

Getting Out of the Way

Frank Crupi is part of a group including people with disabilities, families and staff who are working together to transform a traditional group model day program into one that supports individuals one person at a time to achieve lifestyles which they value, direct and which reflects who they are.

In this article Frank discusses some of the key elements that stimulated the changes and some key points of focus that keep the movement towards transition alive at Milparinka Disability Services.

Six years ago our organisation realised something unfortunate. It was us and others like us that were standing in the way of people we knew who had disabilities getting satisfying and personalised lives. We were providing people with restricted, segregated, and prescriptive service options rather than the opportunity to define and direct what they wanted their supports and lives to look like. While we were well meaning, committed, dedicated and clever, and provided what others described as good services, we had still messed up our frameworks for working with people. For years we had invited people into one sided relationships where we had most of the authority and control of resources, and 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 recognised we needed to create an opportunity for more individualised and personalised supports but that trying to be personalised in our standardized service model wasn't going to work. In response we began a deliberate process of transforming ourselves from an agency based on conventional and fixed day program group models into one that supports individuals with disabilities "one person at a time". We commenced a process of exploratory dialogue with interested individuals with disabilities, their families, staff, and people external to Milparinka, not associated with structured group programs, who were at the forefront of assisting people one person at a time. This initial effort began quite small and has continued to grow until the present.

We learned early in our conversations with people that this journey was not going to be about all the things that funding agencies expected of us – coming up with another solution for people with disabilities, developing new structures, achieving mandated KPI's or putting numbers on paper. It was about thinking deeply about values, principles and getting to know people; understanding how to make sense to people one person at a time and how to shift the paradigm of our organisation from being systems focused to looking at everything through a prism of individualisation and personalisation. It was about listening differently as people other than staff gained more authority, imagined better and expected more. It wasn't about getting to a specific point by a specific time. It was about an incremental progression towards a sustainable capacity where Milparinka could support individuals to achieve lifestyles they valued, directed, and which reflected who they were and what they wanted to be.

Choosing to be steadfast in our commitment to one person at a time and our new paradigm wasn't easy. Our funding bodies wanted shapes and numbers. We didn't have a historical stepping stone; everything that we had done and had designed over the years, our planning, our staff models, how we spent money etc. had an element of cost effectiveness to it. We basically thought the same things would bring the same benefits to each person. Other than knowing that what we were doing wasn't good enough and that we wanted to create opportunities for people to live the best lives possible, we had no idea what this change was going to mean for our organisation, our staffing or our viability. There were high levels of uncertainty and, of course, the risk of failing miserably. When we looked around us for models of services that had transitioned to individualised self-directed services which could lead the way, could help us to take short cuts and provide us with mentoring, we

couldn't find them. What we found was rhetoric without a capacity for implementation. We found, including within ourselves, a consistent capacity to confuse good intentions with good results.

It is common for support services to describe commitments to personalisation such as being person-centred, giving people the opportunity to make choices and do things that they want, or promoting community connections and person-centred thinking with staff as if they mean great things are actually happening for individuals. These broad statements do not tell us what is happening and what is actually being done to bring about valued outcomes in people's lives. We recognised that when rhetoric and the occasional success stories become agency evidence, they serve to bring about delusions of achievement rather than a sustainable capacity to support personalisation. When we got to the point of admitting that there is a significant gap between our rhetoric and what we really deliver we had open and frank discussions about being courageous enough to act on that recognition. The openness and depth of reflection and questioning we were asking people who had invested huge amounts of themselves over the years to undertake was challenging and enlightening to us all.

The recognition of the gap between what we were doing and the sort of lifestyles which we knew people with disability could live had significant impact on how we proceeded. It helped us to clarify our thinking and practices around two key points. First; how to measure success? We knew it would not be by accredited documents, well written brochures or organisational wide evaluations; our key measure of success would not be how we described things, or how committed we say we are but rather the actual positive differences that are occurring in each person's life that they could describe. Second that we would not move from where we were to an alternative structured model of service: we would exist as a fluid process evolving within the context of each individual's life. To provide personalised supports, we needed to be able to be different things to different people.

We have come a fair way down the path of transformation and still have a long way to go. We have seen, amongst other things: people's lives change, dramatic changes in staff roles, a reduction in the dependency on specialised staff and segregated supports, and a huge increase in the use of natural supports. And we are not broke.

Amongst all of the things that we have learnt, there are two tenets that we apply every day in our work. First, "there is nowhere to hide"; it doesn't matter if you are the President of the Board, the CEO, Finance Manager, a visitor or a new staff member, every idea you have is measured against our values of individualisation and personalisation and, if it doesn't fit, it doesn't happen. This has ensured that even when it is tough, and it does get tough, that our shared points of reference with everyone we know is one person at a time. The second is borrowed from poet Nan Witcomb: "we need to step bravely into the mystery of tomorrow". If we are committed to personalised and individualised self-directed services, we can't come up with solutions, as we have in the past, before we know what any one person wants. People's lives and ideas are fluid and we need to be able to respond to these. This sometimes means not knowing how money will be spent, what staff roles are going to be or what relationships we will be in a month's time. It means asking people to be courageous enough to live with uncertainty, not to be in control, and to break with old habits. It meant asking people to have the courage to recognise when it was them getting in the way of people's real lives and doing something about it.

What we do know is if we come up with a solution before we know someone well, if people do not have partnerships with us that enable them to design, redesign and negotiate their supports, if we believe we have the right groups and timetable options for people to slip into, if we think small groups are better than big groups just because they are in some sort of community setting then we are failing. And if we fail, other people suffer the consequences.