Mamre: a vision of inclusive lives and self-direction

Rachel Drew

Rachel Drew has worked with families who have a son/daughter with a disability for over 23 years in Queensland. As Director of Mamre, Rachel has a strong passion and commitment to supporting families to develop a good life with and for their family member, strengthening family, community and sector capacity, and a keen interest in family and sector sharing learnings and experiences of self-direction and management of supports. Rachel has shared Mamre's experiences internationally, nationally and on a State level as part of an organisational commitment to invest resources into capacity development and change agentry support. Mamre believes that ALL families can and should have the authority to direct their own supports, and have opportunities to manage the administration of the funding if this is the family's choice.

Mamre Association Incorporated was established in Brisbane in 1982 to provide support for families of people with disability. A community-driven organization, whose core work has been and is, assisting families so THEY are envisioning, planning and developing a rich, meaningful and inclusive life for their family member with a disability. Working from a deep commitment to its values – hospitality, simplicity, inclusion, community, justice, love, and guided by Christian values, Mamre had a strong commitment from the beginning to listen to families. Currently, within Mamre, 230 families receive some direct paid support, and 400 families are connected in some way.

As an intentional community of families, workers and allies, Mamre seeks to build relationships with families that provide opportunities to families and individuals to develop their own communities of people.

In 1996, because of its strong commitment to listening to families, Mamre began to provide support to families though individualised, flexible informal and formal supports. Mamre had 'heard' families, who wanted to direct their supports and have control, so a consultative process was accomplished, breaking apart their Government block-funding, consulting with Government, and developing an organisational culture that enabled families to take control and still have the supports they wanted.

For the organisation - what does it take?

- Strong vision, mission and values
- Belief in the capacity and resilience of families
- Investment in building family capacity
- Willingness to share authority and responsibility through agreements
- Good safeguards for quality and accountability

Budgets are both large and small, and 100% of families involved self-direct their service. Families are also clear that they want this program to continue.

- Each family directs their own support and determines to what level they choose to manage their funds.
- A Key Worker can assist families to develop their vision and plan, providing support and advice on day-to-day issues – assisting families to manage formal supports whilst always maintaining and developing a focus on informal networks.

How do family-managed funds work for Mamre?

- The organisation receives funds from relevant funding body.
- Has a six-month agreement with each family, outlining the family's goals and how the funding will be spent.
- Transfers funds to the family bank account every 4 weeks, or as the family requires.

- The family accounts for the money spent before the next payment.

What Mamre requires families to consider
- Know where you are going (vision)
- Family Support Plan and budget with the key worker
- WorkCover; household public liability insurance
- Any required Legal Liability Insurance
- Support Worker Agreement with each worker
- Car Insurance
- Dedicated Bank Account

What type of assistance does Mamre offer?
- Key worker support
- Handbook for Family-Managed Funds
- Assistance in finding, training and supervising support workers
- Parent Program –
    - Information, education and leadership activities enabling families and individuals to feel supported and to have peer support.
- Regular weekend live-in workshops – "Creating Meaningful Lives"

For the family – what does it take?
- A clarity of vision and plan for a good life
- A willingness to be creative
- A willingness to direct the service at a level of comfort to them
- A willingness to take responsibility and be accountable
- Families drive the vision and direct the service, providing a flexible response to the families' individual need
- Choice of Support Workers to meet the personalised need of the individual/family
- Use of local networks
- Efficient and effective management of funds
- Looking at safeguarding the future.

How families typically use funds
- Personal support in the home
- Support during family vacations
- Contractors – cleaners, babysitters etc.,
- Host family – where a relationship is built so the person stays with a family who welcomes them, and provides positive experiences away from own family home.
- Trying new experiences – living away from home
- Specialised supports and medication – limited to funding guidelines.

What Mamre has learnt about Family-Managed funds
- The most flexible responses to individual family needs
- Strategies to build respectful relationships with families
- How local networks enhance relationships
- Families use supports to complement and help build natural relationships
- Very cost effective
- Only two cases of deliberate fraud in 18 years, which supports the written literature
- No two situations are the same.

What families say about self-managed funds.
- Having full control over my supports has meant a better life for my family. We choose who, how and when we receive support. It's the first time I have felt listened to and have had my needs met.
- Having Mamre as a foundation for support and also a backup is awesome. I can manage my child's support in such a way that it actually helps not hinders, and still have Mamre there for

when I need them.

The anticipated future for Mamre

After 28 years, Mamre has a confidence about what is possible, and is willing to take risks. As well as to challenge families to imagine better, rather than accept the status-quo, Mamre also understands that families need to be ready, no family is the same – each is unique, and personal circumstances dictate readiness to take action.

- Families 'envision, plan and build' as a way of thinking
- Increased demand for self-managed funds
- Families use technologies to their advantage (internet, mobiles, money management systems).
- Use of local people and places rather than specialised disability services
- Higher consciousness of succession planning amongst families (Circles of Support, wills and trusts.)
- Greater focus by Mamre staff on envisioning and planning rather than co-ordinating, supporting and dealing with crises as families become more confident.

Mamre is also committed to being a public change agentry and has formal strategies that assist in building the capacity of the service, of families and of the wider sector to imagine better, a positive vision for now and for the future of an NDIS with a focus on succession planning and future sustainability.

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