mamre through incorporating itself as a distinct agency. This question has various implications, but it is important that Pave the Way select the option that gives them the most degree of autonomy possible, such that it can operate with its own distinct identity. The latter two options mentioned here both provide these advantages. However, the hosted arms length mini-agency option is a less dramatic change from the current arrangement but which does not preclude eventual independent incorporation should this be advantageous.

Recommendation Fourteen: It is recommended that Pave the Way move to a more autonomous position and identity relative to Mamre. This could mean operating either with an arms length internal hosted mini agency status or to operating entirely separately from Mamre through incorporating itself as a distinct agency. Pave the Way would be served well by either option at this point, so the decision should rest upon Pave the Way’s (and Mamre’s) careful and unhurried assessment of the comparative advantages and disadvantages of each option relative to achieving Pave the Way’s mission.

(c) If Pave the Way continues to part of Mamre, where should it be located? What should its organisational make-up be?

Should Pave the Way stay within Mamre, it could move from its present “hosted project” status to a more mature status as an “arms length”, hosted, internal, self governed mini-agency. This would mean that in almost all respects Pave the Way would function autonomously as if it were its own agency. This could include its image, location, budget, personnel and essential policies and priorities. Nonetheless, it would not be a (completely) independent agency, as this would require it to have its own legal identity. Consequently, Pave the Way would need a working agreement between its governance (as opposed to reference) board and the board of Mamre as to how internal matters between the two entities could be implemented in daily practice to the satisfaction of both sides.

Recommendation Fifteen: It is recommended that Pave the Way develop its own distinct identity as well as establish a governance board for itself. This board could operate to oversee and direct Pave the Way in regards to both organizational options cited in Recommendation Fourteen.

Recommendation Sixteen: The Reference Group that currently exists could be:

- a) Preserved as a distinct entity in either of the recommended options, should its role as advice giving still be needed.
- b) Absorbed into the (proposed) governance board as a sub-committee of that board.
- c) Disbanded if Pave the Way did not see a future role for it.

Since these evaluations are intrinsically bound up with the merit of the recommendation to move to a governance board, Pave the Way may want to wait on the disposition of this matter until it is clearer what has been decided in regards to Recommendation Fifteen.

(d) Should Pave the Way look for alternative or diversified funding?

Yes. See earlier comments and Recommendation Ten.

Additional Issues for Consideration

In addition to the questions raised by Pave the Way, there were a number of additional issues that were raised by the evaluation team. This was in accord with Pave the Way's request of the team to identify any issues that were of concern to the evaluation team. These additional issues for consideration are provided below.

- **Those families who have not yet shown interest in engaging with Pave the Way in planning for their futures**

As has been noted elsewhere, it is not clear as yet as to precisely why these families have opted not to engage with Pave the Way on this issue. It may be that they believe that they have matters well in hand and do not need nor would benefit from Pave the Way's potential contribution to their efforts. Since so little is known about their perspective and reasoning and to avoid jumping to erroneous conclusions, it would be useful for Pave the Way to reach out to at least a sample of these families and explore with them how they see the issue of family directed planning. The information gathered from such exploratory outreach would potentially be very illuminating for Pave the Way as to how it might best relate to such families. (See Recommendations One and Two)

- **Increased inclusion of siblings, men and non English minorities**

Pave the Way has tended to focus on parents more than other family members. This is quite sensible given the central role of parents in regards to future planning. Nonetheless, there is scope for increasing the profile of siblings in regard to this task both in the short term and long term. Pave the Way has been quite accommodative and encouraging in this regard, but may find that it will need to be more proactive to significantly alter the numbers that actually get involved. This is a partly cultural matter and may only yield gradually to an outside influence such as Pave the Way. Nonetheless, this potential of siblings should continue

to be proactively pursued. The same could be said in regards to the role of men and minorities, as both parties are currently underrepresented.

Recommendation Seventeen: Pave the Way should appraise and decide whether it could be more active in strengthening the role of siblings, men and cultural minorities relative to family directed planning as well as exploring the various ways in which this might be accomplished.

- **The programmatic challenge of balancing the needs of families of different ages**

Pave the Way has quite rightly set as its goal the need to encourage family directed planning at all ages of the lifecycle. From a programmatic perspective this viewpoint creates its own dilemmas, since the needs and priorities of younger families would necessarily vary from those of older ages. A single program offering by Pave the Way risks at least to some degree being more or less relevant to some families more than others. There is no easy remedy for such a problem, except by Pave the Way being able to become increasingly better targeted in terms of more specifically addressing the needs of different kinds of families, through strategies that grow out of their specific needs and issues.

Recommendation Eighteen: It is recommended that Pave the Way review its new offerings as well as retrospectively review on an annual basis its current offerings in order to determine whether they could be better adjusted to remain meaningful to families in different stages of life.

- **Shaping expectations concerning systematic follow up to workshops**

Though most families were quite happy with the workshops, information sources and consultations, there were some who mentioned that they would have liked a more ongoing follow up relationship with Pave the Way than eventuated. Pave the Way, for its part, has been very effective in its follow-up on an overall basis, so the principal difficulty is both Pave the Way's clarity about what precisely is within its means by way of being able to meet promises regarding follow up and its capacity to increase follow up of various kinds over time. In both instances, it is important for Pave the Way to be as exact as possible about what can and cannot be expected by way of follow up and to continue to explore ways that it might add to its capacities in terms of follow up.

Recommendation Nineteen: Pave the Way should review the messages it is giving families as to possible follow up by Pave the Way such that these are congruent with Pave the Way's actual ability to deliver on these expectations and that such expectations should be modified to be consistent with what Pave the Way can actually deliver in practice.

- **The role of persons with disabilities within family directed planning processes**

Like in the broader society, people with disabilities are at risk of being overlooked and disempowered in regards to directing their own lives even in their own families. Though many families are often admirable in their advocacy and family habits to counter such trends, there nevertheless remains the risk that families will act in much too paternalistic ways and plan for their family member rather than with them. Nonetheless, it is not at all easy to get this relationship right even under the best of circumstances and in an abundance of good will. Families, like everyone else, have their own particular challenges that they face in overcoming attitudes and practices that may have become somewhat embedded. For this reason, it is useful for Pave the Way to offer specific guidance, encouragement and examples that might help families negotiate these often tricky issues.

Recommendation Twenty: It is recommended that Pave the Way add more information, inspiration and guidance to its offerings to families to better enable them to support the person with a disability to both be more of a presence in whatever planning occurs should they be able and willing to do so and to create safeguards to ensure that their voice and best interests are given appropriate weight in whatever planning conclusions are reached.

- **Instrumental assistance in regards to actualising family vision**

There are many difficulties that families face in actualizing their vision that are not likely to be easily resolvable and may require instrumental assistance in many forms. It is often possible, though not always easy, to obtain that assistance on a local or regional basis and in some instances much further away. Obviously, Pave the Way cannot provide these many forms of material and instrumental assistance itself. Consequently, what Pave the Way can do is to join with many others, who are also interested in this issue, in some form of informal consortium that can study the gaps that exist and to generate options to try to fill them wherever this proves practical. This may involve the better use of existing resources in some instances and the creation of new resources where this is needed and feasible.

Recommendation Twenty One: It is recommended that Pave the Way sees it as part of its mission to actively collaborate with others in Queensland to both study the gaps in instrumental assistance that families face in both planning for their future and in actualizing their dreams and hopes and to attempt to ensure, whenever possible, that these gaps are addressed with new and strengthened options.

- **Coordinative relationship between Pave the Way, DSQ and Parent-To-Parent, QPPD and other key players in Queensland (regarding family issues and needs)**

Though there are a variety of systemic issues facing families within Queensland, such as the kind of shortages of instrumental supports for planning mentioned in this report, limited individualization of services, uneven advocacy, regional disparities etc., there does not seem to be a vehicle present that would

assist in better linking the various key parties that might influence these issues in some sort of coordinated and strategic way. It is conceivable that Pave the Way could be a player in supporting and leading such an effort, even if it were rather informal. It is always a thankless task to try to gather together and unify the efforts of diverse organizations, such that their collective impact is strengthened in a strategic and coordinative sense. Yet, at the moment this is not occurring and countless families may ultimately suffer due to the absence of such an influence. It is also true that these other parties have a similar obligation to rise above their more narrow obligations to search out and to pursue yet even better solutions for families. Admittedly, like Pave the Way, they may choose not to take this challenge on. Nevertheless, the challenge is an objective systemic one and Pave the Way should consider whether it can do its part even if others are less keen.

Recommendation Twenty Two: Consistent with the intent in Recommendation Twenty One, Pave the Way should intensify its efforts with QPPD, Parent to Parent, DSQ and possibly other current key players in the promotion of family directed planning to increase the strength of coordination of their efforts in regards to both encouraging planning itself and the catalysts related to whatever supports families may need to be more successful with both planning and follow through.

- **Expansion of supply of referral professionals to regional areas**

Pave the Way has played a crucial role in demonstrating that there are professionals in the legal and financial sectors that could be available, on a somewhat screened basis, to families. At present, the bulk of these referrals are in Brisbane and it is foreseeable that this list could be expanded over the course of time to include similar professionals from regional areas. Undoubtedly, there are difficulties involved in doing this, but the precedent of what has already been accomplished in this regard should be a source of encouragement to Pave the Way. There need not be a hard and fast deadline in this regard for a fixed number of "referable" professionals of the kind needed. Rather, there should be a determined intent to expand these numbers in regional areas and to systematically follow through over the next few years.

Recommendation Twenty Three: Pave the Way should continue to expand its listing of supportive referral professionals in the financial and legal sectors recognizing that this is most acutely needed in regional areas.

- **Shaping the ongoing connection/relationship of families to each other through Pave the Way and otherwise**

Though it was not necessarily the intent of Pave the Way, its contact with so many families in Queensland has created the beginnings of a quite sizable constituency and resource for families to be in touch with other families in various ways. If you like, Pave the Way is now a new means on the scene in Queensland by which families may usefully find their way to other families that can support them in their search for a better life. However, they will need to believe they can and be encouraged by Pave the Way, to approach Pave the Way whenever it might be possible for them to either suggest or pursue ideas that might possibly help themselves and other families in their challenges. This could include suggesting or exploring specific Pave the

Way course member reunions, developing special subject workshops or conferences, offering up their examples as a source of ideas and inspirations for others, participating in special evaluations and study sessions in regards to important projects underway in Queensland or elsewhere, helping develop and refer families to various family leadership events, producing articles, videos, DVD's or other such presentations, alerting people to relevant conferences, speakers, projects and so forth. The list of possibilities that Pave the Way might possibly play a role in enabling and that might benefit at least some families, could be quite extensive. The import factor is not such a list itself, but rather that PTW sees itself in the role of facilitating such opportunities as may be feasible at a given moment and that the families connected with Pave the Way themselves recognize that they can step forward at any time with good ideas and suggestions and see if at least some of them may be able to be pursued.

Recommendation Twenty Four: Pave the Way should resolve to address, consistent with its resources of time and people, whether it could help add to the many ways that families could network directly with each other through both Pave the Way and various other possible means, so that it is easy for families to be of direct support to each other, should they want this.

- **Pave the Way and potential advocacy sources for families**

Pave the Way has repeatedly and quite rightly encouraged families to seek, cultivate, use and direct the advocacy supports that make it possible for them to more independently pursue a better life. They are also right in indicating to families that the more "official" and funded advocacy supports may either be very limited in quantity and quality since their funding is linked to governments. As a principle, this is a sound one and quite wise in light of the undependability of governments in regards to funding their critics. At the same time, it is important that Pave the Way acknowledge how hard it can be for some families, on occasion, to generate advocacy support beyond themselves that ends up being reliable and effective. This suggests that the goal is valid but that the means could be strengthened by families having more available to them by way of personal support to help sustain them not only in their direct conduct of personal advocacy, but also in locating support and allies in this task. While Pave the Way cannot, and should not, at all be expected to be the answer in itself, it is still useful for Pave the Way to explore the elements that would enable it, in time, to be able to assist with strengthening family advocacy overall.

Recommendation Twenty-Five: It is recommended that Pave the Way anticipate the need for families to access advocacy support in the pursuit of their hopes and dreams and that Pave the Way should be at least one key resource amongst many for families to pursue the advocacy resources that might support their individual advocacy needs. In this regard Pave the Way should provide ample educational information about where both formal and informal advocacy support may be presently obtained in Queensland.

- **Family "Peer Mentors" at a regional level**

Though Pave the Way has tried, on repeated occasions, to become a presence through its staff at a regional level, the result has been limited in terms of any real ongoing presence across regional Queensland. Their

performance at regional workshops has been impressive, but their day-to-day presence has been negligible and will not likely be able to be improved much simply because of expected limitations, on an ongoing basis, of staff resources. Were the matter to stop here, then Pave the Way would have to resign itself to only a very modest regional presence at best. Fortunately, this not need be the end of the matter. When one considers the many talented family leaders that exist in all of the regions of Queensland and their usual willingness to serve in many capacities to benefit their region and its communities, then the possibility opens up of at least some such families being willing and able to be the Pave the Way presence that is needed for purposes of an ongoing local contact person for families. It is also conceivable that in some instances this person might serve in the same or similar roles for other groups such as QPPD. The precise nature of the role of such possible regional "peer contacts" or "peer mentors" could be sensibly worked out by Pave the Way and the other statewide organizations who might also like to support and relate to such (potential) leaders at a local or regional level.

Recommendation Twenty Six: It is recommended that Pave the Way explore the possible merits and potential viability of Pave the Way directly supporting the establishment, recruitment, training and safeguarding of what may eventually become peer mentors in each regional area that work with Pave the Way and aligned and cooperating agencies to ensure that families are properly informed of what may be (eventually) possible for them to advocate for, and subsequently pursue, in regards to their family member with a disability and their life potentials.

Summary of Recommendations

Recommendation One: Pave the Way should randomly interview a small sample of families who have taken advantage of Pave the Way's offerings thus far to ascertain what progress and difficulties they have made with planning for their families and its precise relationship to what Pave the Way has offered (or not) by way of assistance.

Recommendation Two: Pave the Way should randomly interview families that have not opted to take advantage of Pave the Way's offerings for insight as to what their reasons for doing so might be.

Recommendation Three: Given Pave the Way's success so far in inspiring families into the role of taking charge of their planning for the future, it should continue to experiment with new ways in which it reaches out to families, so as to build upon and surpass its success with families in regards to this issue and to expand, evolve and evaluate on an ongoing basis its repertoire of offerings.

Recommendation Four: In conjunction with Recommendation One, Pave the Way should document, through summaries of actual family stories in Queensland, the various ways that families have responded to the challenges they have encountered in managing a planning role in the short and long run as this will offer many other families both role models and insights into the variety of challenges and rewards that come with families taking on the planning role.

Recommendations Five: In conjunction with Recommendations Three and Four, Pave the Way should build upon the demonstrated strengths mentioned here in its future work and offerings, with a special emphasis upon the ways in which Pave the Way has enabled families to "imagine better" as it relates to building vision for the life potentials of their family member with a disability as well as the life potential of their families overall.

Recommendation Six: Even though Pave the Way has already notably distinguished itself as embodying many, if not most of the values emphasized by Mamre, its future performance in regards to these values would be greatly assisted by Pave the Way becoming more explicit about how it wants these values to be reflected in its day to day work and what it sees as being ways to further self consciously strengthen its clarity and internalization of the values with special reference to the values that families believe are particularly helpful to them as they take up strengthened roles with planning.

Recommendation Seven: Given the likely ongoing challenge to Pave the Way of using its scarce resources to maximum effect, it may possibly become necessary on occasion to eliminate or reduce some offerings to families that have less overall impact than others, even if some families did find such offerings useful in their life. Consequently, this question of comparative value should be posed (periodically) directly to a representative sample of families both in the form of their listing of the relative value of the offerings to their family and why this is so, so that PTW has the confidence that it is making the right decision should it have to curtail at least some of its offerings in the future.

Recommendation Eight: Pave the Way has quite rightly emphasized family self reliance as a desirable foundation for families to proceed with self directed family planning and that families can potentially locate and draw upon many formal and informal community supports in the process. Given that many families will lack experience and confidence in pursuing these supports, Pave the Way could play a helpful role by continuing to directly address this challenge that many families still face and to look for any additional improvements in its work that might be a source of further strengthening of families in their role of locating and using supports that they may find helpful.

Recommendation Nine: Given that many families will not proceed with pro-active measures in regards to planning and drawing upon community supports if they lose hope or are deeply discouraged, Pave the Way may want to expand in its offerings on the question of what are sound bases for hope and why is this so, given that many families have already indicated that Pave the Way has a message of hope, this message could possibly be further strengthened on a self conscious basis.

Recommendation Ten: Though Pave the Way may find that some of the time it may be unable to locate or tap into additional financial resources, pro-active efforts to locate and qualify for them should be part of its annual work plan so that this task is not taken up in the middle of a sudden crisis due to the loss of any of its present core operating funds.

Recommendation Eleven: Pave the Way should begin to disentangle itself from being the direct provider of support circle facilitation with these goals in mind. a) To support families who are currently reliant on Pave the Way's assistance to develop alternative means to obtain this support. b) To communicate to families that this support might be available from other sources and that Pave the Way no longer believes it can offer this support. c) To do its part to continue to refer interested families to reliable sources of facilitation support. d) To educate families more generally about how to tap into natural networks for this kind of facilitation support and e) To help families share their learning with other families about the many ways that they have managed to succeed with support circles.

Recommendation Twelve: Pave the Way's role relative to support circles should be principally educational for families in terms of facets such as knowledge of support circles and how they work, acquainting families with published or other media resources, alerting to and informing families of each other's experience with support circles, advising families of potential sources of support for support circles that may be developed or tapped into, advising families of quality challenges with support circles and how they might be managed and other such educational and informational offerings.

Recommendation Thirteen: Pave the Way should continue with its role of emphasizing the potential of family directed planning with an emphasis on the potential variability of methods on a family-by-family basis depending upon their needs and capacities and continue to cooperate where practical with other organizations in Queensland that share Pave the Way's vision and who are themselves willing to cooperate with Pave the Way in referring potentially interested families to its educational and other resources.

Recommendation Fourteen: It is recommended that Pave the Way move to a more autonomous position and identity relative to Mamre. This could mean operating either with an arms length internal hosted mini agency status or to entirely separate from Mamre through incorporating itself as a distinct agency. Pave the Way would be served well by either option at this point, so the decision should rest upon Pave the Way's (and Mamre's) careful and unhurried assessment of the comparative advantages and disadvantages of each option relative to achieving Pave the Way's mission.

Recommendation Fifteen: It is recommended that Pave the Way develop its own distinct identity as well as establish a governance board for itself. This board could operate to oversee and direct Pave the Way in regards to both organizational options cited in Recommendation Fourteen.

Recommendation Sixteen: The Reference Group that currently exists could be a) preserved as a distinct entity in either of the recommended options, should its role as advice giving still be needed, b) it could be absorbed into the (proposed) governance board as a sub committee of that board or c) it could be disbanded if PTW did not see a future role for it. Since these evaluations are intrinsically bound up with the merit of the recommendation to move to a governance board, Pave the Way may want to wait on the disposition of this matter until it is clearer what has been decided in regards to Recommendation Fifteen.

Recommendation Seventeen: Pave the Way should appraise and decide whether it could be more active in strengthening the role of siblings, men and cultural minorities relative to family directed planning as well as explore the various ways in which this might be accomplished.

Recommendation Eighteen: It is recommended that Pave the Way review its new offerings as well as retrospectively review on an annual basis its current offerings in order to determine whether they could be better adjusted to remain meaningful to families in different stages of life.

Recommendation Nineteen: Pave the Way should review the messages it is giving families as to possible follow up by Pave the Way such that these are congruent with Pave the Way's actual ability to deliver on these expectations and that such expectations should be modified to be consistent with what Pave the Way can actually deliver in practice.

Recommendation Twenty: It is recommended that Pave the Way add more information, inspiration and guidance to its offerings to families to better enable them to support the person with a disability to both be more of a presence in whatever planning occurs should they be able and willing to do so and to create safeguards to ensure that their voice and best interests are given appropriate weight in whatever planning conclusions are reached.

Recommendation Twenty One: It is recommended that Pave the Way see it as part of their mission to actively collaborate with others in Queensland to both study the gaps in instrumental assistance that families face in both planning for their future and in actualizing their dreams and hopes and to attempt to ensure, whenever possible, that these gaps are addressed with new and strengthened options.

Recommendation Twenty Two: Consistent with the intent in Recommendation Twenty One, Pave the Way should intensify its efforts with QPPD, Parent to Parent, DSQ and possibly other current key players in the promotion of family directed planning to increase the strength of coordination of their efforts in regards to both encouraging planning itself and the catalysts related to whatever supports families may need to be more successful with both planning and follow through.

Recommendation Twenty Three: Pave the Way should continue to expand its listing of supportive referral professionals in the financial and legal sectors recognizing that this is most acutely needed in regional areas.

Recommendation Twenty Four: Pave the Way should resolve to address, consistent with its resources of time and people, whether it could help add to the many ways that families could network directly with each other through both PTW and possibly various other means, such that it is easy for families to be of direct support to each other, should they want this.

Recommendation Twenty-Five: It is recommended that Pave the Way anticipate the need for families to access advocacy support in the pursuit of their hopes and dreams and that Pave the Way should be at least one key resource amongst many for families to pursue the advocacy resources that might support their individual advocacy needs. In this regard Pave the Way should provide ample educational information about where both formal and informal advocacy support may be presently obtained in Queensland.

Recommendation Twenty Six: It is recommended that Pave the Way explore the possible merits and potential viability of Pave the Way directly supporting the establishment, recruitment, training and safeguarding of what may eventually become peer mentors in each regional area that work with Pave the Way and aligned and cooperating agencies to ensure that families are properly informed of what may be (eventually) possible for them to advocate for and subsequently pursue in regards to their family member with a disability and their life potentials.

Attachment A: Terms of Reference

Pave the Way has asked a team external to Mamre Association to carry out an evaluation of Pave the Way in October 2008.

The primary purpose of the evaluation is to find out whether families in Queensland find the approach of Pave the Way to be useful in assisting them to plan for the future and whether Pave the Way could do anything more to assist families with their future planning. We are keen to hear what families are saying about the focus and work of Pave the Way.

The Terms of Reference for this evaluation are framed as a series of questions we would like the evaluation team to address, as follows:

1. Pave the Way's vision is that "people with 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".

How effective is Pave the Way in contributing to the achievement of this vision?

2. In working towards this vision, the aim of Pave the Way is to "work with families throughout Queensland to clarify their vision and to plan for a good life and a secure future for their relatives with a disability."

(a) How effective is the work of Pave the Way in meeting this aim?

(b) What have families done as a result of contact with Pave the Way?

(c) How have families changed their thinking as a result of contact with Pave the Way?

3. The work of Pave the Way is grounded in the values of Mamre, which are set out on page 21 of the Mamre Policy and Procedures Book 2008. Mamre, and Pave the Way, values dignity, community, relationships, hospitality, service, fidelity, simplicity, justice and humility.

In its work with families, does Pave the Way embody these values?

4. Pave the Way uses a number of strategies to achieve its aim. These include providing information (phone, written, website, email); presentations and workshops; individual family consultations; facilitating a planning session; or assisting a family to develop a network or support circle.

What do families find most useful/least useful in these strategies?

5. Pave the Way aims to work developmentally with families by assisting them to find their own solutions to planning for the future, rather than offering them a solution.

Can families throughout Queensland achieve the sense of hope and confidence they want from this developmental approach?

6. Pave the Way states that it cannot promise to be there for families indefinitely. One reason for this is that Pave the Way is funded by the Queensland Government and it cannot be assumed that any government funding will continue indefinitely.

What other responses are you aware of that may inform our practice around this issue?

7. In its work with individual families who want to set up a support circle, Pave the Way has been assisting some families in an open-ended, ongoing way. This has involved not only assisting the family to find a facilitator for the support circle, but sometimes paying and providing ongoing one-on-one supervision to facilitators. Three Pave the Way staff also provide ongoing facilitation to one support circle each. Some of these “ongoing” commitments have been in place for 5½ years with no plans in place to bring them to an end.

This “ongoing” work is more like family support, whereas the remainder of Pave the Way’s work might best be described as providing resources to families. These resources include providing information, presentations and workshops, and time specific involvement with individual families such as individual consultations, assistance with one or two planning sessions and time limited assistance to establish a support circle.

The “ongoing” work has resource implications for Pave the Way, given the cost of paying facilitators and the staff time involved in facilitating circles and supervising other facilitators. However, the professional development benefits from this longer term involvement, both to individual staff and Pave the Way, are considerable.

If Pave the Way was to withdraw from this “ongoing” involvement, it would not mean that families were left without any resources to assist them to establish and sustain a support circle. Pave the Way could still offer to:

- Consult with individual families interested in setting up a support circle to help them to clarify if this is what they really want, the purpose of doing so and to discuss what is involved and how to start.
- Assist families to find facilitators (if requested).
- (Perhaps) offer one-off grants to help with payment of a facilitator where needed – perhaps \$1 500 initially with max \$3000 – subject to funding.
- Attend the first meeting of a support circle (if requested).

- Be available to discuss any issues as they arise but not offer regular one-on-one supervision with facilitators.
 - Be available for reviews of progress of support circle and facilitation of planning sessions.
 - Convene regular meetings of facilitators to which all facilitators of support circles are invited.
 - Offer training and information re facilitation.
 - (Perhaps) support the development of an external "Circles Network" of people interested in support circles, by providing assistance with photocopying, mail-outs, meeting room.
- (a) **Should Pave the Way continue with its "ongoing" support circles work with some individual families, or should Pave the Way restructure that involvement so that all work with individual families wishing to set up a support circle is in the form of offering only to be a time limited resource?**
- (b) **Does Pave the Way paying a facilitator weaken the long term sustainability of a family's support circle, by encouraging "dependence" on Pave the Way?**
8. There are a number of aspects to Pave the Way that makes it different from what else is happening in Queensland and elsewhere in Australia. Pave the Way works across the State, yet is located within a family support community and service that operates only in the Brisbane area. Pave the Way is funded totally by the State Government (though there has been limited other income from consultation and presentation fees).
- (a) **What makes Pave the Way different from what else is happening, and not happening, for people with disability and families in Queensland?**
- (b) **Where should Pave the Way be located? (ie, within Mamre? If not, where?)**
- (c) **If Pave the Way continues to part of Mamre, where should it be located? What should its organisational make-up be?**
- (d) **Should Pave the Way look for alternative or diversified funding?**

Attachment B: Evaluation Team Members

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Attachment C: Basic Background Information about Pave the Way

History and Background

Project Formation

1. The biggest fear of families who have a family member with a disability is "What will happen when I die?" For the majority of such families in Queensland whose family member receives limited or no funding for support, this fear is even more acute. Amongst those few whose family member does receive funding, many are unsure about their role in decisions about how best to use those funds.
2. In September 2002, Mamre established the Pave the Way Project, to help families who have a family member with a disability to address this fear and to develop a vision and plan for their family member, now and in the future.
3. In establishing the Project, Mamre was responding to an idea developed by a group of people who had come together to discuss how best to assist families with this issue. The group felt there was no coherent response available for families in Queensland which addressed all the elements of future planning. That group became the Reference Group for the Project. The Project was funded initially by Mamre and Jeremy Ward commenced working 3 days per fortnight in early September 2002.
4. The Project's goal was to work with families to help them develop a vision and a plan which includes strategies aimed at safeguarding their family member when they are not able to do so. The Project also aimed to give families information and guidance in relation to legal issues relevant to planning and preparing for the future. While the Project was located at Mamre, it was never intended to be exclusively for families receiving support from Mamre.

Family Meetings

5. As an initial step in the Project, Jeremy Ward held 10 meetings with families throughout Brisbane during October 2002. These meetings were held to help gauge the interest of families in pursuing issues relating to future planning. Eight meetings were held in family homes, one at the Mamre Community House at Stafford and one at the Mamre Community House at Coorparoo. 5 meetings were during the day and 5 in the evening.
6. A total of 73 family members plus one service provider attended the meetings. The family members were all parents except for one grandmother and one sibling. In all, 56 families were represented, 7 of whom had no previous association with Mamre. Meeting sizes varied from 4 to 13 family members.
7. There was a significant number of younger families at the meetings. The ages of the respective family members with a disability varied from 4 years to 44 years. 24 of the families had a family member with a disability under 18.

The Next 12 Months: December 2002 – December 2003

8. In the next 12 months following these early meetings the Project developed its focus and approach. The Project was developmental, assuming that a considered and thoughtful approach, that works respectfully with families, is most likely to produce sustainable proposals to assist families to plan for and safeguard the futures of their family members. The work with families has informed research and analysis into what families throughout Queensland need to assist them on these issues.
9. During this time, the Project Worker, Jeremy Ward:
 - Researched issues around the long term safeguarding of people with disability and their and their families' vision and plans for their future - including research of organisations such as PLAN Canada, the US PLANs and Lifetime Circles, Ontario.
 - Wrote and distributed papers about planning for the future and the associated legal issues.
 - Conducted 10 large presentations (1 day) on future planning issues to families throughout Queensland.
 - Presented on these issues to the 2003 Community Resource Unit (CRU) Conference.
 - Gave information to approximately 25 individual families, in their homes and by telephone, both in Brisbane and in other parts of Queensland.
 - Worked with 1 individual family facilitating a Support Circle.
 - Worked with 6 individual families interested in developing a Support Circle, arranging and supporting facilitators.
 - Met regularly with the Project Reference Group, including two ½ day meetings specifically about Support Circles.
 - Continued research and analysis on the best ways to support families to safeguard their family members in the long-term.

Stage Two of Project: January 2004 - 2005

10. In December 2003, the Project was provided with funding by Disability Services Queensland (DSQ), under Innovative Funding 2003 – 2004. With this funding, Stage Two of the Project began. Funding enabled a second project worker, Sharon Bourke, to join the Project in March 2004, working 5 days per fortnight, and for Jeremy Ward to increase his work on the Project to 5 days per fortnight, from April 2004.
11. The goal of Stage Two was to continue and enhance the work carried out in Stage One of the Project, by increasing the resources available to families and the Project's capacity to conduct more in-depth workshops. It was also intended that during Stage Two decisions would be made about the future direction of the Project, including whether it remains located within Mamre.

12. The funding for this stage of the Project included an amount for an external evaluation, which took place in September 2005.

Work of Stage Two of the Project in 2004 - 2005

13. Work of the Project during this period included distributing information to families; conducting workshops throughout Queensland; supporting the facilitation of individual networks, including support circles; developing a Brisbane Solicitors Panel and working on long-term safeguarding issues. Details are as follows.
 - Continued distribution of papers on developing a vision, planning for the future and the associated legal issues.
 - 26 one day presentations (Planning for Now, Tomorrow and the Future") throughout Queensland.
 - 4 one day presentations (Building Informal Networks and Support Circles").
 - 2 two day, live-in, workshops each for 7/8 couples (14/16 people) on developing a vision, future planning and legal issues.
 - 3 six day, live-in, workshops, each for 6 couples (12 people) on developing a vision, future planning and implementing visions and plans (two parts of 3 days each).
 - A number of short, informal gatherings of families and conference presentations on future planning, networks/support circles and legal issues.
 - Facilitation of one support circle and support to a number of other support circles.
 - Development of a panel of Brisbane solicitors, to whom families could be referred for assistance with wills, trusts and estate planning.
 - Provision of information to a number of individual families on future planning issues, including legal issues.
 - Research of strategies for long-term safeguarding of individuals'/families' visions and plans and of safeguarding family members with a disability.

Stage Three of Pave the Way: 2006 to present

14. In November 2005, Pave the Way was invited by Disability Services Queensland (DSQ) to apply for funding under DSQ's Succession Planning Funding Round. We were successful in that application and additional funding commenced in April 2006. Sharon Bourke and Jeremy Ward both increased their time to full-time and by August had been joined by Catherine Raju and Michelle Schneider. In July 2007 Julie Van Oosten completed the team.
15. The following notes set out the current team, work of Pave the Way, and some facts and learnings from the last six years.

The current Pave the Way team:

Jeremy Ward – full-time - team leader

Sharon Bourke – full-time - development worker

Catherine Raju – full-time – development worker

Julie Van Oosten - full-time – development worker

Michelle Schneider – 4 days / week – administration and support worker

The scope and focus of Pave the Way’s work with families:

- Queensland wide.
- Developmental approach – work with, not for families.
- Family support framework – part of Mamre.
- Focus on “family business”, not “service business”.
- Focus on importance of vision for now and the future, and how to plan to implement that vision.
- Focus on developing informal networks or support circles to safeguard vision and the individual with disability – “people keep people safe”.
- Not case workers or key workers.

Pave the Way offers families:

- Support to clarify a vision for a good life.
- Support for planning.
- Information sessions and workshops.
- Assistance to develop networks and circles of support.
- Information needed for planning, eg housing and legal information.
- Referrals to relevant professionals, eg solicitors.

Pave the Way information strategy:

- Website – www.pavetheway.org.au.
- Brochure “The Future Starts Now”.
- Quarterly newsletter.

- Booklets.
 - "Planning for Now, Tomorrow and the Future"
 - "From Dreams to Reality – Ideas and Strategies for Planning"
- Information Sheets.
 - Housing (published)
 - Preparing a Will (published)
 - Centrelink (published)
 - Employment / Funding (in preparation)
- Professional panel – information about experienced professionals.

Workshops and presentations:

- 2 hour presentation/discussion - "Planning for Now, Tomorrow and the Future".
- 2 hour presentation/discussion - "Building Lifelong Supports and Safeguards - Exploring Support Circles and Networks".
- 5 x 2 hour sessions – "Getting it Together, Working Together".
- 1 Day w/shop - "Planning for Now, Tomorrow and the Future".
- 1 Day w/shop - "Building Lifelong Supports and Safeguards - Exploring Support Circles and Networks".
- 2 Day w/shop (live-in) - "Developing a Vision and Plan".
- 6 Day w/shop (live-in) - "Visions to Action through Planning".

Individual Assistance to Families:

- Individual family consultations re planning issues.
 - developing a vision and plan
 - developing support circle or network
 - legal information
 - other information (eg, housing, Centrelink).
- Assistance with clarifying family's vision and planning – including facilitated planning sessions.
- Assistance with developing a support circle or network as long term safeguard - includes assisting family to find a circle facilitator and providing support to facilitator.

Safeguarding Strategies

- Convene regular meetings of circle facilitators.
- Research, analyse and develop ideas around safeguarding strategies.
 - individual to families
 - external to families/organisational, eg PLAN Canada or PIN Perth.
- Liaise with others involved in similar work.

Some Facts

- In last six years, Pave the Way has:
 - distributed approx 2000 copies of booklet “Planning for Now, Tomorrow and the Future”
 - developed and continued to refine the Pave the Way website
 - held 55 one day workshops - “Planning for Now, Tomorrow and the Future” (throughout Qld)
 - held 23 one day workshops - “Building Lifelong Supports and Safeguards – Exploring Support Circles and Networks” (throughout Qld)
 - held 3 two day live-in workshops: Samford, Yungaburra, Toowoomba
 - held 8 six day live-in workshops: Samford, Coolum (x4), Stanthorpe, Rockhampton, Townsville.
- Currently 940 families throughout Qld on mailing list.
- Currently working with approx 40 families, throughout Qld, facilitating or assisting them to develop support circles.
- Working regionally.
 - bi-monthly visits to Far North Qld and South West Qld
 - similar focus developing in North/Central Qld and Gold Coast.

How Pave the Way works with services

- Pave the Way invites services to:
 - provide information to families about Pave the Way (eg, mailing list, brochure, website)
 - suggest that families contact us if looking for assistance with future planning – families need to make contact themselves
 - ask us to provide presentations or workshops for families they support (or families of individuals the service supports)
 - support families to attend Pave the Way workshops (incl live-in).

What we have learnt

- Families everywhere have a deep seated fear of the future.
- Widespread interest in information/assistance around this issue.
- Widespread interest in Support Circles/networks but limited practice knowledge of how best to develop Support Circles.
- Widespread interest in legal issues relating to wills, trusts, guardianship, administration and in the need for competent, experienced solicitors to address the particular needs of families.
- This interest applies across families with family members of all age groups and disabilities.
- Many families with little or no funding are coming to workshops /presentations or seeking out information in other ways.
- Families respond positively to the involvement of parents as workshop presenters and facilitators.
- Families respond to these issues in different ways and take them up at a different pace – we need to work with families at their pace.
- Considerable interest in this issue among small services – few approaches from large non-government agencies.
- Qld Disability Sector Training Fund (through local training coalitions) has been very supportive and funded many of our 1 day presentations.
- Additional resources are needed to address this issue across Queensland.

Attachment D: Principal Documents Examined by the 2008 Evaluation Team

- Pave the Way Brochure.
- Succession Planning Funding Application.
- Innovative funding Application.
- Reference Group Minutes.
- Workshop Overview "From Vision To Action".
- Disability Sector Training Fund: Report on Pave the Way Workshops.
- Pave the Way 2008 Survey of Stakeholders Results.
- Raw Survey Responses: 2008 Survey.
- "Building Lifelong Safeguards": One day Workshop Evaluation Forms.
- Six Day Visioning and Planning Workshops: Value for and Impact On Families Report, May 2007.
- Pave the Way Vision and Values.
- Pave the Way Job Descriptions.
- Pave the Way Information:
 - Housing
 - Preparing A Will
 - Centrelink
 - From Dreams To Reality: Ideas and Strategies For Planning 2008
 - Employment
 - Transport Options For people With Disabilities
 - Tips for Budgeting
 - Money Tips For Families
 - Rent Assistance
 - Carer Business Discount Card
 - Extent of Website Resources: Discussion Topic.
- Pave the Way Newsletter: December 2006 through to September 2008.
- Pave the Way list of Solicitors, Accountants and Financial Planners.
- Pave the Way Team Minutes.

Attachment E: Pave the Way Vision and Values

Vision of Pave the Way

The vision of Pave the Way is that people all over Queensland who have a disability are supported and safeguarded by their family and others to have a good life now and in the future.

Pave the Way assists families and people with a disability to develop a vision for now and the future, to plan towards making that vision a reality, and to develop ways to safeguard that vision and individual when the family is no longer able to do so.

Pave the Way will contribute to achieving this vision by:

- assisting people to clarify their vision and plan
- providing relevant information (including legal)
- supporting people to develop further their strategies towards realising their vision
- assisting people to develop networks and support circles
- providing relevant ongoing support
- developing and supporting panels of relevant professionals
- providing workshops
- supporting local people to promote and develop their own community responses
- developing and documenting safeguarding strategies for people throughout Queensland
- contributing what we learn from Pave the Way statewide, nationally and internationally.

Values of Pave the Way

- the giftedness in all people
- people taking charge of their own lives
- reciprocity
- relationships
- community
- inclusiveness
- family
- contributing
- listening
- being with (not doing for)

- integrity
- openness
- respect
- simplicity
- humility
- peoples' histories
- learning
- diversity
- fidelity
- congruence
- creativity
- working it out/having a go
- vision
- meaningful lives.