

Life through relationships

Penny Osborne and Rodney Mills

Introductory comments:

This paper was presented by Penny Osborne and Rodney Mills. Rodney had prepared his speech, using facilitated communication, prior to the Conference. It was read by Penny.

Rodney:

I'm Rodney Mills and I have autism.

I would like you to listen to what Penny has to say today because what she has done for me has changed my life for the better.

Two years ago I couldn't stand still, let alone sit down and I was a twit who flapped and ran away at any opportunity. I had no control of my behaviour. I was out of control to the point I hated myself and my life.

I came to meet Penny as my key worker from Mamre. You will hear how I needed to find a way to control my behaviour because it was out of control. I was running away at any chance I got. I was seen as a freak in my neighbourhood. How to stop was what I needed to know

Before I started typing, I didn't have any control over my body. Now I can sit and type for really long times without needing to move. I am so glad that Penny got mum to take me to see Alice (a FC facilitator) and get me typing. I have never known the happiness I feel now that I can tell people what I think.

It's good you have the chance to listen today - you may hear something that helps you to give someone a better life than they have now.

Penny told me that I could do anything if I wanted to try hard enough. She was the first person to say that to me. I want people to know how good that makes me feel.

The support Penny and Mamre have given us has been so very special to me and my family. We wouldn't have made the changes we've made and made the plans that I have toward the new life of Rodney Mills.

That's all I want to say. I'm handing over to Penny.

Penny:

Today I would like to share some factors that I believe need to be considered when supporting families that are supporting a son or daughter with challenging behaviour. I will be presenting a collective of ideas of how Mamre supports families. This information was gathered through conversations with family members, workers and with Rodney who shared his insights from his perspective as the family member labelled with challenging behaviour.

First I would like to introduce Mamre as an organisation.

Mamre association was established in 1982 as a Christian community based on gospel values. All practice within Mamre is underpinned by the Mamre Community Charter.

The charter talks about supporting families by walking alongside them in their journey, that through building a relationship with families, sharing time and listening that together we can find a method to support them to remain strong and continue to care for all family members. This fits the framework of family centred practice where the focus is on the family as a whole at the centre, and the service providers are partners and collaborators.

At Mamre, we aim to empower families. The family members are the ones that will be there in the long run, therefore in our work we aim to support families to direct their own future. We do this by providing information, opportunities to develop networks and support to advocate for themselves. Families have as much or as little involvement in coordination of their support they choose.

In 2003 Mamre hosted Ann Greer's positive responses to challenging behaviour workshop. The information presented by Ann had a profound impact on many people. Here was someone who presented a positive image of people with challenging behaviour. She acknowledged the gifts and talents of people who struggle with challenging behaviour. She encouraged us to listen to what these people are trying to communicate

through their behaviour. I saw great potential in looking at Rodney's situation through Ann's framework, so I booked Rodney's mum Helen into the next Brisbane presentation and provided support to enable her to attend. She had the same reaction. She connected with Ann at the workshop, and so began the new journey for Rodney.

The issue of challenging behaviour had been an ongoing concern for a number of families supported by Mamre. It was decided that we would trial an organisational response whereby Ann Greer was employed as a consultant to work with the four most critical situations where families were able to participate.

It was explained to family members that this approach to supporting their son or daughter is not a quick fix, and that they needed to be in a space where they could take on new information, look at family dynamics and modify old behaviours patterns in the process of building positive supports around their son or daughter. It was explained that this was not going to be easy and that if they were not able to make the commitment at this time, that was okay. It is important that families are in the right space to embark on any new strategy because it can be a confronting process for families and they will need the energy to cope with change.

Ann's support began with an initial workshop followed by individual family consultations; the development of a behaviour support plan and follow up with families and key workers to support the implementation of the strategies.

At this point I would like to acknowledge the experiences that are typical of families supporting a son or daughter with challenging behaviour.

- Families are tired and worn out and they just do what they have to do in order to survive. This often results in isolation from extended family, friends and the community.
- Families have been told a thousand different ways to think about their son or daughter which leaves them confused and frustrated because they don't know what to do to make it better. They too are often engaging in bizarre behaviour patterns just to keep the peace.
- Families are so bogged down in surviving the day that they have limited capacity to think about the future.

Often we begin working with families at a time of crisis or when they have reached their lowest point. Therefore, in order for families to be able to cope with change, you can see that it may be necessary to spend time deliberately working to reenergize family members as part of the beginning of any process of dealing with the issues the family face.

As I gathered the ideas for this presentation, some themes emerged that indicated there are 4 key principles that need consideration when supporting families to support their son or daughter with challenging behaviour. These include relationships, information, the right support and hope for the future. I will now address these principles.

1. Relationships

“Families need people they can talk to. They need to know they can call someone when an incident happens and that they will respond in a positive way” (Rodney Mills, 2005).

- Families need to have time to develop a relationship with the people and the organisation working with them that are built on respect, trust, honesty and a shared commitment to their son or daughter with a disability. Rod and his family have been part of the Mamre community for approximately 20 years.
- The quality of the relationship and time spent together will determine the progress the worker and family are able to make.
- Families have their own values and culture that must be respected at all times.
- Understand that often families find it difficult to make changes and move along this journey as easily as workers might, due to their history with their son or daughter.
- Spending time talking with families and continually providing information and opportunities to broaden their knowledge and awareness allows the identification of moments where people are open to new information. Some people call this a ‘teachable moment.’ Whatever you want to call it,

the important thing is that information is presented in a non-threatening way and families are allowed the time and space to process it in their own way. The skill of the worker is to grab the moment and make things happen.

- I can think of numerous situations where information or ideas have been rejected in the first instance but down the track, the ideas have re-emerged as a possible strategy. No matter how the idea was born, the important thing is that the time is right to put it into action.
- There will be times that you don't agree. There will be setbacks as well as gains. There will be challenging times, as well as moments to celebrate.
- If it is necessary to challenge families in order to continue to move forward, this must be done gently, respectfully and at the right moment.
- Your ability to work through these times correlates directly with the quality of relationship you have developed.
- I met Rod's mum Helen over lunch at her local footy club.
- In working with Rodney's family, I have spent time with him and his family members in different combinations and contexts in order to develop an understanding of them both as individuals and as a family unit.
- We spend time sitting on their back-deck, talking about the possibilities and throwing around ideas.
- Helen shares things she has been trying with Rod, I share any new information or achievements Rod has made with support workers or with me, and we consider how this can be incorporated into other contexts of his life.
- In the more difficult times, it is not surprising for Helen and I to speak on the phone every day, more if necessary.
- Helen also knows that if there is a crisis we will respond in a timely manner. If I need to attend to another crisis, she is happy to renegotiate less urgent appointments knowing that other families are getting the support they need.

- The relationship between support workers and family members is equally important in providing effective support. These workers have carefully matched to individuals and families. In Rod's case it is not unusual for them to be chatting over a cuppa with the family for half hour after their shift finishes. They give detailed accounts of their time with Rod and spend time with them as a family chatting informally. They also model the strategies they use to support Rod to be as independent as possible and to best manage his behaviour.
- I also spend time in supervision with support workers to ensure an informed and consistent approach is maintained.
- We all come together a minimum of twice per year to review and plan for next set of goals. We meet at other times throughout the year to celebrate achievements and keep us all clear about our role in Rod's journey.

All of this takes time. This presents a challenge for organisations: if they want to support families effectively they need to make it possible for the time to be spent with them.

The other consideration is that this simply cannot happen between 9 and 5, Monday to Friday. Families cannot be expected to fit into business hours; workers need to be spending time with them at times that are conducive to the development of the relationship with all its members.

We can think of the relationship between the family and the worker as a journey. After meeting the family, they travel along spending time getting to know each other. They then make some plans. In the next leg of the journey, the worker doesn't always walk right beside the family but is always there to touch base if need be. Celebration of achievements is critical to progress and is my favourite part of the journey. The next phase involves me walking closer to one member of the family for a while. It's always important to take time to stop and reflect about what you have achieved and where you need to go. There will always be challenges along the way and sometimes it will feel like you're walking in circles, but through the relationship the answer to moving onward and upward will emerge.

- The concept of developing relationships with families in order to best understand and support them is universal within Mamre. We place great importance on this as it provides a foundation to ground all work that we do with families.
- Families require informal supports and links in their community, in addition to paid disability support, in order to survive in the current funding environment. As an organisation we are committed to the development of circles of support and accessing informal and community networks in order to build support around families.
- In the case of Rodney's family, we began by bringing a group of people together in April 2004. We developed a plan based on the vision they had for Rodney and their family. Rodney has progressively finetuned his plans as he has developed his own vision of the future. This is the motivating factor for Rodney to work really hard at being able to manage his obsession with running away because he knows this will limit his ability to achieve the things he wants.
- Informing families of upcoming workshops and conferences, and sponsoring people to attend;
- Gathering families;
- Acquiring resources and loaning them out;
- Participation in Mamre community events;
- Mamre hosts forums that are specific to the needs or interests identified by family members;
- As workers we also incorporate the concept of story telling into our practice. Families love to hear that they are not the only ones dealing with these issues and are always interested to hear what strategies other people are using in the process of identifying how to work through their own situation.

The final piece of information that is integral to being able to develop strategies that will work towards a better life for people with challenging behaviour and their families is what their son or daughter wants for their life. All people (including those labelled with challenging behaviour) need goals and dreams. They need a reason to get out of bed in the morning. We need to be looking for the things that motivate the people we are supporting. It is only then that we will find ways to move forward. People need to be engaged in their lives in whatever way they can manage. This builds a sense of esteem and ownership over their life that provides the motivating to make change.

2. Information

“Families need information specific to their son or daughter’s disability so they can get an understanding of their experience of the world” (Rodney Mills,2005).

Rodney and his family have learned about the meaning of Rod's behaviour through reading about autism and movement disturbances, through meeting others and hearing people's stories and of course listening to Rodney himself. This has been life changing for Rodney and his family. They continue to seek greater understanding of Rod's view of the world.

- Families need to hear information related to how other people cope with the issues that arise from supporting a son or daughter with challenging behaviour
- They also need to find out “what's out there” in terms of the community, the service system and their entitlements

As an organisation Mamre makes a high level of commitment to providing information by:

In trying to establish what Rod wanted for his life we considered the adequacy of his communication system. Rodney had used a voice output device for a number of years, in a very competent way. This raised the question of what Rodney might say if he had an open slate to work from, like a keyboard.

- Rodney began using facilitated communication (FC) in November 2003.
- Having access to FC has opened a door that has endless possibilities for Rodney.
- When people start using FC, some family members, understandably, find it hard to accept their son or daughter can communicate so efficiently when they haven't seen examples of this in their schooling etc. These people look for validation to confirm it is really their son or daughter typing the words they hear.

- The thing that couldn't be argued with, when Rod's parents looked for validation, was that he is a willing participant. A guy who couldn't stand still for a minute and would never sit down 18 months ago can now sit and type for up to 45 minutes. He has delivered a 30 minute presentation at a forum for parents of young children with disabilities. He attends a writers group where he sits and writes and here he is today – it is amazing what can be achieved when someone is focused and motivated.
- While FC does not take his movement and communication disturbances away, it does provide a better understanding of Rodney as a person. This information is crucial for his family when they are planning with him.
- Rodney is now able to articulate what he wants to do with his life. None of which is any different to what you or I want from our lives. He wants his own home, a girlfriend, a baby, and the opportunity to be a good father. He wants to study science at uni, and enjoy good times with his friends and family.
- This provides us the opportunity to engage him in his life by finding ways to work toward these goals. It also presents a challenge for the people who know him to perceive him in a different way and change the way they interact with him.
- While Rod is engaged in his life he is less inclined to engage in negative or challenging behaviour. It has become clear that the time Rod spends hanging out with support workers is closer to what he wants for his life than being at home with mum and dad. His behaviour communicates his preference quite clearly, as does his dialogue when he facilitates to his mum "I want you to get on the phone and find me my own place now".
- usually involved a lot of driving and a lot takeaway food.
- The first thing to eliminate was the centre based post school activity.
- Rod needed to be out pursuing his interests.
- We knew Rod has always used movement to manage what was going on in his head. His parents drove for miles because this kept him calm. Rod has also enjoyed boating and loves hanging out the back with his hand dragging in the water.
- We wondered whether Rod's love of speed was a factor that contributed to his running.
- We started upping the activity level in his week by getting support workers to be out walking and rollerblading with him.
- When this didn't make a difference, and we were faced with another of more than 30 police pursuits in one year I recall very clearly saying "right that's it Rodney Mills, you're going to Dreamworld!" – strange as it may sound, regular visits to Dreamworld where Rodney rode up to 30 rides in a day presented a new challenge to Rod which appeared to have a positive impact on his behaviour.
- This has been accompanied and eventually replaced by activities such as bike riding, sailing, trampolining, rock climbing, 1:1 basketball, diving and most recently Rodney is learning how to water ski.
- Rodney's ability to communicate more effectively allowed us to gain insights into the negative impact staying at respite houses was having on his ability to manage his behaviour.

3. The right support

"If families get support it must be right for the kids as well as the parents" (Rodney Mills, 2005)

- For example, when we started looking at Rodney's support he was accessing two respite houses, centre based post school activity and the support workers were taking Rod out for outings. This

Rodney's needs were not met in respite houses. He was always supported under lock and key and the behaviour exhibited by other people staying there made him feel like he was going mad. He told us that his obsession with running was actually stronger after his stays at respite houses. This defeats the whole objective of respite. If Rod came back worse than when he left and

his parents hated leaving him there, it didn't leave much hope for them feeling reenergised from accessing this type of support.

I'd prefer to think that respite time involves both parents and their children spending time doing things that they like with people they choose.

- Now Rodney spends time at his family's second home at Bribie Island with a support worker developing his independence while his parents have a break from the day-to-day grind – essentially this can be called respite (It is funded by respite dollars). The critical point is that it is valuable and meaningful to Rodney as well as providing his parents a break – this actually improves his ability to manage his behaviour.
- There is a tension that presents when trying to implement the right support when multiple agencies are involved. In this case, there needs to be decisions made around how to best utilise the supports available. This could be streamlined through brokerage arrangements or a team approach involving interagency meetings. Otherwise the family need to be good advocates and work as the negotiator in achieving the best support for their family.

4. Hope for the future

“Families need the possibility of seeing things differently for their future [and] to hear success stories so they can see there is a way out, there is a light at the end of the tunnel” (Rodney Mills, 2005).

One of the most difficult things for families supporting a son or daughter with challenging behaviour is to be able to look beyond what they are coping with on a day-to-

day basis and think about how they would like to see their future. Often families resign themselves to thinking that this is it; they will be supporting their son or daughter into old age.

We hope families' visions of the future includes parents waving off their son or daughter, surrounded by their circle of support, at a reasonable age to pursue their own life.

Helen has found hope for the future in her new understanding of Rodney, developed in the workshops she attends and the networks she has developed along the way. For example, the Fiona McGill workshop “Beyond Group Homes” sparked the formation of a group of parents that meet monthly at Mamre to share ideas on how they can achieve a good life for their adult son or daughter without a funding package.

Families develop a sense of hope for the future by being able to put things in place now for their son or daughter's future, rather than dreading what will happen when they're gone.

When supporting families that are supporting a son or daughter with challenging behaviour, the emotional support the family will need cannot be emphasised enough.

There will be steps forward and back along the way.

Through the supportive relationships, access to information, the right support and hope for the future, families will be able to develop and work toward their vision for a good life for their son or daughter and themselves.

Penny Osborne has worked in the area of disability for fourteen years. The roles performed in that time include direct support for adults with intellectual disability living in group homes, staff development and management of direct support workers and key worker supporting families. Penny has a Bachelor of Social Science (Human Services) and works from a strengths perspective within a family-centred framework.

My name is Rodney Mills. I have Autism and I present on topics such as challenging behaviour and fostering independence. I aim to promote the understanding of Autism and the challenge to have an inclusive life for people with disabilities. I have lived with obsessive behaviour all my life and have much to offer on educating the community in how to respond to people with challenging behaviour. I hope to also include the community in Facilitated Communication to achieve positive outcomes for people with disabilities.