

**Report to
Mamre Management Committee
and
Mamre Director**

**Research related to 'Hosting' a family governed or
community governed service for adults who have been
supported previously by Mamre**

**Trish Murdoch
31 May 2007**

*“And what is it to work with love? It is to charge
all things you fashion with a breath of your own
spirit.”*

Kahlil Gibran

Acknowledgements

Thanks are expressed to the people who contributed to this research. Their experience and insight is sincerely appreciated.

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- CRU, Brisbane
- Collective Action Group, Brisbane
- Homes West, Brisbane
- Real Living Options, Cairns
- Family Advocacy, Sydney
- Personalised Lifestyle Assistance project, Melbourne
- Melba Support Services, Melbourne
- One By One, Melbourne
- Living Distinctive Lives, Melbourne
- CCS, NZ
- My Place, WA
- Matthew and family and staff member, Sydney
- Getting A Life, Canberra

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Introduction

This research and report is a start to Mamre exploring the concepts of hosting and auspicing, and the concept of providing a new kind of support to adults known to Mamre. The report will not have all the answers, but will have plenty of guiding information for people to read, reflect upon, discuss and act upon. People have opinions about the concepts addressed in the report depending on where they sit in the picture, so to speak. Some common themes emerged throughout the project, as did some one off questions and insights. It is impossible to present every person's every thought or opinion in this report, but it is offered as an extensive collection of information and as a working document for those concerned with its outcome.

The Mamre Management Committee needs to consider this report along side of other reports such as Building Informal Networks and the Bravo auspice experience, and in context of the current operational plan.

It has been a pleasure doing this project. The empowerment in the young adults and families is palpable and it is clear they are on a forward mission. This is not without hard work though, as families have each had their share of dissatisfaction and even insulting dealings with some services, but have been buoyed by a completely different way with Mamre.

Everyone has been very generous with their time and information, and conversations have been thoughtful and provocative. People and organisations outside of Mamre have been very willing to be involved. They have in some instances provided written information that may be helpful, and have indicated a willingness to be of further assistance.

Summary

What was very clear during conversations for this research was that “Mamre” does not equal Mamre staff or committee. The community aspect of Mamre and the Mamre Charter were consistently talked about. Families spoke of their community membership, of giving and receiving. In many ways Mamre has already begun its work with adults, not just because of already doing some adult support, but by being a community and inviting people of any age into the community as equal members.

It is time for Mamre to reposition and clarify the work it does or does not do with adults. It is clear that Mamre wants to see young adults continue fulfilling lives and that young adults want good support and involvement in planning and choosing their own lives. Mamre staff and management members seek to make an informed decision.

There is a general openness to Mamre hosting or auspicing a response to young adults. There are only a few people who do not think Mamre should do this, especially in the long term. Most people think that Mamre should assist something new for adults to develop, without increasing the current structure and size of Mamre, and without deterring from Mamre’s current work of family support. There are several concerns. There is lack of clarity as to the details of hosting and auspicing. This research and report was commissioned to provide further information about all of the above.

There is a steadfast commitment evident amongst all staff and families to Mamre’s current role and a desire that this is not diminished in any way. Most people spoke of the importance of Mamre continuing to do the developmental work with families early, so that young adult alternatives might become clearer earlier and via more natural pathways.

There is no intention or desire by Mamre to attempt to meet all accommodation or post school needs, just as it doesn’t meet all family support needs that exist. It makes decisions about taking on new family support loads, as it can at the time of requests. In the same way, Mamre is considering how it can take on the request of young adult support. Mamre is clearly not looking for something new to do. It is responding to a demand which remains ‘in its face’.

Part of Mamre's passion about this is they do believe there are better ways of supporting adults and want to see the young people they've known develop good lives. People intuitively know Mamre could 'give it a go', but are asking if that means Mamre should give it a go?

Hosting has excellent potential for Mamre. There are some examples of well established hosting arrangements in Australia and elsewhere. These have been examined and are presented in this report. The host arrangement examples explored were all slightly different, impacted by where the initiative came from, what funding people had, what relationship people required of the host agency and what individual support arrangements looked like.

Therefore, the flexibility observed in the examples of the host arrangement concept in practice, would make this a definite possibility for Mamre to proceed with a response to young adults. However, Mamre needs to be reflective about the aspects presented in this report.

Mamre is in an informed position to continue this work because of long term relationships with families and young adults, and the experience and success with the recent support to adults. Mamre is in a good position to host, because it already does and understands individual funding and planning; it is a small organisation with a director who is involved at grass roots level; and it knows the families and young adults well.

As identified by several people, Mamre would need to remain very conscious of the differing aspects of this work to family support. It does not follow that just because Mamre is Mamre the work would happen effectively. There would need to be very intentional strategies developed and guidance from those known to Mamre who do adult support well.

Whilst there were several concerns or acknowledgments that Mamre is not yet experienced in the full gamut of adult lifestyle support, and that this is very different from family support, there is the willingness on Mamre's part to consult with people more experienced. It is presumed that in a Mamre hosted arrangement, a family support framework would be continued in any adult support initiative. Mamre is experienced and good at supporting families to vision and implement strategies. This is required regardless of the age of the person. Mamre is very skilled and well respected in family support. Mamre is well

linked in the community to identify excellent resources for assistance. It is also worth considering that there are many adult support organisations that are providing adult support services in a less than satisfactory manner, and that Mamre, even as a beginner (and recognizing this) has a very good chance of doing an excellent job!

Regarding a response to the request for adult support services, it would appear that Mamre has 3 choices:

- 1) refer people to existing services
- 2) expand Mamre significantly
- 3) assist in the creation of a new entity

Mamre knows that most existing services are providing segregated options for people and can undermine and dishonour the empowerment which families and young adults have developed. Mamre has indicated it does not want to expand significantly, so this leaves the option of assisting something new to develop.

Of course there are risks with any new venture and this would be no exception. It is hoped that this report will offer information to weigh up those risks and lead to a confident decision.

It is evident that for most people, this research conversation was the first opportunity to discuss the topic in depth. A broader opportunity for people to come together and talk would be appropriate in light of this report.

Mamre's considering hosting something innovative has arisen from the requested need for alternatives for young people, not a requested need for family governance. Family governance is likely to eventuate and could be encouraged as a very important part of keeping design and control of supports as close as possible to the person using them. Evidence that this process has begun is highlighted in the building informal networks report - *the changes in the people themselves and their willingness and ability to take more control over their own lives has been much greater than expected.*

In moving forward excellent attention to detail is required. In (external evaluation team member) Kevin Cock's words *Mamre must be clear about what is being done, why it is being done, who it is being done for and how it relates structurally to the governance of Mamre.*

Aim

This project was requested to:

- research the concept of 'hosting' and 'auspicing' – the real meaning and advantages and disadvantages for Mamre
- examine the different models available, including the more traditional models
- propose other models, if appropriate
- gain an understanding of the impact of 'hosting' or 'auspicing' on Mamre should Mamre decide to undertake either
- consult with agencies already engaged in hosting
- examine the current position of Mamre with regard to potential hosting
- consult with personnel engaged in the Bravo project
- write a full report with recommendations to the Director and Management Committee by 31 May 2007
- determine the resources that would be needed

Methodology

The methodology reflects the fact that this was a small project rather than an extensive quantitative data collection and analysis. Information was gathered by conversations in person, via phone and email; participation in two family governance group meetings in Melbourne; literature research, (though there is not much specifically on this subject); and reference to Mamre documents from review.

Invitations to respond to this project were extended. Some further people made contact as the project developed.

Mamre Staff: An invitation for one on one or small group discussions was emailed to all staff. 15 Mamre staff were interviewed.

Management Committee: All members were emailed an invitation to respond. 2 committee members were interviewed.

Families: It was decided not to contact all families, as the capacity of this project could not accommodate a large response, and it could easily raise false hopes or expectations in what is a preliminary phase. There had been extensive parent consultation in the Mamre review process last year. Parents who are part of the Building Informal Networks were sent a letter inviting them to respond if they wished. Parents who have been thinking about these issues were nominated and contacted. 15 parents were interviewed.

Young Adults: Young adults who are part of Building Informal Networks were sent a letter inviting a response. One young man responded. One young man was happy for his mother to respond for both of them. Another young man who is supported by Mamre wanted to contribute. Comments from young adults which were used in staff training earlier in the year have been considered. 2 young adults were interviewed.

External Review Team members were emailed and asked for their reflections on 2 questions. 2 people emailed a response and 2 people had phone conversations.

Contact was made with several organisations and agencies where examples of hosting are in operation. These will be illustrated shortly in this report. Visits to Melbourne and Sydney were very useful. Phone calls to Canberra, Perth, Sydney, Cairns and New Zealand were also very helpful, as were local conversations in Brisbane.

Contact was made with 4 people who have been in the disability field a long time and are known to Mamre as innovative thinkers, allies and critical friends.

Papers by Michael Kendrick were examined, in particular one which documents hosting arrangements in Massachusetts. Email contact with Michael was also very helpful.

Where the Issue Has Emerged From

Hosting or Auspicing

The consideration of the concepts of host arrangements or auspice arrangements have emerged for Mamre from a desire to make some response to the young adults' needs in a climate of little innovation happening in the sector. Mamre has had a successful auspice arrangement with Bravo, bringing with it some valued lessons. The concepts were signalled in the 2006 review paper presented to Mamre from Michael Kendrick. Recommendation 10 reads *Mamre should continue to explore and expand its hosting role, particularly for innovative projects that show evidence of being able to eventually be self-sustaining*. It is also known that hosting arrangements are successfully in place elsewhere.

Supporting Adults

This is not a sudden emergence. It has been around since before Building Informal Networks, as workers listened to families whose sons and daughters were moving into new phases. The idea of supporting adults hasn't only emerged but it has happened for Mamre. Young people and families approached Mamre. Other families have seen the success for some young people and want to have the opportunity too. It has given families confidence to give something a go for their son or daughter. This response has catapulted Mamre to a next level of asking what can happen next. Mamre's way of listening to what families do and don't want, has seen Mamre inviting families to come together to reflect on the future. Not all families express their concern for the future by asking Mamre to do something, but they are worried and they see little 'out there' to continue the good life approach Mamre has supported them with. Several families and adults have asked Mamre directly to develop ongoing responses in the areas of moving out of home and/or finding a good life after school years. Some

families want Mamre to show them how to do it, and others want Mamre to be very involved, and some families have not thought as far as asking Mamre anything.

Mamre is well aware of the need in Brisbane for different support arrangements for young adults than what is currently available. Mamre therefore is looking at its capacity to contribute to the development of something innovative.

Trust was a well used word in the conversations for this project. This trust is an excellent base from which Mamre could extend families' own trust in themselves to be innovators and governors, whilst being alongside them somehow in the adult years of their son or daughter. Families and adults trust Mamre enormously because of their experience of being part of Mamre and in a partnership with Mamre. Families and young people have confidence in Mamre. This is a credit to Mamre, though not surprising because of the values on which it operates, and as Michael Kendrick wrote in the evaluation report, the extent to which the values are actually lived. This long term partnership relationship has contributed to the young adults being able to say what they need. Young people experience services that do not offer the individual respect and response that Mamre has done for most of their lives. This dignity and respect has empowered the young people to know that they want this in an ongoing way.

It is 4 years since Building Informal Networks began. Mamre made a staff member available half time to experiment and walk with people in the request to move out of home. It could be argued that Mamre has a moral responsibility, having been part of developing something new for people, to see people to a next stage, as nothing stays stagnant. Those young people who have been part of Building Informal Networks are not the only young people or families who have approached Mamre or who would like Mamre to be part of their adult lives.

Current Political Climate

A brief reflection on the political climate surrounding disability service delivery would be beneficial. There is pressure on large services to get even bigger with most money going towards adult packages and not new service development. There are few services for people who receive funding to actually access. There seems to be a governmental resurgence in the support of group accommodation. There is minimal pro-active planning within the 'content free management' model within

DSQ. DSQ appears to be more supportive of large established organisations than small, particularly innovative agencies – this might make hosting arrangements appealing to them, as a new initiative would be linked to a strong existing service. The Victorian government affirms hosting because costly administrative structures are not duplicated in multiple small services.

Some Terms Explained

Auspice

‘Auspicing’ or ‘auspice’ has a few meanings in different contexts, but for the purpose of this project the local history in the disability arena has been examined. The term ‘auspice’ is used in DSQ agreements to identify which agency is receiving individual funding on behalf of those funded.

In a wider context, an auspice refers to an arrangement whereby one existing organisation assists a new one to get started. During the agreed auspice period, the auspice agency takes on the administration, financial and legal dimensions, and provides mentoring and assistance in the set up of the new agency. Auspice is a short term arrangement. The new agency becomes a completely autonomous, separate incorporated legal entity.

Brisbane and Qld has a strong history with successful auspice arrangements. There are at least these examples. QPPD auspiced QAI and CRU many years ago; CRU recently auspiced Workscope. Most recently, Mamre auspiced Bravo in Gympie. Mamre some years ago began a third house called Manuka in Toowoomba. It was subsequently realised that its own local management and governance would be more appropriate. Whilst this was not an auspice arrangement, it was a similar involvement on Mamre’s part.

Given that Mamre has recently auspiced Bravo and the full experience and learning from this will be documented in a separate report, and that these examples are quite clear as to what ‘auspice’ means in Qld, the rest of this report will address hosting. Auspicing will be referred to again in the section on advantages and disadvantages.

Hosting

'Hosting' or a 'Host Arrangement' refer to an arrangement whereby one existing organisation assists an individual or collective of people to develop responses, by entering into an ongoing relationship. The new initiative is not incorporated, hence the need for ongoing 'hosting'. It receives funding which is transferred from the funding body to the host agency who takes on the legal and fiscal roles required, and is a buffer between the project and the bureaucracy. This bureaucratic buffering is often referred to as a 'bureaucratic shield' or a 'firewall'. The decision making and support arrangements are governed by the individuals or families involved – they are not part of that host agency's service. The host agency delegates this authority to the initiative. The hosted entity is a semi-autonomous body because of this delegated authority. Host arrangements are intended to be long term. The hosted entity does not need to have the same core business as the host agency, but some alignment with values and philosophy is enormously helpful.

At its most basic description it is this – a project has funding and then invites an established agency to "host" that funding for them. The project purchases admin and legal services from the host agency, whilst retaining decision making about most things via delegation from the host agency. The host agency provides a buffer from the bureaucracy of the funding body.

We could think for a moment in our human social context about the notion of being a host. When we host, we welcome someone as a guest into our home or gathering place; we share resources such as food and wine, accommodation, information; we offer hospitality and friendship and laughter. Someone else benefits from our resources, and we enjoy that. We can think about the Mamre Host Family program. One family invites a person from another family to be their guest and come and stay with them and share their home and resources. The Sunshine Coast Family Networks recently advertised for host workers. The add read .. *the Host Support Worker will need to offer a supporting, secure and stimulating environment*. These social contexts can give us insight into the use of the term 'host' arrangements.

Exploring the Notion of Host Arrangements

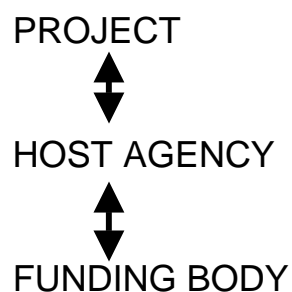
The purpose of a host arrangement is for a group or individual to create individual, natural supports in peoples' lives, while not dealing with the administrative and bureaucratic aspects of being an incorporated service. Hosting is supporting the vision and arrangements developed at the individual level.

For the host agency, hosting is a way of supporting new initiatives and expanding the availability of needed options for people without itself directly running projects. (Mamre review report)

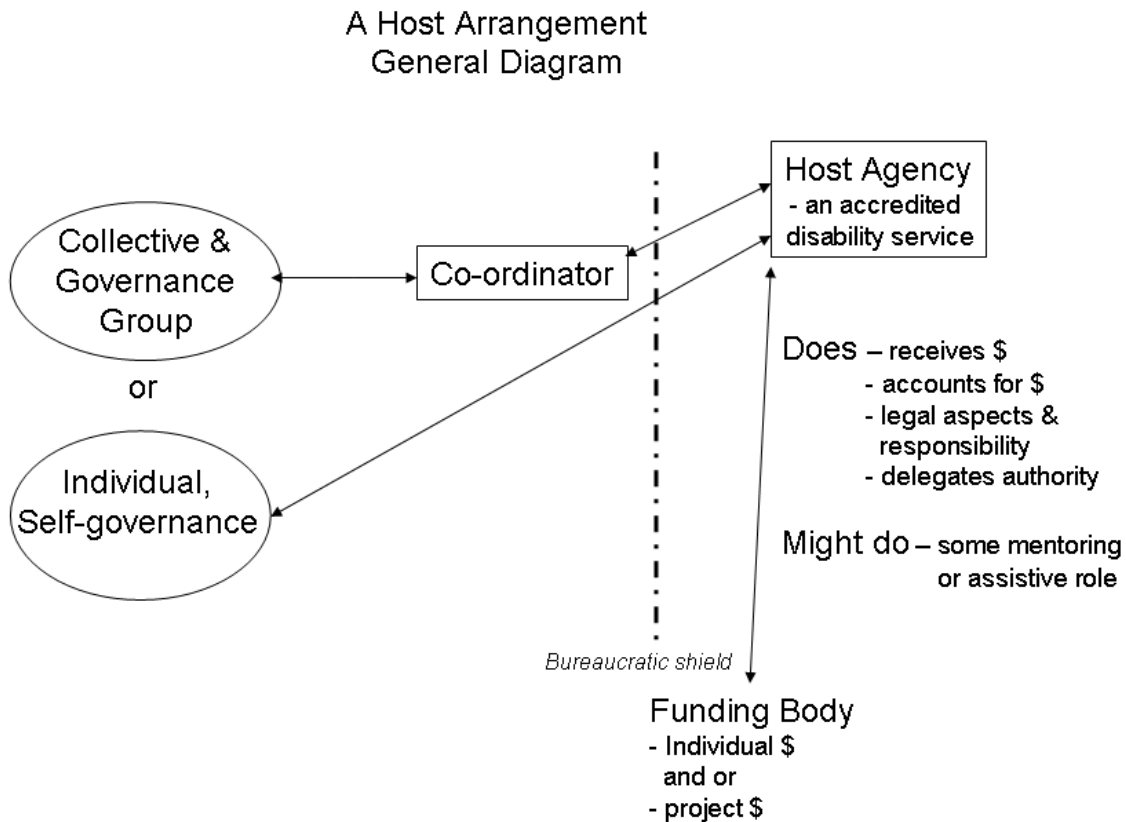
“Semi-autonomous” is a term used by Michael Kendrick in his paper about host arrangements in Massachusetts. The hosted entity is semi-autonomous because it governs its vision and activities but is not a legal entity in its own right, so cannot be completely autonomous.

There are 3 main parties in a host arrangement. There is an individual or a collective of people (could be called a project) with a vision and goals, a host agency and a funding body.

The following diagram is a basic illustration of hosting:



A more detailed diagram of host arrangements is illustrated below:



In all the examples except NZ, the host agency was approached to consider this. The approach was from either an individual or a collective of people. Groups of interested persons (some groups are parents; some groups are individuals with disability and allies) formed small organisations with a vision and purpose. They then looked for an established organisation to become the host agency, and entered into a host arrangement with an agreement.

Note:

In Mamre's situation, individual needs have arisen and Mamre is brainstorming an ongoing response, including imagining itself as a host agency for something new – the initiative for hosting, if that is what happens, is actually coming from Mamre. Mamre will need to be very aware of this and find ways to put the initiative back with families and adults. Many comments were made, especially by people already involved in hosting, to be very cautious of a top down approach. Perhaps Mamre would do well to ask families and adults to bring their requests to Mamre for consideration.

Most people involved in host arrangements, including directors and families have been encouraging and have said things like *go for it, this isn't rocket science so there should be more of it; this is easy when it is set up well; for little host agency work there is enormous individual outcomes; it is quite a small output and risk for a big gain for people.*

Examples of Host Arrangements

Several examples of host arrangements are detailed in this section of the report. After the examples there is a section which looks at the details of host arrangements and the vulnerabilities. The most examples of host arrangements are in Melbourne and having visited Melbourne and having spoken with those involved from both sides the examples begin here. Having had the opportunity to converse with the host agency executive director and business manager, the detailed explanations of how the arrangements work are taken primarily from the Melbourne examples. The Victorian story is quite detailed to give readers an understanding of the emergence and possibilities of host arrangements.

Examples 1-7 Victoria

There is much to be learned from the Victorian experience, most significantly that hosting didn't 'just happen', but was in response to ideas and needs. The evolution is outlined below:

2002

Interest developing around establishment of support options which were more personalized, typical, and influenced by the people themselves. Deb Rouget and Michael Kendrick toured Victoria (funded by Dept Human Services). It became apparent that even though people wanted personalised options, they had difficulty imagining these options, and were unsure of where to begin or how to do it.

2003

Proposal for a small assistive project to help people create such options was submitted. Personalised Lifestyle Assistance (PLA) began. PLA is a very small committee with Deb Rouget as a 20hr per week Project Facilitator. The PLA project works with individuals and families to develop the following: lifestyle options that are natural, typical, and one person at a time responses; influence and self determination over their own lifestyle; the opportunity to govern their own project/arrangements; and sustainability.

Several grass roots projects developed. Some are individual and some are collectives of individuals with similar hopes and vision for an individual life. Whilst being an active and supportive member of the collectives, each family focuses on their son or daughter's lifestyle and vision, and no two people with disability share activities, resources or support workers. Each project operates from its own set of principles developed by those involved, with the assistance of Deb Rouget from the PLA project. These principles are identified as absolutely critical. Most of these grass roots projects use a host arrangement. This allows them to be self governing and responsible for most things, but relieved of the fiscal and legal administration and responsibility. This concept interested families greatly, and families expressed relief and satisfaction with it. To date, people have not wanted an auspice arrangement.

'03, '04, '05, '06 '07

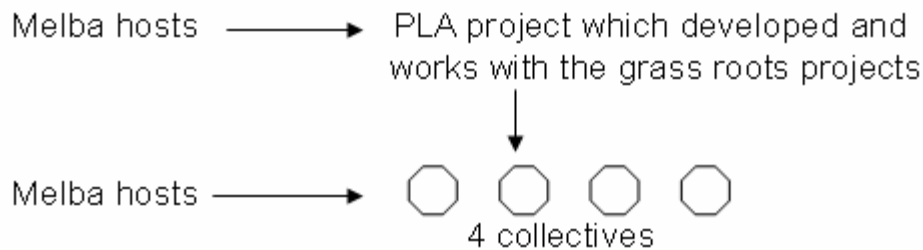
Many small gatherings of families, much visioning, principle development, proposals and submissions and changes in peoples lives was happening in many places. Several collectives came to fruition. The names and descriptions of these projects are in the diagrams which follow shortly.

During this time there were two examples of host arrangements not working, and the collectives needing to find a new host agency. There was also one example of the PLA project withdrawing from one collective, because of a different direction emerging. That collective continued its host arrangement.

2007

Because of being approached by these grass roots projects one at a time, Melba Support Services in outer eastern Melbourne is now the host agency for 5 small collective projects. Melba is a medium sized traditional disability service, whose core business is group homes and adult day services for approx 110 people. At the time of being approached to take on the host agency role, Melba had made a decision not to expand, but rather concentrate on how to improve its existing services. However, Melba was interested by the principles of the PLA project and agreed to support a new venture while knowing that Melba did not own or initiate the project.

Melba hosts the PLA project whose facilitator (assistive role) works with the other grass roots projects which Melba also hosts.



As well as hosting the semi-autonomous projects, Melba Support Services have an internal program called Individual Support Arrangements (ISA's). This is a new approach for Melba, as traditional services of group homes and day services are its core business. The full time manager employed by and located in Melba, oversees 1 self governed arrangement and 8 family governed arrangements. Melba hosts the funding for these 9 people, charging a 10% admin fee. Then there are 5 further individual arrangements predominantly managed by Melba, at the family's request, in consultation with the person and family, charging a 20% admin and management fee. In addition to these 14 arrangements, 8 people are waiting or have expressed interest.

Impact on Melba:

- a) 5 collective projects – about 25 individuals
Additional staff – part time accounts; part time pay roll
Fee for service – 10%
- b) Internal (ISA's) 14 individual arrangements
Full time manager
Fee for service – 10% - 20%

To recap an understanding of hosting, recall the earlier basic diagram of a host arrangement. An initiative wants to begin and implement some individual support arrangements with its funding. It approaches a host agency from which it can purchase admin and finance services, thus having the relief of that buffer.

A right brain way of looking at it: use your poetic reading skills for this.

“Said the Project to the Host” (by Trish)

Said the project to the host:
*We see with dollars and laws you coast,
and for us, all that is ... most.,
..boring, confusing, alarming, nightmarish,
oohhh, ... I feel I've seen a ghost!*

*So may we buy **your** skills please?
so we can get on and use **our** skills, jeeze!!
Of dreaming, imagining, safeguarding, creating and
finding one's natural place ...with ease.*

*And of what we've achieved,
and how you've relieved,
throughout Australia and the world
we'll be well perceived.*

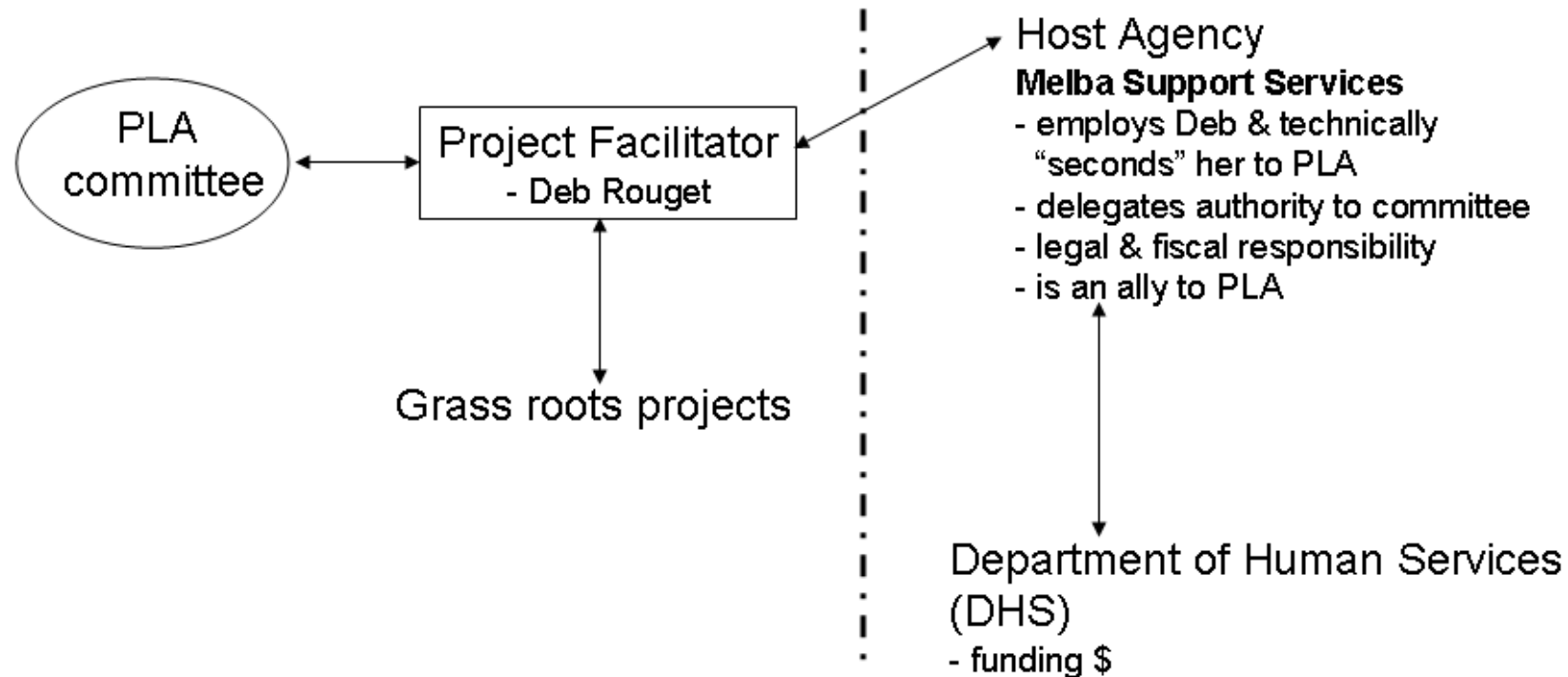
And people will say what a wonderful way
to team up and have a say
about where to live and how to live
and build confidence and give!

ooooooooooooOoooooooooooo

More seriously, following are diagrams of 5 examples illustrating the various hosted arrangements in Melbourne. These diagrams are adapted from a diagram used by The Collective Action Group in Brisbane.

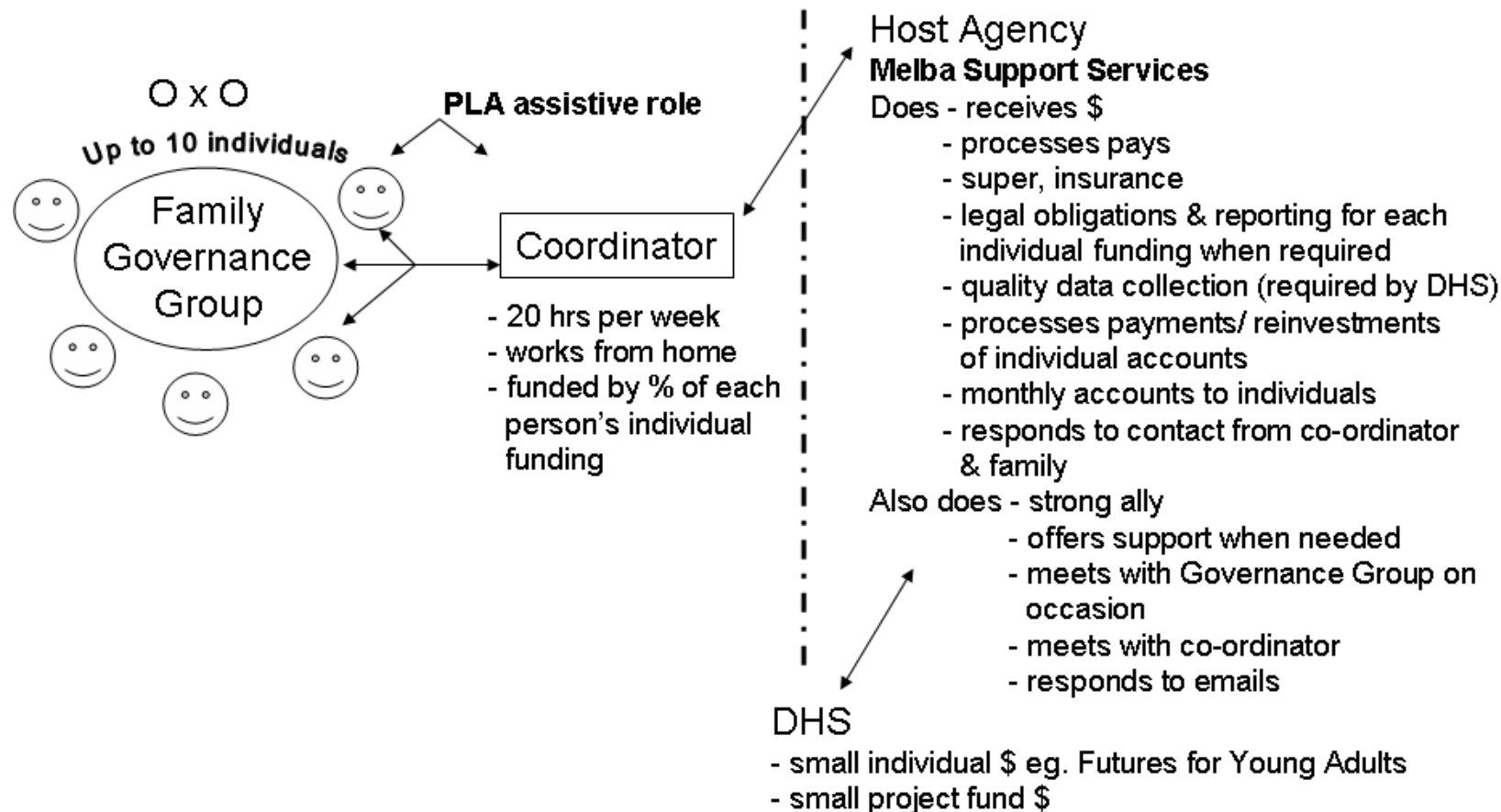
(Victoria) *Personalised Lifestyle Assistance Project (PLA)*
Host Arrangement

Throughout Victoria, PLA supports the development of small individual grass roots projects, designed created & governed by the people who use them. It assists with vision, planning, submissions, principles, agreements, ongoing guidance, evaluation & renewal. PLA also supports the project members to present at conferences etc. PLA started in 02/03



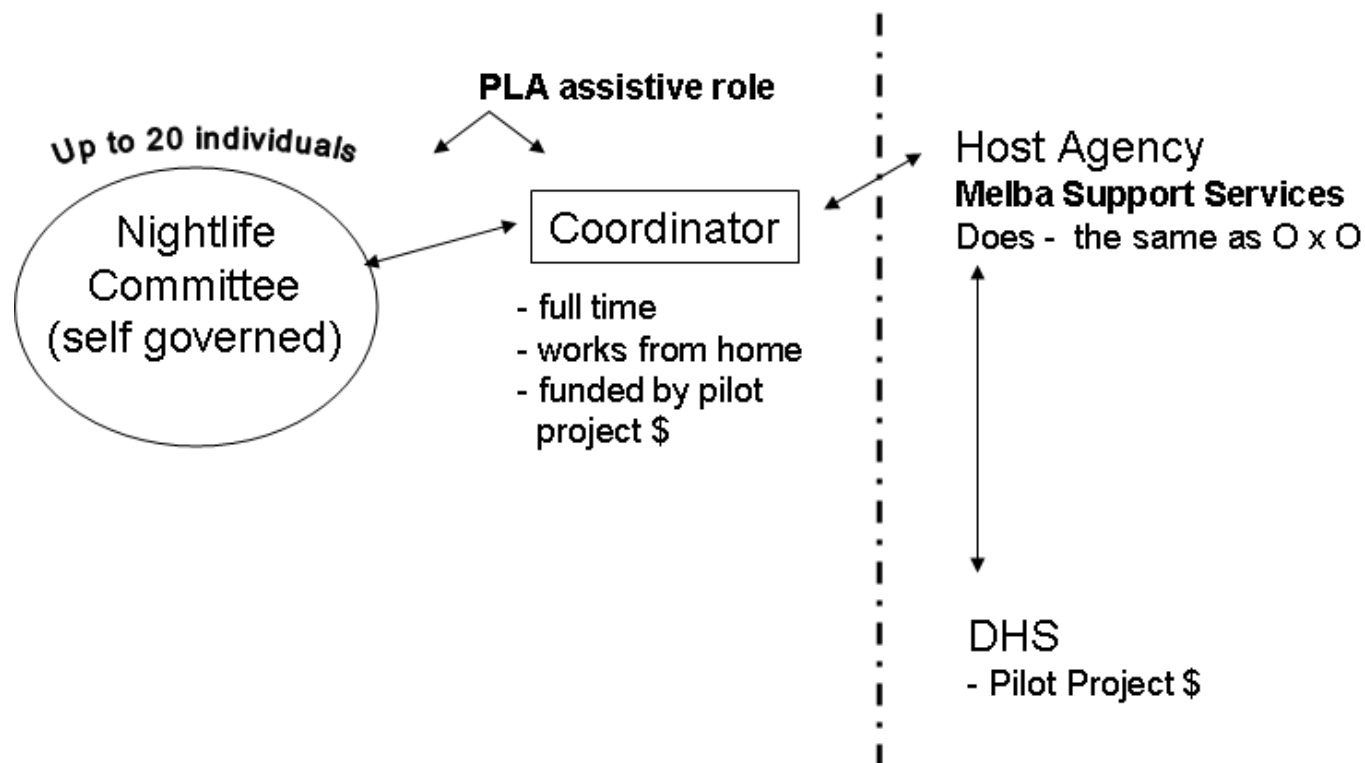
(Melbourne) *One by One* (O x O)
Host Arrangement

One by One started in 02/03. It creates highly tailored personalised support arrangements around each of their daughters so they can follow natural pathways eg. work, recreate, study and friendships in the community. It supports people as individuals rather than members of a group.



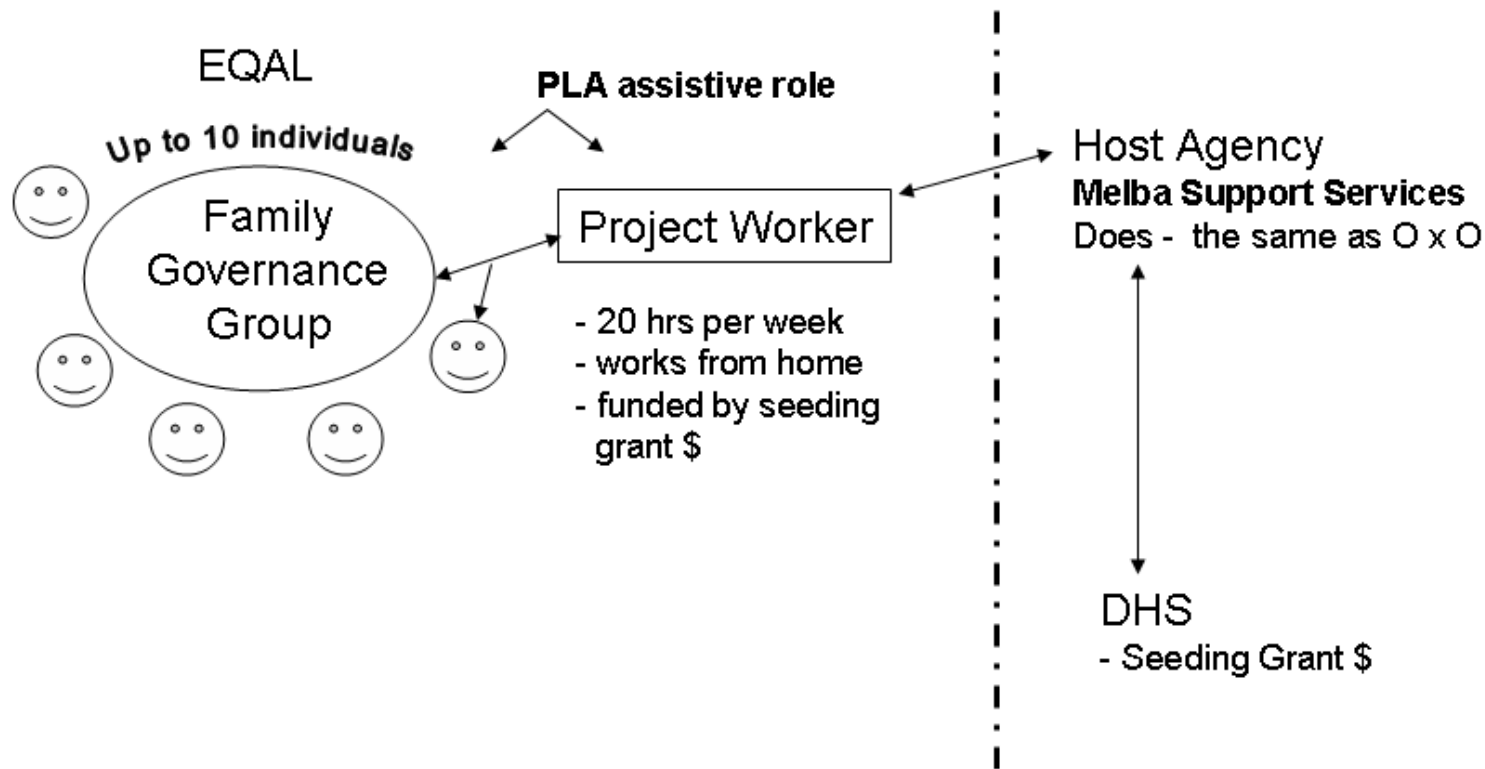
(Melbourne) *NightLife* Host Arrangement

NightLife aims to provide a flexible night time service for people with physical disabilities living in their own homes. People supported by *NightLife* will be able to ring mobile support workers and obtain support between 8pm – 6am, 7 days per week, 52 weeks of the year, without pre-booking support. Support will be varied and could be called upon several times per night. Support will be for brief periods of ½ hr so the mobile support workers are available to others. *NightLife* began in 06.



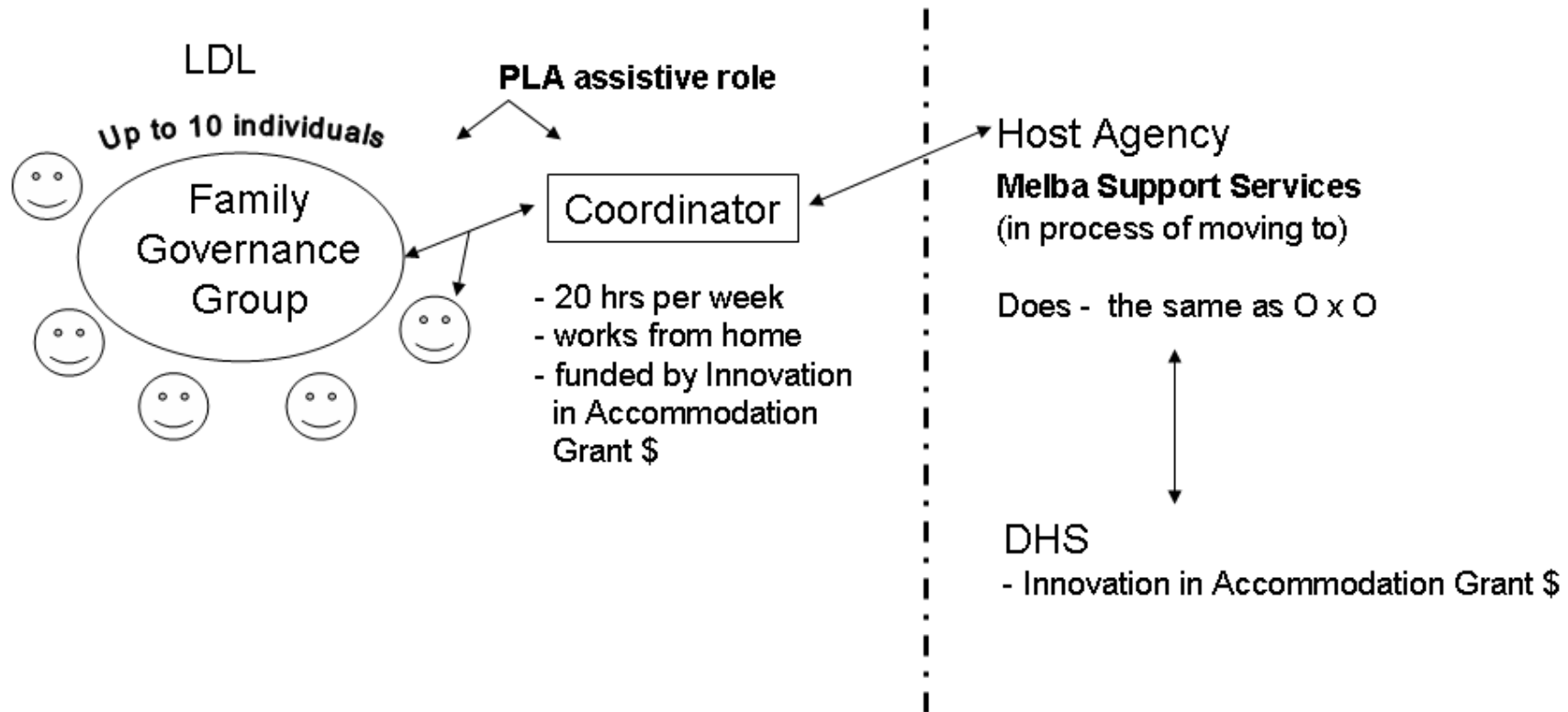
(Melbourne) EQAL – *Empowerment of Quality Active Lifestyles*
Host Arrangement

EQAL was designed to identify & facilitate uniquely tailored business, lifestyle & social opportunities in the community around each person supported & their unique passions and abilities. It was initiated by two families whose sons have quite complex needs. EQAL began in 05.



(Melbourne) LDL – *Living Distinct Lives*
Host Arrangement

Living Distinct Lives families are each building their own visions for a good life for their son or daughter, including moving into their own place & pursuing a unique lifestyle in the community.
In 05 families began by establishing circles of support around their sons & daughters.



Example 8 Brisbane

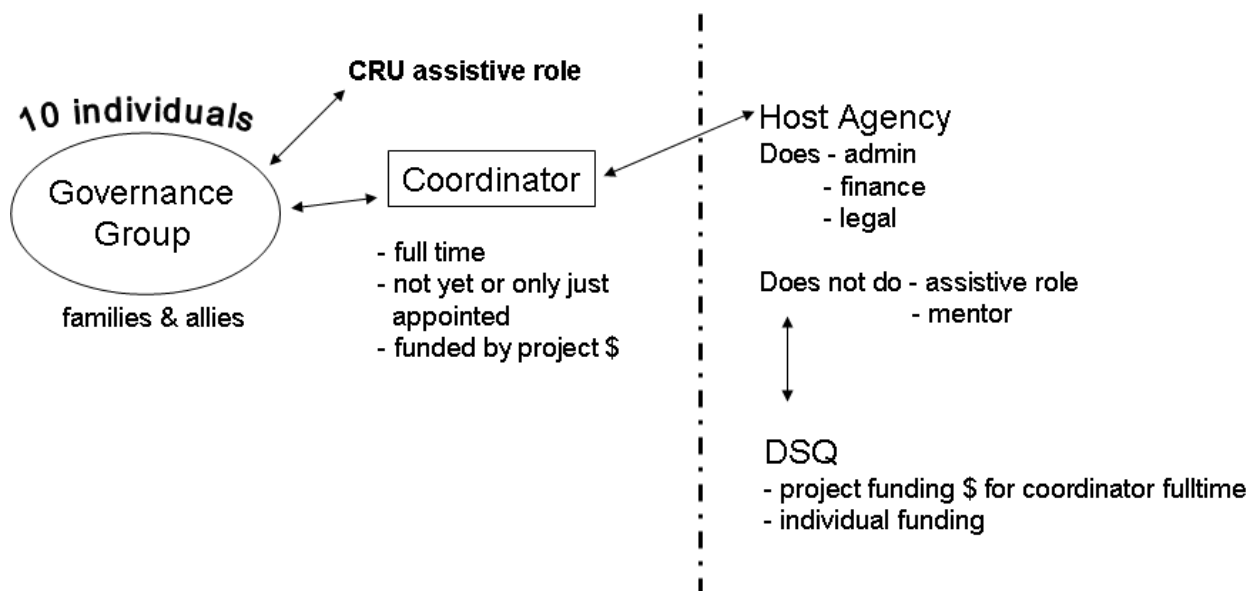
The Collective Action Group

A group of adults with disability, some family members and some friends have been meeting for about 3yrs to look at developing individual arrangements to get good lives. A collective of 10 people emerged. They have very recently entered into a host arrangement. The host agency has a different core business to the Collective Action Group, and is not involved in mentoring or visioning. The collective has made a conscious decision to keep this role separate to its relationship with the host agency. CRU has been supporting the group with this role. In May 07 the collective received funding for a coordinator position. The governance group drives and directs the project and will direct the coordinator. The coordinator will know each person and will coordinate the implementation of their visions.

Impact on host agency:
unknown

(Brisbane) *Collective Action Group*

The *Collective Action Group* is a network of 10 adults & their family and friends, ensuring the vision & values of a good life are supported in practice. Most of the people have experienced disappointing services.



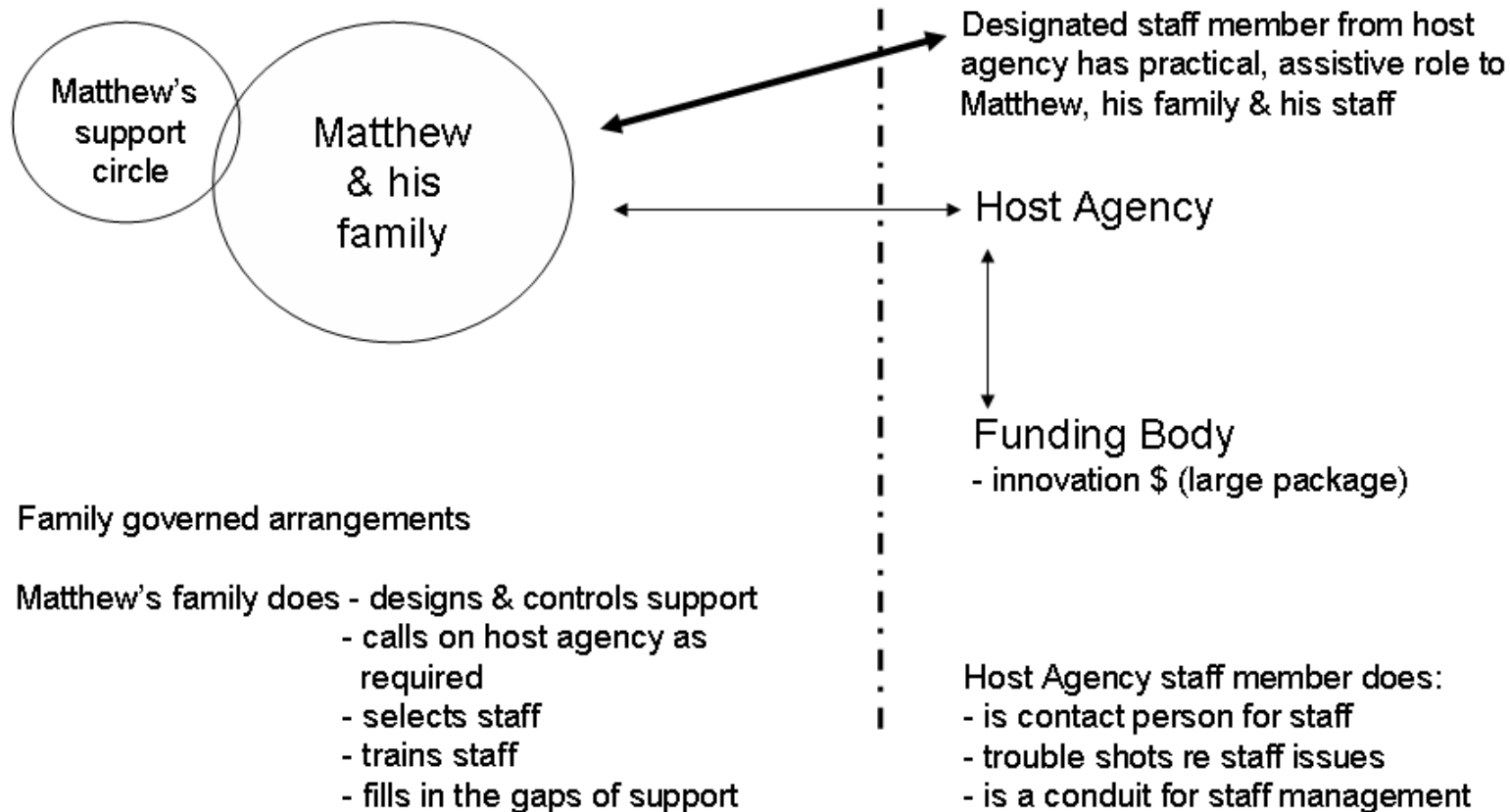
Example 9 Sydney

Matthew lives in his own home in Sydney. Matthew is a man in his 30's who has very high support needs, including support around his autism. Matthew's supported living is highly individualised. His day time involvements are yet to become individualised. His family was unaware of 'host arrangements', but they knew they wanted a better life for Matthew and they wanted to design it and control it with Matthew. They knew they did not want the task of beginning a new incorporated service. They asked an organisation to work with them. This worked for a couple of years before dissolving due to policies and procedure getting in the way after the departure of significant staff in the host agency. Matthew now has a new host arrangement in place since Jan 06. The core business of the host agency is day services and group homes. This is the only host arrangement they have, but are open to more. Given the breakdown of one previous host arrangement, Matthew's family has begun the process of asking exactly where Matthew sits within the organisation.

Matthew has a significant funding package and a large number of support hours per week and 4-5 part time support staff. These are Matthew's staff and they do not work in the host agency programs. His family has chosen to request a strong assistive role from the host agency, though the family is in control of how and when the agency comes into their lives. The agency contact person supports the family with staff management and keeping the support arrangements going. The written agreement is always used as a reference point when there are things to be worked out. The vision for and safeguarding of Matthew's life happens within his support circle. The liaison person within the host agency manages support for several people within the agency's traditional services. The time commitment for Matthew's arrangement is not more than for others, it is just done differently and more flexibly. The liaison person expressed that it is a shame that Matthew's arrangement stands out and is seen as so irregular, when in fact it is so achievable and it should be more accessible to more people. Following is a diagram of Matthew's host arrangement.

Impact on host agency:
Admin for 1 host arrangement
Staff member's time
Fee for service – not known

(Sydney) Matthew's Individual Host Arrangement
 (there is a strong supportive role from the Host Agency)



Example 10 New Zealand

CCS is a medium sized NGO which offers family support and adult support services to approx 700 families throughout NZ. It is a national body operating in regions. It has a long history and in more recent years has emerged into a service which aims for individual responses to need. Host arrangements in CCS Waikato region were researched.

Hosting arrangements have been in place for 5yrs. This emerged because people were unhappy with their fragmented funding and dissatisfied with available services. After thinking and talking amongst those wanting support and the agency, it was decided to try hosting as a way of supporting people to design and manage the support they needed. Currently 14 families/individuals have their packages hosted by CCS. CCS will increase this to approx 20 host arrangements as needed. There are no collectives hosted by CCS.

The host arrangements are supported within the existing structure even though there is no spare capacity. The only increase in capacity has been a result of other program growth in the 5yrs. That is, with additional staff for other projects, the hosting arrangements can be carried. This has been a decision so that CCS can contribute to innovative responses, and demonstrate the success of these by the improved outcomes for the people involved. Another decision was to keep cost low for the individuals to assist them with better outcomes. There is a small fee for administration of 3% which CCS estimated was the cost for the admin/finance/payroll component. It does not cover any general organisational overheads or indirect organisational costs for example the time of regional coordinator.

Many of the key features are similar to those named in the Melbourne examples. Additional features are:

- the written negotiated agreement is only about 5-6 pages long, unlike the Melbourne and Brisbane example. CCS see the relationship more as a moral one than a legal one.
- each host arrangement is different. Some need more contact than others. Some have very little contact with host agency.
- there is an active contact person within host agency (the supported living senior coordinator) who assists the person and coordinator with troubleshooting and relief staff
- each arrangement has a coordinator role located with the arrangement not CCS, either paid or a family member
- the hosting arrangements are done around other work for CCS staff, and this at times can stretch the agency staff

Impact on CCS:

14 individual arrangements – admin costs

No additional staff as arrangements are ‘absorbed’

Fee for service – 3%

Example 11 Canberra

Getting A Life is a small family governed arrangement set up by three families to support their sons to have a good life in the community. Jackson, one of the young men is 20yrs old and lives with his family. He loves doing many things, and he also happens to have very high support needs requiring one-on-one assistance all his waking hours. Based on Jackson’s interests, and supported by a circle of support, he has a plan, and now has a business. His business is a PO Box mail pick-up and delivery service. His support worker will be the driver of the van. Jackson has met other small business owners via his business.

Getting A Life is the small structure which supports Jackson’s family and the other two families with their vision and implementation of their plans. One of the men has individual funding and Jackson’s business has some funding. The project has very small funding to employ a coordinator for 7.5hrs per week. This role supports the families’ initiatives. *Getting A Life* chose a host arrangement to avoid a layer of complexity of incorporation that they felt they could do without, and so put their energies into developing alternative responses to the existing segregated services. Other than the hosted finances and administration, they require very little contact or support with their sons’ arrangements from the host agency.

Impact on host agency:

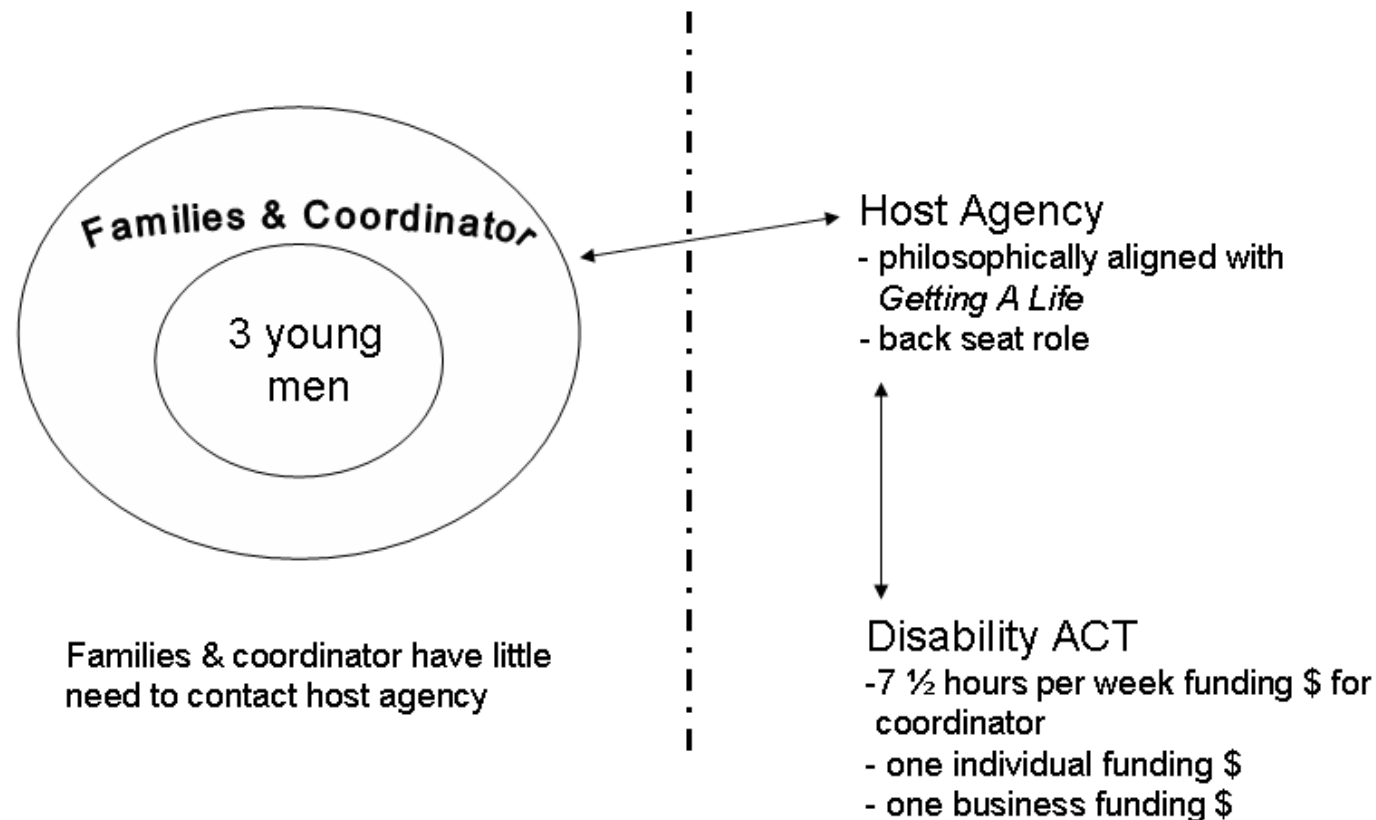
One collective with 3 individual arrangements

Little contact with host agency

Fee for service – 20%

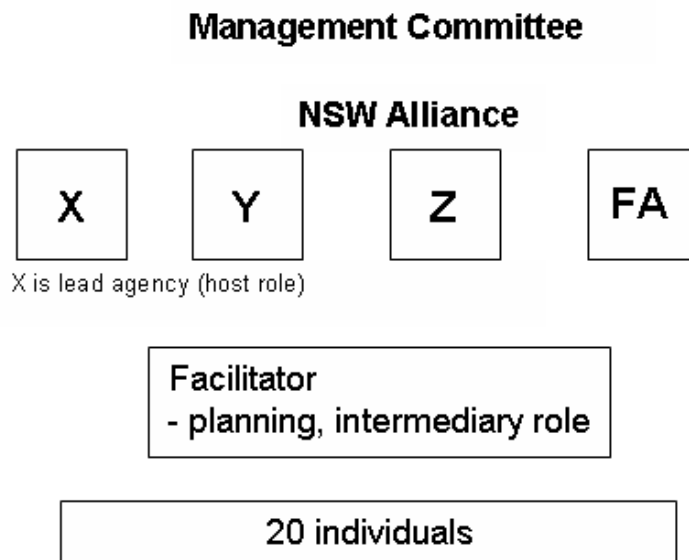
(Canberra) *Getting a Life*
Host Arrangement

Getting a Life is a family governed project, to support three young men in developing real lives in their local community. It began in 05.



Example 12 Sydney

This is an interesting response to post school services in NSW. This example was initiated by Family Advocacy in Sydney. Family Advocacy has joined with 3 service providers to form an alliance called *The NSW Alliance for Self-Management*. They formed the alliance to tender for the Self Managed Packages, one of 3 funding streams in the Community Participation Program. This is an entitlement program for young people with disability who are considered not to be able to work. The alliance will be an intermediary, not a service provider, to support individuals who choose to self manage their funding and future. Individuals will be asked to put in an expression of interest, and the process will proceed from there. The following illustrates the concept.



Principles of

- individual, natural community arrangements
- self management of support arrangement

Funding \$

- the Alliance receives set-up \$ for promotion and facilitator for 1yr
- individual packages between \$20k - \$50k, of which the Alliance takes 12% for their intermediary service

Impact on agencies - other resources needed.

Each of the 4 agencies will make contributions within their capacity eg printing brochures; willingness to second a staff member for

development period; admin hours; the lead agency will host the funding etc.

Considerations for Family Advocacy

Of particular interest to Mamre, Family Advocacy had to seriously consider if this fitted within their purview of family advocacy.

Recognising the limitations in current service provision, they decided to move on this idea because it was a project which enhances a goal in their strategic plan. The goal was *Family Advocacy will strengthen families to develop and negotiate alternatives to current service practice consistent with building positive social roles for people with developmental disability.*

This model is very interesting and it would be good to follow the progress. Perhaps it highlights the fact that Mamre may have an opportunity to implement some similar outcomes for people in quite a simple way because of the existing community and potential ability to host.

Example 13 USA

Michael Kendrick documents hosting arrangements (as they have been explained earlier) in his paper *Family Governed Flexible Family Support: The Massachusetts Small Project Example*. A pilot project in the early 1990's led to the development of about 50 small grass roots projects, serving probably thousands of families in some way. These are now 10 – 15 yrs old and are sustaining themselves exceptionally well. The overriding principle is that these projects do not provide a 'fixed' or pre-determined menu of services, but that the support offered is defined by the people served. Virtually nothing is excluded from the category of family support if that is how families define it.

The families grouped in various ways, some thoughtfully, some casually, but usually there was some form of facilitation available as support. In Michael's words, the host agency acted legally as the designated agency funded to provide family support, but did so via the mechanism of a family governed project. The projects had to abide with all state imposed obligations on service providers. The projects have over the years, identified a vulnerability about possibly being very slowly reconverted back into the traditional systems.

Example 14 Western Australia

This example is not a host arrangement example, but has been named briefly because it is another way of people receiving individualised supports and may want to be examined by Mamre at a further date. *My Place* was incorporated in 1996 as a response to the growing need for personalised support. It supports approx 120 adults with disability to live in the community. 30 of these people have chosen to self manage their arrangements by forming, in effect an 'individual agency' which is registered with the ATO and the Disability Services Commission. Their funding is received by My Place, who charges a 15% fee to do the administration side of their business. Whilst the individual governs their own arrangements, My Place is available for support.

Resources required:

My Place indicated that the dedicated staff required to do the details of these arrangements was approx 1.25 full time equivalent. This would be almost split between admin and finance, and a coordination role. They could add approximately 10 more arrangements before needing new staff.

Some Insights from These Examples

- Melbourne families only knew this was possible by being inspired and presented with info via the gatherings with Michael Kendrick and Deb Rouget (initial resource role).
- This resource role has been critical especially in the development phases
- There are some differing thoughts on where an initial or ongoing resource role should be located – Michael is of the opinion that it could be located within the host agency if it has been requested by those being hosted, if the right relationships are in operation, if the new group is confident in its autonomy, and if the host agency genuinely does this as support and not in any control way. Others are more certain that it is a good safeguard to keep this resource role as independent as possible, therefore not from within the host agency.
- The examples where the host agency plays an assistive role eg Matthew in Sydney, it is noted the agency is a structure which deals with those needs every day, even though it is in a traditional service context. That is, they work with adult support in supported accommodation 24hrs per day, and have the experience in staff issues.

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- The amount of funding affects the details of a host arrangement
 - Time and lots of it was a really important part of developing the arrangements
 - The written agreement with the host agency board is critical
 - Family self governance was very important to all involved

What a Host Arrangement Relationship Can Look Like

Each host arrangement is negotiated individually, so there is likely to be small differences in each agreement. There is the flexibility for the relationship to be clearly negotiated from the outset. The important thing is having the principles and working details out in line with these. A written agreement is developed and signed. This agreement outlines clearly who is responsible for what. (One By One in Melbourne) has agreed to make this agreement available for people to read. Some projects have very little contact with the host agency and what contact they do have is mostly done via their coordinator; some projects want the host agency to have a small supportive role in understanding some organisational issues; some projects may want a small amount of mentoring from the host agency; some projects will want a larger amount of mentoring and visioning assistance from the host agency; and some projects will seek a strong involvement of a host agency contact person. An example of a strong involvement of the host agency is Example 9, Matthew's arrangement.

The following outlines the roles and responsibilities in a host arrangement.

The Project/Initiative will: (examples)

- choose what to spend their money on
- choose and manage coordinators and support workers
- develop and manage support arrangements for person
- decide who comes into the project
- develop vision, direction and principles
- develop specific policies if needed
- focus on their family member getting a good life in the local community
- form a governance group

The Host Agency will: (examples)

(Melba Support Services in this example)

- receive the funding on the project's behalf
- account for the funding separately
- arrange that all concerned are covered by insurances
- employ staff, but delegate selection and management (staff do not work in the Melba service) Melba does not allow families to employ workers. The NZ example does allow individuals to employ own staff.
- process pays, Workcover, Superannuation
- legal obligations associated with funding
- reimburse individuals/families
- monthly accounts to individual/family
- meet with Governance Groups occasionally
- liaise with PLA project regularly meet with coordinators regularly
- receive correspondence from funding body and respond to what it can and if needed liaise with coordinator and governance group

The project coordinator will: (examples)

- support individuals and families with all day to day aspects of the project, including employing and supporting staff, and assisting with developing people's visions and support arrangements
- seek and access community information and resources appropriate to people's goals
- the coordinator does not coordinate the project (governance group does this) but know each person and coordinates arrangements
- be accountable to the governance group

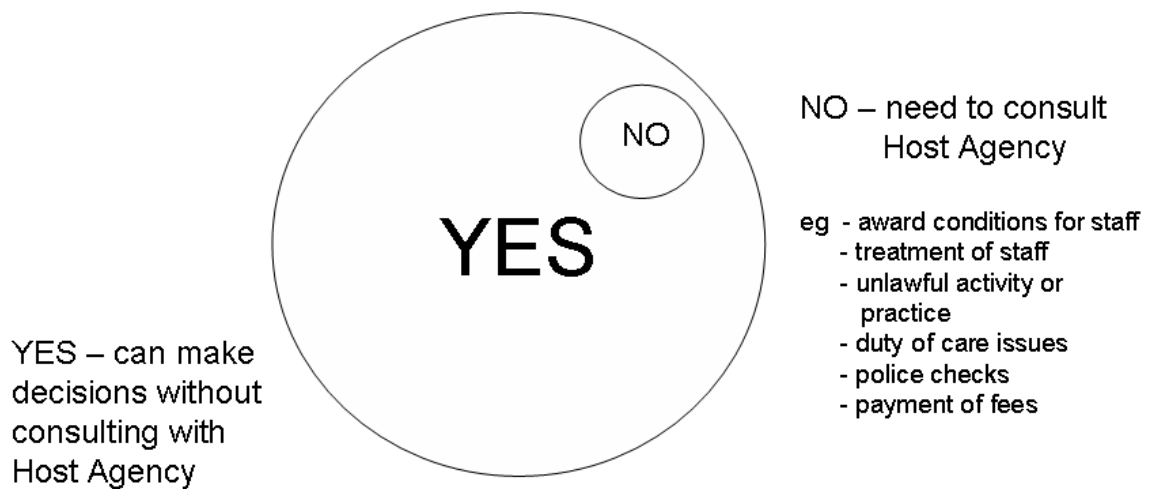
Decision Making:

Melba Board of Management, being the legal service receiving the funding on behalf of the individuals, delegates authority to the Governance Group of the project to run the initiative and make decisions to best suit their individual support arrangements. What naturally rests with the governance group is delegated to the governance group – purpose, vision, strategies; decision who is invited into project; how many people will be supported by project; expenditure of project \$; application to funding bodies for additional collective \$; employment of project worker/coordinator (after liaising

with and taking into account any suggestions from admin expertise of host agency); supervision of and accountability of project worker; decisions around support required.

There are a just a few decisions the governance group cannot make without checking with the host agency.

Therefore, the authority and responsibility looks like this:



Drawn from Terry Kilmister's (2000) model of governance
sited by Deb Rouget in PLA Report 06

Some Details of How Melba Makes Hosting Work

Being a traditional service and invited into a host agency role has been a developmental process for Melba, one which all those involved would not change now.

Administration Fees

- 10% admin fee
- 1.2% staff development fee (inbuilt in funding and set aside by Melba in separate account, but used as the project determines)
- seeding or set up grants have been important to change admin capacity
- fees for Superannuation, Workcover etc are calculated on the support staff hours used by individuals.
- when the project coordinator's salary is made up of contributions from each individual, this is charged to the individual according to the coordinator hours allocated to that individual
- in the examples of the Individual Support Arrangements which Melba manages itself, a 20% fee is charged

Employment

Melba has legal responsibility for staff, therefore it is written in agreement that:

- families and individuals are aware and responsible for safety and support of direct staff (OHS requirements)
- any illegal activity expected of staff will cause Melba to intervene
- a Melba representative is on the selection panel for employing a project coordinator (OHS requirements). Melba will employ who is recommended by the selection panel.
- Melba asks that the coordinator be involved in at least the initial interview of support staff. Families choose support staff.

The Governance Group

- members of the governance group are registered as volunteers of Melba and are therefore covered by public liability insurance (funded individuals are technically 'clients' of the host agency and are therefore covered)
- Melba's board of management has delegated authority for the relevant project to the governance group.

The Coordinator of the hosted project

- the coordinator has been selected by a panel of mainly project members, and a Melba representative, and is legally an employee of Melba, but does not work in Melba services
- technically they are seconded to the project – on the Melba payroll, but doing a job outside Melba.
- the project governance group manages and supports the coordinator and the coordinator works for the family/individuals and governance group.

Main Impact Areas on Melba

A big impact for Melba has been that of mind shifts. Being a traditional agency, Melba needed to shift from seeing themselves as a provider of services to a facilitator of alternative arrangements. They also had to have a mind shift from congregated services to individual possibilities. They quickly realised that individual arrangements produce unique and enhanced lives.

The next major impact was administration detail, with the biggest impact being on finance and payroll areas, as the individual arrangements take more time than the other programs. Some details are:

- an early problem, was achieving the critical mass necessary to enable the creation of internal supports, to support and monitor arrangements. Only small income initially, but needed someone to look after the arrangements, but not enough for specific position/role. Responsibility given to an existing manager, who was provided with an assistant manager. As hosting grew, accessed a 'bridging' grant to create the full time position.
- existing admin systems were not able to host, track and report on individualised supports. The semi-autonomous projects give Melba approx 25 individual fund accounts; Melba internally has approx 14 individual funds.
- to begin with, infrastructure was developed on the back of traditional services and therefore subsidized, because of commitment. Still working on a formula for true cost of service, but covering costs now. How should ongoing capital costs be incorporated into fees? Eg new accounting systems.
- cost codes eg 40 people in an existing Melba day service is still one cost code, but with individuals and families, if there are 40

-
- families, there are 40 cost codes. Increase in number of cost centres from 13 to 43.
- Chart of Accounts – how big do we want the Chart of Accounts. Maybe something like 0-500 is organisational and 500-1000 is for individual arrangements. Melba is still working all this out.
 - accounts are family specific therefore must be absolutely accurate, therefore system must be excellent. Needs dedicated soft ware, as any codes not in the system will be blocked. It took Melba about 12 months to work this out, but is now going smoothly.
 - some items for accounts to be split between members in the collectives eg cost of coordinator's insurance premium, hours, car, holiday hours etc
 - approx 35 individual arrangements, with profit and loss statements, monthly reports, takes time and even small things like uses much more paper, printing ink etc. Keep in mind though, that individuals are buying this service.
 - each individual has own support staff who are added to the payroll system.
 - not just about solving the immediate problem, but asking 'what are we getting into for the future'?
 - when the business manager was asked if he could see the benefits of the model clearly, a delightful conversation took place. He was excited and talked about the enhancement in people's lives being amazing.

Some Details from the Perspective of a Hosted Project

Parents on one governance group said they couldn't imagine doing the governance and goals any other way. They also said that it is good to give lots of time to talking and working out the vision etc, then start things in people's lives, and then look at a host model along the way to support the vision. Some more insights are:

- families become more empowered in family governance as time goes on. Many didn't know what family governance was when they first became involved.
- the 'bureaucratic shield' aspect of hosting is enormously helpful and a relief. This works best when the coordinator liaises with the host agency and funding body on most issues. Individuals and families do also sometimes liaise.
- given that these arrangements are seen to be out of the ordinary and that they are family governed, and may not be fully understood by all funding bodies, the shielding can also be important in a way other than the admin and finance. The host

agency can have a critical role of shielding the family/project from any exposure it does not need from disability departments.

- role of coordinator is critical, so the right person is essential. The person needs to be experienced and skilled and committed to family governance. This has been an issue and a learning for at least two of the projects.
- clarity about role of coordinator and expectations of the coordinator (and right relationship to keep developing this)
- exchange of regular information to families about what the coordinator has been doing
- having the coordinator work from home saves money and it keeps this role out of the structure of the host agency
- excellent working relationship between coordinator and host agency is needed
- the designated contact person within the host agency must be the right one, as in understand and support the project vision, be flexible and find ways to make things work. They must have the right values, be reflective and guided by families. Families don't want to have to explain or justify the concept to the person in the host agency who they are immediately associated with.
- It is really important to have allies in the funding body.
- right relationship with host agency, all staff and other families
- good mentoring and encouraging. This is done day to day predominantly by the coordinator with individual families, also by Deb Rouget in the PLA project, and by Melba being supportive and encouraging (Melbourne example)
- flexibility of host agency and listening to families is critical

Families are encouraged by each others' strengths and insights, and further encouraged by the success they see their sons and daughters achieving. These small grassroots initiatives are between 2 and 5 years into life, and are strong and getting visions enacted, and are showing strong signs of being sustainable for the long term. In Deb Rouget's words *it is expected that they will require ongoing and periodic assistance to continue to strive for their collective and individual visions, staying strong and focused along the way.*

What Makes a Host Arrangement Work

The things which make a host arrangement work can be grouped into three areas: communication; clarity; and commitment. They are required by all those involved in the arrangements. Some examples follow.

Communication

- clear communication from outset. What is expected of each partner. Knowing who to contact re inquiry to get a quick response.
- right relationship
- very clear, signed negotiated agreement with host agency board and project/individual
- financial systems of reporting that families can understand
- host agency put time into assisting families to understand the business/admin aspect. This will assist as the arrangements progress.

Clarity

- very clear signed negotiated agreement
- hosted support arrangements are not part of the host agency
- role of host agency – facilitator not provider, letting go of control
- host agency to involve administration and finance people from beginning of the possibility of becoming a host agency. The project emerges out of values and commitment and clear vision, therefore everyone who will be making it work needs to be part of discussions and planning from beginning.
- clarity about negotiated roles of host agency and roles of project
- host agency confident they can take on the work load, having thought this through clearly
- clear that either party can end the relationship given reasonable notice and reasons. Individual funding belongs to the person and person can take it elsewhere.
- mentoring and guidance, to stay motivate and well resourced to continue with the vision and the work

Commitment

- a commitment to the vision which has come from the people who are seeking a better life
- the underpinning values of a host agency need to support the type of arrangement they are hosting

-
- genuine delegation of authority from host agency to project
 - finding ways to make it work
 - acknowledge from beginning that it takes time to work everything out, but this is critical and time well spent.
 - guiding principles for the collective or individual arrangement are critical
 - flexibility to achieve outcomes for each individual

What Contributes to a Host Arrangement Breaking Down

The things which contribute to a host arrangement breaking down can be grouped in three areas: inflexibility; relationships; and authority. Some examples follow.

Inflexibility

- host agency wanting project staff to attend agency training
- host agency wanting to use logo when staff were being advertised for family
- host agency not open to alternate ways
- hosted projects not understanding the legal obligations of host agency

Relationships

- large bureaucratic leadership
- unclear communication and lack of right relationship
- when designated contact person in host agency 'doesn't get it' ie individual responses for individual people, operating principles, that the host agency doesn't own the project.
- having the right coordinator and keeping support staff.

Authority

- host agency hanging onto authority that genuinely lies with the project
- host agency trying to drive the project
- host agency just not getting the concept of power with the individuals and meaning of a good life
- if a strong charismatic effective leader leaves an organisation, creative structures can be at risk

Vulnerabilities of Hosting

There are some acknowledged vulnerabilities of host arrangements. Whilst they are a reality, many of these can be discussed and to some degree pre-empted in a negotiated agreement. Many of them are not likely to have impact if open, clear and honest communication exists from the outset. Much depends on right relationship. It would appear that the hosted entity is the most vulnerable. The research showed this clearly in two examples. Some examples of vulnerability are:

- relationships consistently present a vulnerability to arrangements when right relationship is not forthcoming
- if there is a change in board membership or policy, or if the leader of the host agency leaves, or if the key contact person in the host agency leaves
- if the nominated contact person in host agency is someone the family finds difficult to work with
- the arrangements are not always understood by funding bodies and therefore possibly under scrutiny
- the hosted project is always a “guest” of the host agency with delegated authority, not ultimate authority
- the project exists in a hosting arrangement subject to the agency’s voluntary agreement with the project that this be so

To conclude the vulnerabilities section on a more positive note, Michael Kendrick has this to offer: *So, in the end, the key is to define a “right relationship” that is both honourable and ethical and functionally clear. This is not always as easy as we might hope, but once done properly it can endure for long periods of time.*

Advantages and Disadvantages of Hosting and Auspicing

From observing and talking and reflecting on experiences of organisations the following advantages and disadvantages of hosting and auspicing are offered.

Hosting

Clear Advantages

- not a Mamre service, so grows Mamre only in the supportive roles required, and not service delivery or structure
- the examples noted in this report are self sustaining
- host agencies say it is very achievable and quite easy

-
- the host agency can decide how many people it can host
 - Mamre already has flexible admin and accounting operations in place
 - Mamre already works individually and flexibly with families and adults, and in some ways almost 'hosts' now
 - Mamre already works in 'right relationship' and partnership with families and adults
 - Mamre could have input, but structurally the entity is outside Mamre's service
 - potential for leadership and self management for young adults and families. This is possibly family support at its best.
 - opportunity to demonstrate new ways
 - entity would have own governance
 - the hosted project does not need to be about the core business of the host agency
 - would relieve families of the task of setting up and managing an incorporated organisation. *The bureaucratic shield would save our family* said one family.
 - assistive role of Mamre can be negotiated between parties
 - there are strong examples of host arrangements operating successfully
 - always possibility of moving to an auspice arrangement
 - parties can amend or cease arrangement
 - small growth in host agency for big outcome of innovation, ideas and relevant individual arrangements

Clear Disadvantages

- entity or individuals require funding
- entity could rely too much on host agency
- vulnerability of families and adults if host agency personnel change
- a host agency could generate control issues and inflexibility
- the entity has delegated authority, not ultimate authority
- entity is legally subservient to host agency
- project will always be a 'guest' of the host agency
- would Mamre (host agency) feel a moral obligation to a person if their support network fell apart?

Could be both advantage and disadvantage

- long term arrangement

-
- very much based on right relationship
 - flexibility in ongoing assistive role gives host agency the opportunity to mentor and contribute to the shaping of the entity
 - more suitable for small to medium numbers

Auspicing

Clear Advantages

- short term with independent new organisation formed
- opportunity to contribute to new leadership development
- would support those families interested in setting up and managing a new incorporated organisation
- organisation has complete authority, with no room for ambiguity to creep in
- no Mamre growth, but outcome is new innovative responses
- Mamre has done this recently with Bravo

Clear Disadvantages

- no ongoing influence unless mentoring requested
- does not appear to be families ready or asking to do this at the moment

Could be both advantage and disadvantage

- Potential for ongoing mentor role
- More potential for sustainable growth in numbers

The Current Position of Mamre With Regards To Potential Hosting

People require more information about the concept of hosting and the scope it has for Mamre and families. This report is intended to provide such a resource. Most Mamre members would like to see Mamre make some ongoing response to the young adults, but are aware that much is to be considered. Many members are quite clear that Mamre needs to do continue its work with adults. Some members think that adult supported living is beyond Mamre's responsibility. There was a question that if Mamre is thinking of doing something for adults it implies that Mamre has residual capacity or 'vacancy' and should that residual capacity be used for the young adults or for additional core business of family support.

There was a very strong commitment from many people that this is not a question of if, but how. This is based on the reality that Mamre started as, and has continued to be a community not just a service. It has invited people in as community members as much, if not more, than as service users. Many people, and certainly the people who are imminently in need of an adult service, who have been supported via service delivery are also active and contributing community members. Reference to the Mamre Charter was frequent and sincere. One staff member reflects what many people have been saying in different ways, that Mamre *should host something new for adults, keeping the spirit with which these things begin.*

Mamre staff do not want to see families and young adults pushed into service provision by (mainly large) organisations with congregation and segregation. They believe that so much work and companionship of families has happened over the years, this is unacceptable. The families and young adults deserve and desire alternative and individual approaches. Mamre's style of work with families has encouraged family decision making and trying broad experiences for their son or daughter based on possibilities not presumed limitations of the person. It is quite a reasonable expectation that families want to continue doing this and finding their vision, but the problem is finding organisations which can support them with this.

Mamre young adults and families do not want to take backward steps in achieving what they have been working towards. It was said that *Mamre is a way of life, not a system.* Families do not want to move to a system, especially an unsatisfactory system. People expressed interest in the host arrangements concept and could see its potential for Mamre to assist families and adults to move to another 'way of life' of their own, associated with and infused by Mamre. Mamre can be beside and near or far, but something new develops – something which has already been nurtured by Mamre for many years because of the way in which families are worked with, but which is not necessarily Mamre or Mamre's. One mother spoke strongly of Mamre's value being in its unique relationships and working partnerships with families and its living out the Charter, which is different to what other services offer. If Mamre was not passing this on within a host arrangement, she felt there would be no point in hosting.

It is very clear that as well as a practical outcome, families and adults are genuinely seeking the spirit of Mamre because it is real and it has shaped their lives. One young man says *at this stage of my life I'm*

still very vulnerable and I need the familiarity of Mamre to help me stand on my feet by myself. When asked more about the familiarity, it was about being known, trusting Mamre and not having to start all over again.

There were several conversations about how new initiatives begin in Mamre. To consider these progressions might contextualize the request for a new dimension which is adult support. Mamre opened a community house 25yrs ago with no government funding, because there seemed to be a need with families; Mamre listened to parents and noticed that they were tired and stressed and wondered and talked about what they could do about it and the parent program began; it was realised that siblings had particular struggles and needs and a sibling support program began; support in the families own home seemed like it would assist some families, hence the home based support program; early support might assist families to get a good life early on, hence the very young children program; existing relationships enabled young adults to come forward and ask for assistance in finding a home of their own, hence the building informal networks and transition programs.

It could be said that Mamre's growth and development has not always been completely rational, but rather, an intuitive dimension of the community to take on an idea and live it well. Recently a guest was on a radio program and was heard to say that the opposite of rational might be spiritual – an interesting reflection for Mamre.

On an operational level, Mamre is in a good position with regard to potential hosting. It already has flexible and individual admin and accounting systems and it already works in genuine, individual partnerships with families. In fact some ways in which Mamre administers family support is quite like a host arrangement. The endorsed principles from which it operates would enhance a host arrangement. Mamre is also in a good position to engage in future auspice arrangements, as it has proven its capacity to do this. At this stage though, people are not saying they want to start a service. This does not mean though, that it won't emerge.

A quote from one family affirms the capacity of Mamre to achieve with young adults:

Mamre has not only supported us but also educated us, widening our horizons and understanding of what is possible for our children (as children) and especially our children as adults. They have inspired us (the whole family but in particular our son) and shown

him and us a vision of life that I would not have imagined and that does not appear to be possible for him with existing services. Therefore it seems natural and understandable that we would want Mamre to continue their innovative, person-centred work and help this vision become a reality.

The wisdom, experience, openness to learning, and skill of Mamre can contribute to shared development of something new.

Expressed Concerns

There were many concerns named during the research conversations. Many were named several times. Some people saw no reason for concern, as the relationship base between families and Mamre was so strong, that issues could be worked out.

These concerns would need to be considered in context of the next phase of this project eg an implementation group. There would be information in the examples of the host arrangements studied which would assist in addressing these concerns.

The following covers areas of concerns named:

- is supporting adults *Family Support?* (There is a section in this report on the purview of family support)
- how much will it tax/overload Mamre's personnel and finances?
- that Mamre might end up owning property eg a Mamre adult accommodation community
- sustainability into the future, for Mamre, for families
- something new might affect other Mamre projects and staffing especially Building Informal Networks and Transition program.
- Mamre/the new entity would need to be very clear as to what it will and won't do. This is related to the 'all domains of life' worry. Some expectations might arise for congregated living, or organized activities rather than unique individual responses, so clarity is imperative.
- belief that there are no other services to connect people into – if Mamre did things on this argument it would be huge and responding to lots of requests
- the people wanting something new would need to come with additional \$ resources
- not at the cost of families who's child is born today – Mamre needs to still be there for new families.

-
- Will this 'open the flood gates'?
 - if we don't consciously define it, boundaries can be pushed to other things
 - if Mamre was to host and the governance group/family group becomes dysfunctional – what are Mamre's legal responsibilities; and what would Mamre see as their moral responsibility to the person being supported in the hosted arrangement?
 - will this draw some Mamre staff away from their existing primary activities?
 - to host will be to grow Mamre in some way. Need to think this through.
 - seems to be a high need for quality post school services – will Mamre be inundated?
 - hosting could be more risky to Mamre than auspicing, if the organisation stayed too reliant on Mamre.
 - role's clear - Mamre's role, family's role, governance
 - who is going to do it, and is it do-able by the people who are available now?
 - need strategies to have families strong long term, or it could slip into mediocrity
 - many young adults have different slants on dreams for their life than the rest of their family may have, especially around moving out.
 - losing connections between people in Mamre if Mamre was to grow too much eg people being known if they drop into the Mamre locations
 - making this opportunity equitably available to people
 - families are not all 'on the same page', so we need to make no assumptions about what people know or don't know when talking about something.
 - Bravo was exciting, but worrying from afar – distance issue

Some further comments about concerns:

Identifying "Mamre families" is not as easy as it once was, given the many innovative responses Mamre has invited families to participate in. For example, there may be families who have been with Mamre for 20yrs, families who have not received Mamre services for one reason or another (even if they would have liked to) but are now working with the Pave The Way, or Not Waiting Creating. These families may have visions very aligned to Mamre and might be ready,

willing and able to establish a family governed organisation. There may be other families long associated with Mamre who have not expected that Mamre would be involved in adult support and have looked elsewhere or developed something themselves. Some of these families may not be satisfied with what they have, and given an opportunity would love Mamre to be involved in support with their adult son or daughter.

There needs to be some equity in making this available to families. Some families who have been part of Mamre for a long time, may not expect any continued adult support, so have worked at finding something else, could feel almost betrayed to then find out Mamre is doing adult support and they didn't know, especially if their arrangements are disappointing. They are likely to have taken an opportunity to have Mamre involved but didn't hear about the possibility. Mamre could ask some questions like: Who's ready? Who's got funding? Who might be interested but doesn't know about the option? Who can't articulate their need?

Opening the flood gates!! The flood gates are there anyway, and are already opened up because people are seeking better options. Kedron house opened up the floodgates in 1982!

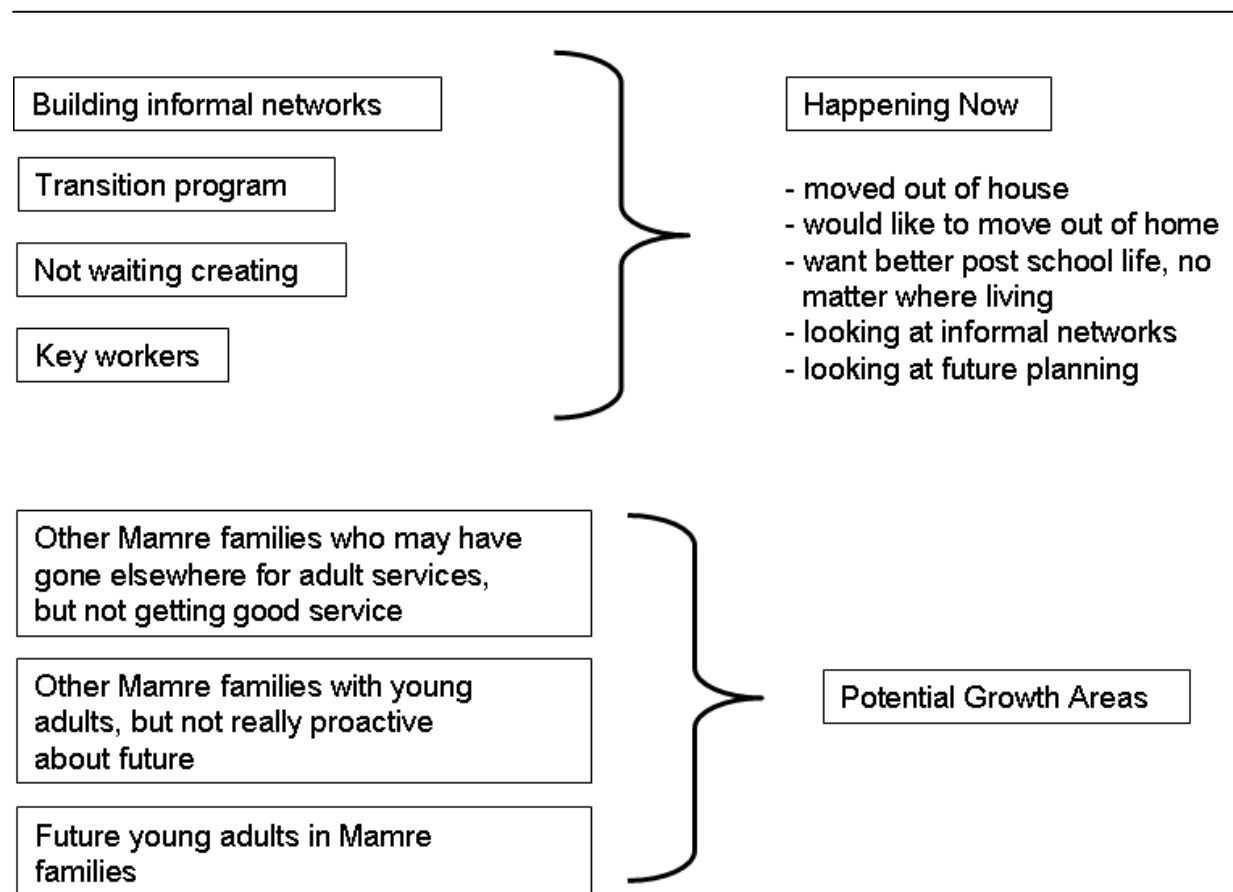
Sustainability was mentioned many times. The grassroots sustainability is largely up to the members of the group around a person, and the members of a collective. Mamre would be responsible for making its role sustainable. It would also work hard to support young adults and families to keep their individual arrangements sustainable eg getting others to walk with them. Right relationship significantly enhances sustainability. Sustainability does need to be carefully considered in the developmental stage of any new initiative.

On Growth

Mamre has been concerned about growth for many years, but growth is obviously inevitable as reflected in the increase in Mamre programs, staff and location sizes. Mamre has not grown without deep thought, and this project is no exception. Potential growth within young adult support is perceived as a concern, but Mamre has the authority and wisdom to manage this in a way which is limited and sustainable. The reality right now is that Mamre is working with many young adults and their families, having adjusted some of its structure and capacity with BIN, NWC and Transition programs. Keyworkers too are working with young adults. To move to a more formal and ongoing commitment to the young adults will be more of a structural shift, than much of a growth.

That is however, until more young adults request ongoing support from Mamre. This seems to be the question of 'opening the floodgates'. Perhaps the floodgates won't open for the following possible reasons: the ability of Mamre to do adult support will depend on people having some funding and this is likely to happen at varying times for people so could be naturally managed due to timing; not all families will want to go this way with Mamre; the future demand from families with younger children might be dispersed due to family mobility, earlier genuinely inclusive opportunities, and possibly families developing more family governed services. To some degree, Mamre needs to trust its ability to manage something new in an attentive and adequate way. It has done this in the past with all the demands which have come before it.

The following diagram might provide some framework for looking at growth in terms of adults in Mamre.



Mamre has not set out to look at doing adult support or dive into another area of service. Nor is it trying to do something that already exists elsewhere. In a climate in Brisbane where there is little or no inclusive and innovative services to which these empowered and thinking families and young adults can transit, a huge need has arisen. And it has arisen for the young adults Mamre knows and loves and who are community members.

However Mamre needs to operate from its strength, rather than 'a lack of services' motivation. Mamre has developed its strengths, not just because of Mamre's own historical development and individual skills, but largely because of its relationships with and intimate knowledge of families' lives and experiences, particularly difficult ones at the hands of systems and bureaucracies. The skills developed in Mamre by knowing families well, can return skills to families. Mamre does do this because of the principles from which it operates, but it could do it more intentionally now, by relating to families and adults in new ways in new phases of their lives and by skilling families and young adults to take control of their own entities.

Perhaps an approach could be that Mamre respond to the young adults ready for the next step by hosting a project – demonstrate

and trial this, then be available to host small family governed arrangements who request that or auspice a new young adult service in Brisbane at a later time.

What a New Initiative Might Look Like

This question had many responses. Some people were really unsure, many people thought it would definitely be accommodation, some people thought it would be individual ideas for individual people, especially when no longer at school. Some people were quite excited and some people were worried.

There are already a number of young adults who have better, more interesting lives because of the recent ways in which Mamre has encouraged this. Some people have left the congregated place of employment or day service and are doing genuinely individual life development opportunities. Some of these people live in their own home and some of them still live at home.

Two young men interviewed both want to be supported separately from Mamre family support. They are asking for flexibility from Mamre to do something new, but that Mamre be behind it.

The examples of host arrangements earlier in this report give a range of ways of responding to young people's lives and a range of ways of being hosted. A response to support people moving into and remaining in a home of their own has emerged for Mamre. The other area which has emerged is requests for Mamre to support post school initiatives for people. *One by One* and *EQAL* in Melbourne, and *Getting A Life* in Canberra are good examples of innovative, one person at a time responses to having a quality adult life. They are not 'services' as such, they are collectives of people with a coordinator, implementing unique individual goals for people.

It would appear that Mamre could host or auspice an initiative that is not just for supporting people in their own home, but has individual responses for people. There could be some natural grouping of people based on interest and need as the initiative develops – grouping in terms of common goals, vision and planning, or location, not doing activities together or living together.

The concern about being involved in all domains of a person's life was raised. This is for Mamre and the potential new entity to discuss further. The examples cited in this report, and the examples in

Mamre are models of facilitating good outcomes for people in their communities, not providing the services. A person's life is naturally developing with all domains interlinked – the person is involved in all domains of their own life. A family has the natural authority to be involved in all aspects of the person's life unless the person requests otherwise. The support would exist to assist an individual in whatever domains they had goals around.

The appendix lists people's ideas about a new adult support entity or response.

In summary, the following aspects have been articulated as critical:

- that it ought be closely aligned with family support, in that families are supported to do much of the work at ground level, as well as the visioning, thus building family capacity and ownership
- that it would be separate to Mamre with its own small structure eg coordinator who does the ground work with families, and assists families to manage support staff and support arrangements
- that there needs to be part of the response at least, that supports people in their own homes with formal and informal support arrangements
- that the informal networks are kept as core components of people's lives
- that it needs to be sustainable

Following is an example of a family ready to be individually hosted by Mamre:

One family interviewed is ready for Mamre to host their adult's individual funding tomorrow! They have been a part of Mamre for near 20yrs. The adult is well connected to the Mamre community, though does not live in the family home. They receive an unsatisfactory service, and do not want to continue with this wasted energy. An important reason for wanting Mamre to host for them is that the relationship exists with Mamre, they are community members, they believe in and see Mamre live the Charter, and see that it is a natural extension of their community membership. They have confidence that Mamre could support them to maintain good individual lifestyle and accommodation supports. They have confidence in the mutually positive relationships being a core

component. In a host arrangement with Mamre, this family has articulated how they could see it operate.

The family would

- continue development of support circle
- identify personal goals and support arrangements
- support person with decision making
- work with Mamre on selecting and training staff
- have a working relationship with staff and liaise re the persons support arrangements
- troubleshoot with staff, prevent problems
- continue family involvement with person

The family would like Mamre to

- host the funding
- do legal, financial and employment side of things
- coordinate the staffing based on the vision and plan ie have an active contact person within Mamre
- listen and walk with them
- continue being their community

Unlike the Brisbane and Melbourne examples, but like Matthew in Sydney and CCS in NZ, this example seeks a supportive role from the host agency. This support could actually come from the structure of a new hosted entity, not from Mamre.

Family Support Purview of Mamre

A major issue raised was whether or not supporting adults still fitted into the family support purview as Mamre has known it. The main argument to support it not fitting, was about adult lifestyle support being quite different work to working in context of family, and the family home. The majority of people were quite clear that working with adults was an extension of the current way in which Mamre does family support. The main argument supporting this, was that families will always be around their son and daughter and need support in this new phase. If Mamre was to host or auspice a new initiative it does not technically need to be 'family support'. This aside, it is quite clear from conversations that Mamre would want to approach adult support from a family support foundation. Other comments from the research follow for perusal.

- its all family support - the young adult needs the family around them

-
- Mamre ought only consider something new which works to empower families and keep supports close to and governed by families
 - Mamre can shortcut trials and tribulations of families because of its experience and values
 - family support doesn't stop being needed because someone grows past 18yrs
 - family support is planning with the family to meet persons needs while lives are enmeshed. We are now being led by young adults, not families.
 - parents age and siblings leave home or find work overseas/interstate, so the need for support of parents as their son or daughter leaves school and then wants to leave home becomes even more important.
 - trust built over years, and shared history, not easily replicated. This trusting relationship is family support, and why walk away when it exists
 - families don't stop being families because their children grow up. The fact is that people mostly grow into adults. Mamre's long term relationships with families make it easy for them to continue working and working in the family-focused way it always has.
 - *Without family and allies our son can't achieve a vision for his life, even when he is an adult. It is all family support, as we will be getting a good life for him all our lives no matter where he lives, and we will need support to do it.*
 - *I am proud to say that I have grown with Mamre (and not just fat from the morning teas either!). Also, I am aware that Mamre has grown with us, by seeing our needs and our families, foibles and all, and by providing the information, guest speakers etc we needed as our children reached the various stages of development. This is family support and community support.*

On Governance

The type of governance is really up to the individual or the collective seeking a host arrangement. In an auspice arrangement it is quite clear that the new entity has its own governance. In a host arrangement the new entity is semi-autonomous in that it operates outside the usual commands of the agency, the host agency having delegated most decision making authority to the project governance group. If Mamre was to offer to enter into a host arrangement, it would be delegating authority, so cannot own the governance.

Most people involved in conversations for this report thought that a shared or combination style of governance would contribute significantly to a new entity/response. A combination of family, the adults seeking support, a friend, an ally, maybe a Mamre member, an interested other. This would need to be considered along side the notion of right relationship. There is strength in a combined or 'community' governance ('community' meaning broad community not Mamre community), as is attested to in the long standing community governance style of Mamre. Interested others can and do have much to offer. This can also be a way of supporting and empowering young adults and families to move into governance roles, and possibly onto self or family governance. One of the young adults interviewed wants to manage his own service. Many families indicated a strong interest in having others govern with them, in the interests of shared energies. There were several comments about the requirements of accountability and regulations associated with an incorporated service having increased considerably in the last 10 years, and some families just don't want to go there.

All except one of the hosting arrangements examined in this research are family or self governed. NightLife in Melbourne is combined governance, 75% of the governance group being service users.

Families spoken to who do family governance would not have it any other way. Family governance enables families to take responsibility as well as power and authority. It strengthens families. Families support each other and teach each other. As one parent said *families will be in a person's life long after any director or CEO or coordinator*. Family governed initiatives utilize skills and effort from people outside the family as they need to, for example in support circles, using resource people. Some families may not realise how possible family governance is. Host arrangements are one example only of family governed arrangements.

Mamre could, in the process of this continued work with adults, provide opportunities for adults and families to learn more about and increase their confidence about family governance. Forming incorporated new services and developing companies or trusts are other options.

Approaches for Mamre to Consider

On reflection of host arrangement examples and listening to Mamre people, approaches are offered for consideration. There could be two or more approaches in operation simultaneously. When considering how to move forward, recall for a moment the adults Mamre knows and see them as people who: might want to pursue an interest or skill during the day; might want to move into their own home; might want to improve their social life; might want to get a job; might want to study; might want to get fit in their local community; might want to start a business; might want to work towards a couple of goals at the same time; and many more options.

As Mamre considers moving forward, it could be useful to revisit Recommendation 10 in the report from the '06 review:

Recommendation 10: Mamre should continue to explore and expand its hosting role, particularly for innovative projects that show evidence of being able to eventually be self-sustaining.

Mamre has most certainly demonstrated that it can manage a hosting role through its Pave The Way work and its role as auspice for the recent Gympie initiative. In doing this, Mamre has opened the door to other such hosted projects. Having said this, it still remains for Mamre to be very selective in what sorts of projects it will commit to, as otherwise any project will do.

Various considerations may need to be weighed including whether the proposed initiative is genuinely innovative and needed, whether it could succeed without Mamre's hosting in both the short and long term, whether the hosting may trap Mamre into a long term commitment it cannot afford, and so on. Nonetheless, providing the answer to questions like these is reasonable, Mamre may well be able to achieve indirectly what it had formerly achieved by taking on direct responsibility.

It seems the general direction for Mamre to move forward could be:

Action	Structure
Support families with visioning, building circles and informal networks, as they become ready for this.	keyworkers within Mamre Parent support Program
Create space for families and young people to lead Mamre as to what support they want. Invite their detailed expressions of interest. Provide opportunities for families to talk with other families <ul style="list-style-type: none">- this is what Mamre has seen happening elsewhere- available to assist something similar to happen re host/auspice	Mamre
Host an initiative for individuals or collectives that support moving out of home, and/or post school goals.	Semi-autonomous entities outside Mamre eg <ul style="list-style-type: none">- location- coordinator- staff support procedures eg who gets call if staff sick- young adult leadership

The approaches are not listed in any order of priority.

Approach 1

Auspice a new incorporated agency to work with young adults

- could be around accommodation; post school or both
- could be an agency which supports adults and families to self manage their funding by designing individually tailored responses

(similar to example 14 My Place in WA)

Possible impact on Mamre:

- commitment as Bravo. Intense for auspice period.
- learn labour saving tips from Bravo experience
- the shift of some young adult work from Mamre to new agency would have staff/program implications

However, the natural emergence of people for an auspice does not seem to be present yet. That is not to say it would not emerge.

Approach 2

Host an assistive role which exists to develop new, individualised initiatives, either with one person or with a collective – work on vision, principles, funding application etc

(similar PLA project – Deb Rouget)

However, this role may already have been filled to a degree in Mamre, for the young adults who are ready for the next step.

Perhaps Mamre has the capacity to keep doing this for the families they work with now, until they have funding or are ready for more of a coordinated approach and structure.

This role could also be sought elsewhere.

Possible impact on Mamre:

- initiate a funding application
- second a person to this role with 'spare' Mamre money?
- if it was a small role, it could possibly be viewed as a time commitment not dissimilar to Mamre staff being involved in other outside projects eg reference groups etc

Approach 3

Formally host a small number of individuals with funding who are ready. This could be done without any structural change and little cost, but would probably best be done as part of a new initiative and focused structure.

(similar to Melba individual funding example; Matthew's example; and NZ)

Possible impact:

- small admin cost
- supportive role time
- demand could grow and have increased impact

Approach 4

Host an initiative which does not have a location. Coordinator works from home and meetings are held in people's home. Meetings could also be held in local facilities eg library meeting room, services clubs, community centre meeting room.

(similar to One By One and Living Distinctive Lives in Melbourne)

Possible impact

- work out best way to get funding for coordinator eg submission; each person contribute from individual funding
- coordinator would be on Mamre pay roll in hosted arrangement
- admin for hosting of individual \$

Approach 5

Host an innovative entity which is only to do with accommodation.

However, it is unlikely that the only single thing happening in someone's life is moving out of, or living away from home. What happens to the rest of their life if they need support in areas, especially post school? It could work if accommodation is the only gap of support in the person's life.

Possible impact

- as for other approaches

Approach 6

Host an innovative entity which is only to do with post school goals. Given the paucity of choices in this area for people in Brisbane, Mamre might stand in good position to attract money for 'pilot' or 'innovation' projects.

(similar to One By One in Melbourne)

Possible impact

- as for other approaches

Approach 7

Host a Northside and a Southside entity

Possible impact

- as for other approaches

Approach 8

Host an initiative which starts off with the young people who have funding. They could possibly decide to apply for collective funding for an ongoing coordinator role.

Possible impact

- as for other approaches

Approach 9

Host one or more collectives within an entity rather than individuals. This could offer more potential for families to support and strengthen each other and develop strong connections.

Possible impact

- as for other approaches

Approach 10

Look at example 12, The NSW Alliance for Self Management. Would there be any benefit in Mamre working with another organisation on a new initiative? Would it be more work or less work?

Final Thoughts

Mamre is encouraged and wished well by many people consulted during this research and by the author of this report. We look forward to knowing of Mamre's decisions and progress. We wish the young adults and their families every opportunity for fulfilment.

Appendix - What a new initiative/service might look like

- not within current structure of Mamre
- Support families to develop a service where they develop a structure which supports them. This does not need to be large structure eg a coordinator and governance group
- People who are asking for it need to say what they want it to be
- A place where people are welcome, and a place where people can be pointed in the right direction – having a person to be linked with and see how different areas in life are going. A place or a person that helps families see their son or daughter differently and explore what they like and are good at. Don't do it, but assist people to get things going. Everyone needs encouragement.
- Something which looks at individuals not groups, and something only where the families are willing to do the hard yards. Mamre can't be left with a person's life.
- not a Mamre service so that when parents die, the person is taken care of
- families need to initiate what they want (may need kick start); families need to own and drive it (Mamre needs to encourage this from outset); identify an area and a size;
- Support for individual responses for individual people. No group or segregated responses
- don't buy or build accommodation: don't tie support to housing
- avoid property
- not just to move out of home into own place
- I think it still needs to be a small, quality service, which follows the values of Mamre
- combination of paid and unpaid – keep the informal strong. A separate entity. The huge gap is post school services. Do we set up a service for creative options for anyone over 18 OR accommodation or particular type of response/service eg daytime/accommodation. OR adult service around eg 10 adults and work individually. Need for all this in Bris.
- a given that it will be person centred/individual.
- needs to be sustainable
- it would be young adults with some sort of funding, even with the possibility of pooling some funding for some creative things. In whatever domain the person needed at the time.

-
- Maybe creating a small business of his/her own to suit. They could get together and see what could happen.
- young adults running it (have real power) with family members support. Though a mix of perspectives from allies and Mamre members would be good.
 - focus still coming out of importance of unpaid networks safeguarding people. Co-ordinating support around the informal networks.
 - decision re domain of service come from person and network, not what a particular service says they can offer = what is going to best enhance person's life at the moment. Is it about a place to live? Pursuing an interest, meeting people in the local community? Getting a job? INDIVIDUAL
-
- I think it should assist young adults to plan and timeframe their lives. This will determine what the service needs to support the young adults to do. If they want work they are supported to find work, if they want love they are supported to find love. (from a young adult)
 - Firstly listen to the adult's dreams, goals and aspirations. Try to help them be as independent as they can to allow for their integration into community. The service needs to make sure that the young adults are communicating from their hearts and not going along with what others think. The service needs to be a combination of whatever needs the young adult really needs to have a meaningful life in the community so as they can truly feel in charge of their life. (from a young adult)
 - Young adults want their families involved but not at the centre any more
 - small – max 10 people, needs good establishment work, to then maintain what people are looking for.
 - they would have more choices about what supports are going to assist verses picking from a) b) or c)
 - PTW and BIN have focused on 'non-service' solution/responses. Further this. Not commitment beyond being there to advise and guide. Mentor. Sustain the network, but not the work the network does. The network then finds arrangements for eg day activity, employment etc.
-
- needs to be local, more chance of meeting need. If a collective, more chance of success if local

-
- could something work where Mamre has a separate program, not part of Mamre work group because of different nature of work; has own coordinator who reports to Mamre management committee ?
 - maybe 2 arms – accommodation if they want it, and living as a young adult.
 - not part of Mamre. Located separately
 - Coordinator role is crucial.
 - young adults ought be actively involved in the management of the service itself
 - it would need to be a separate service but still joined to Mamre in some way.
 - perhaps Mamre could assist the Young Adult Service to get started and it might become more independent as it became established
 - perhaps an arrangement/structure something like “Pave the Way”.
 - Mamre has a good name in the community and that would assist the new service. I think the young people who have been supported by Mamre should be given the first opportunity to access the Young Peoples Service.
 - support adults in leading a good life ie to communicate needs and wishes; Work; Play; Learn and extend skills; exercise; make friends; maintain friendships; keep in touch with family; laugh & have fun; stay safe and healthy
 - The principles stated by BIN are what people are talking about.
 - the new entity needs to be something that can do both paid and unpaid. Not a follow on for just the BIN people, but a new entity. Tap into the NWC parents, parent program etc.
 - One person at a time, individual reponses – own support workers, staff own home.

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