

Taking a deep breath and moving forward. Transforming Milparinka

Frank Crupi is currently the Chief Executive Officer of Milparinka, a disability service in Melbourne which is undergoing a major change process. It is transforming from a traditional group model of support to working in partnership with families and individuals one person at a time in individualised and self-directed supports.

In this article Frank explores the early days of this change at Milparinka; its inspiration, how it redefined quality and how it made Frank question the truth of his words. This article is based on a presentation Frank did at the 2012 Family Advocacy NSW conference – “The Odyssey, from getting a service to getting a life”.

I think many significant changes start with a point of transformation... a moment when a light goes on. For Milparinka that switch was flicked over about seven years ago when we came across an interview with Deb Rouget, from Belonging Matters in Melbourne.

Deb spoke about the importance of knowing people, dreaming and thinking together to help someone find a life that makes sense. She shared stories from the lives of people with disability she knew and they sounded great. Full of choice, value and included in their communities alongside peers who shared common interests rather than common disabilities.

After reading this interview I walked through our building with some of the people I work with, talking to service users and wondering why their lives weren't as full as those of the people that Deb had spoken about. We asked ourselves a question, “What is getting in the way of the people we know getting individualised and personalised lives like the ones Deb had described?”. To our embarrassment, we realised that a lot of what was getting in the way was us.

Changing our minds

We hadn't been silly or frivolous in our work. We had always been well meaning, organised, responsible, accountable, dedicated, and even clever. Lots of people told us our services were great. We had gone around for years saying that we worked together with people with disabilities to help them find a good life, but really what we had been doing was to invite people into one sided relationships where we had most of the authority, the control of resources. Being in partnerships with individuals and families was really a measure of how well they could fit into our systems rather than being about mutual design and development.

We wanted to support people to find a good life but weren't sure how to do this. We decided on the spot that we needed talk to people in a new way. We commenced an informal exploratory process and began to look around to see if we could find local examples, in the same sorts of services as us, in order to grab onto other peoples learning, be mentored and take shortcuts. We didn't need to reinvent the wheel. Strikingly, despite gaining some instructive insights from some local agencies, we did not find any that could show us what we knew we needed to see.

We found that agency goals, words and stated intentions had changed for the better. Practices had remained largely the same and the lives of service users hadn't changed all that much. In effect, organisations seemed satisfied with these new symbols of a good life, but did not have much substance by way of really important changes in people's lives.

Ultimately, we realised that these organisations were just like us. They hadn't gotten to a deeper level with people and their lives either. Like us, they meant well but had achieved only a small portion of what was really needed

and wanted in people's lives. They were also, like us, getting in the way of individuals achieving good lives that made sense to them and who they were.

People sometimes ask me - what was it that was getting in the way, what are the things you needed to stop doing. Well there were lots so I will mention just a few here:

- We needed to stop coming up with solutions for people's lives before we even knew who they were or what they wanted – we were just creating new boxes for people to fit into.
- We needed to stop putting timetables in front of people, when we met them, and saying pick something you like from this and then calling it a choice.
- We needed to stop planning our policies from the top down and develop them ground up, from what we learnt from the people who we supported.
- We needed to stop confining and limiting people's dreams by planning from a starting point of how much money or how many resources were available. Instead we had to plan from a basis of people's dreams and what they really wanted in their lives.
- We needed to stop getting in the way of good ideas by confronting the misconception that, as service providers, we were the forward thinkers and that it was communities and families that got in the way of progress.
- We needed to stop meeting people and telling them we were there to provide them with a service. Instead we had to recognise that we were there to be a tool, a tool they could use and reshape to help them get the life they wanted.

Changing our Thinking

In response to our initial conversations and thinking we did, what for us, was probably one of the most risky things. We decided to step bravely into the mystery of tomorrow and not be the ones to set the direction. We would live with the uncertainty of putting the development of our organisational shape and identity behind what people wanted. We would find out what people wanted from life and let this design our future.

We realised that any measure of personal fulfilment was intrinsic to people's lives and what was fruitfully accomplished in their lives. We were no longer quite as interested in defining our success by bureaucratic or organisational factors (such as audit outcomes, positive client feedback forms and acquitting funding) and in turn assuming that they bought satisfaction to everyone we supported. After all, a fulfilled human being is a very different thing from an efficient organisation.

One of our dilemmas in measuring success is our government partners. They are 100% behind our transformation and what we are doing and they support intensely our personalised approach and people getting the best lives possible, but they still measure success by how many hours 100 people spend in the community each month, as if it tells them something about quality and people's lives. For us to measure success we need to know that all of these hours were meaningful for the person or they are empty hours, no matter where they are spent.

Changing what we do

Because we are fallible we need to be very conscious of establishing benchmarks and points of reference that keep us focused as an organisation. We think of these as critical measures of success; ways of working and thinking that we need to be able see in our work and relationships if we are to keep moving forward. Here are some of these critical measures and their elements:

- **See everything through a prism of individualisation.** Every idea or relationship you have with us is measured through a prism of individualisation and personalisation which reflects our values and commitments, and, if it doesn't fit, it doesn't happen.
- **Communication.** Our view is that if we (or others) are not spending significant energy and resources on giving people their own voices then we (or they) are not serious about listening to people.
- **Including staff in the journey.** We know that we need to constantly show staff and everyone else that we are responding to issues about individuals within a framework of values and principles rather than a framework of systems and rules. There can be no exceptions
- **We need to control our excitement.** When we started on our path of individualisation, we started to get width and breadth in our supports and not depth. Things like thinking deeply, keeping connections, responding to vulnerabilities and dreams, need depth and focus. Spreading ourselves too thinly didn't work and resulted in reduced quality and thinking around individuals.
- **Having the right partnerships.** We went from many large-scale partnerships with other community resources to individual relationships based on each person we work with. We now have over 100 partnerships with one place or one person for (and with) one service user at a time. Does this take more time? Yes it does. Are people who have a disability who we know getting more people in their lives, more valued roles, more relationships and better social inclusion in their communities because of these new types of partnerships? Yes, they are.
- **Recognising and understanding plateaus.** We need to be aware that just because someone gets to be in a better space than they were before, that this is just part of the journey... it doesn't end there. Decisions are not forever and we need to be vigilant in staying connected with people's lives to understand when it is time to seek more out of life.

Changing who is in charge

Families tell us that they can now see us responding to their personal differences or uniqueness. They tell us this is better because we move at the pace of the individual and family and that we understand that some families need more time to think or different ways of thinking.

Families appreciate that we know them much better now and talk with them in ways that make more sense to them. We fit into their lifestyle and avoid standardized, prescribed ways of getting to know people. We work with people as individuals and work out the best way to get to know them and we also acknowledge that this is a good intention that we will probably fall short on far too often.

Families tell us that they appreciate that we are more self-consciously ethical now. Families and individuals tells us they have been surrounded for years, by us and others, with great ideas, clever words, promised opportunities with a minimum of these ideas and words being translated into realities that brought about measurable differences in individuals lives. If we say we are going to do something we do it and we expect to be able to show it to people. We expect to do this at both an individual and organisational level.

CONCLUSION

Seven years later we are still talking and seeking answers but we have learned a lot that has changed us for the better.

- We have seen some people's lives change as they defined and described what a meaningful life meant to them. Notably, most people who have connected to new lifestyles have moved closer to their communities and further away from us.
- **Changes in staff roles.** Staff are now working proactively and developmentally alongside people who are designing their own pathways. They are in new roles that include relationship facilitators and community capacity building.
- **A reduction in the dependency on specialised staff and segregated supports.** There has been a huge increase in the use of natural supports as people are now connected to community, and are in places alongside other community members, without support staff being there.
- **A good life means everybody.** It doesn't matter about skill levels. When we introduce people one person at a time, in a way that allows them to know and be known by others, good things happen. It also isn't the case that we are always talking about whole of life. For many people, it has been finding the right moments to taste life in a different way and knowing what can be achieved.

To achieve this we desperately needed to stop thinking of people as collective groups. We had to start knowing each individual one person at a time so that we could assist them better to be able to describe and define their own support needs. More than anything, we needed to be ethical and stop rhetoric, grand statements and the occasional success stories becoming agency evidence which serve to bring about delusions of achievement rather than a sustainable capacity to support personalisation. We needed to remember that being truly person centred is not about a couple of meetings a year and a written plan but is about an ongoing relationship with one person that expands, shrinks and reshapes itself in the context of that person's life.

At this stage Milparinka has come some way down the path of transformation, but we still have a long way to go. None of it has been easy but we have seen meaningful and even inspiring outcomes that have been well worth the challenges. All this being said, we are not there yet. I just think of us having taken a deep breath and moving forward.