CRUCIAL
TIMES

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Editorial

CRU exists to create and promote positive change so that people with disabilities can belong to and participate in community life. Our stated mission is to inspire and encourage individuals and organisations to challenge ideas and practices that limit the lives of people with a disability and to Influence and equip others to lead positive change.

With that mission, at this time in our history, we will again tackle the topic of change in this edition of CRUcial Times. In recent previous editions, we discussed a variety of ways that each of us could influence change. We explored principled leadership and innovation; the importance of a change of heart; being inspired and having good examples to follow; working in partnership and coming together to form a growing, evolving movement for change rather than working on our own.

In this edition, we have invited our writers to explore what is needed to help us implement the changes we want. Being inspired, wanting change and having a vision for what is possible is unquestionably important but they are not enough on their own. We must pursue the authentic and enduring change required so that people with disability can take their place in community, confident that this community is where they belong; where they will be safest and where they will stay. As we seek to move from the ‘why’ to the ‘how’ we also need to be able to understand how we change our thinking; our frameworks; our focus and priorities.

Martin Elks writes about mindsets and how critical they are to our attitudes, assumptions and expectations. As a parent and academic, he has changed his mindset a number of times during his long involvement in the lives of people with disability. He outlines what is required for us to change our mindsets and why it is so hard and he reminds us that the extent to which new mindsets are embraced will determine their effectiveness in change.

Greg and Dianne Exelby speak as parents about their initial vision for their son Scott as a young child in regional Queensland. They illustrate in this article the importance of engaging Scott himself as he has become an adult. They also highlight the value of being supported well by their service provider and family friends to develop and strengthen this vision. This partnership has delivered inspiration; ideas and a shared discovery of what is possible, all of which has contributed to big changes in Scott’s life. A key turning point for the family was when they were challenged by a guest speaker to shift their thinking from filling Scott’s days with activities to creating valued social roles. This thinking is drawn from Social Role Valorisation theory.

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Editorial Margaret Rodgers, Director

Greg Mackay also writes about Social Role Valorisation and particularly shares its importance and potential as a robust thinking framework for informing the way we serve people. Social theory like this can be used to inform our assumptions, beliefs, intentions and direction. Greg tracks its influence in Queensland and explains why it continues to be relevant as a means to stay firmly focused on the needs of people with disability, rather than being distracted by the many competing needs in modern service delivery.

When Frank Crupi heard some inspiring stories of people in Melbourne, he was open enough to ask himself why the people supported by his service didn't have lives like those he was hearing about. Having faced and been embarrassed by that critical question, Frank shares how their organisation has worked to redirect their efforts and their resources to create a better match between what they offer and what people actually need.

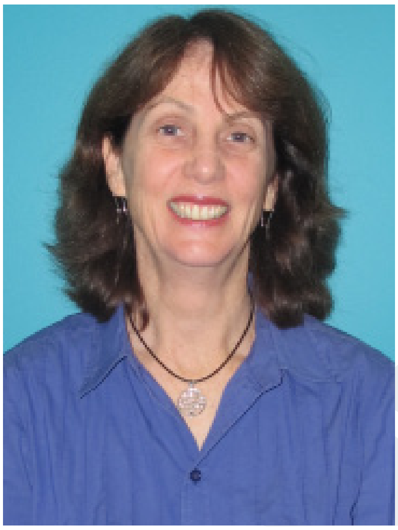
In her article Libby Ellis explores the relationship between being inspired and taking action. She writes about how she and her family knew they wanted something very different for her brother, Matthew, and what it took for them to understand what that meant and how to make it happen. She describes how an external trigger ignited their thoughts of what was possible for Matthew. They then needed to develop the ideas specifically for their family, and work out what would be best for Matthew. Being inspired by other people's stories is only the beginning of the process. She reassures us that once started, change might not be as daunting as it first seems.

The National Disability Insurance Scheme will be introduced in Australia over the next few years. To maximise the potential of this opportunity, sharpening our understanding of change is critical. This collection of articles reinforces that change is personal but that each of us needs to engage both our head and our heart to understand what is most likely to lead to real change. Without a holistic framework and sound thinking, we face a number of risks. We risk focusing on the things immediately in front of us and neglecting other things that may be even more important. If we focus only on funding and paid service, for example, then we could compromise the critically important things in life that money can't buy. We risk assuming that people with disabilities and families know exactly what they need and that they too don't need to unlearn old ways and be 'triggered and ignited' and supported to think in a new way about what is possible. We need ways to understand the difference between what something is called and what it actually is. We risk following fads and changes that don't last.

We need to recognise the risk that there will be changes that are more in the interest of parties other than the person with a disability. We need to acknowledge that in the past we have seen changes that are designed to improve the lives of the family, workers, service providers, general community or the funders – at the expense of the person.

We are the people who will bring about the change that is needed and we need to invest in developing our skills to do that. Positive change is critical; it is possible but it doesn't just happen. We need to understand both the process required for change and also become more discerning about what the change needs to entail if it is actually going to make a difference.

Margaret Rodgers
Director



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From the President

While Manager of a small family-support service, I worked within a leadership team committed to making a positive change in the lives of people with a disability. It didn't take us long to realise that creating change was not going to be easy, instant, or at times, even likely. We also learnt very quickly that we needed to know what we thought positive change would look like, have some ideas on how to achieve it, and be able to communicate our change strategy to others. Of course, we didn't have all those ideas and strategies clear in our minds at all - but we knew that people's lives could be better – so work for change we did.

We concentrated on what we learnt from Social Role Valorisation theory to help us. We encouraged the families we were working with and our staff to do the same. Once we started to focus more deeply on valued roles, image and competence - things did change. The way we thought about people changed. The way we spoke about people changed. The ways in which we engaged with people changed. The service changed. Over a period of some five years, we came to understand much better that our job was to be of *service* - not provide a *service*.

The initial changes we made might have seemed superficial at first. Many were related to the way we described our work and the people we worked for and with. The team stopped talking about "taking" and "doing to" people and started to describe their role as 'being alongside' a person. From this new position of alongside, our viewpoint began to change. It became easier and more natural to guide staff meetings into deeper and more thoughtful conversations on issues such as friendship, social connections, participation, contribution, life purpose and meaning. I understood this to be because we were journeying with people. We started to see that we were all in this together- the person with a disability, their family and supporters, the service and the wider community.

As we endeavoured to move from just being a *service* to being of *service*, we saw new roles for staff emerge – those of facilitator, developer, networker and connector. Not minder, body-guard or gate-keeper. The change for the people we served was seen in the valued social roles they acquired: Neighbour, Host, Hostess, Employee, Commuter, Volunteer, Artist and many more.

I feel extremely privileged to have experienced and witnessed such positive changes in people's lives during that time. I learnt from this experience that change depends on what I do. What we do. Change isn't something we must wait for. It is something we can all contribute to. It is intentional and requires a great deal more thought, creativity and strategy than I ever realised.

> ***We seek change because people with disability deserve to live lives of purpose and value just like any other citizen.***

CRU is about change but we don't seek change for change's sake. We seek change because people with disability deserve to live lives of purpose and value just like any other citizen. We therefore seek authentic change – the sort of change which would allow people with disability to belong to and participate in community life. Our current strategies include leadership development activities (with a particular focus on family leadership); promotion of person-centred responses including investment in service workers and allies, and information dissemination through our publications, website and resource collection, among others. In this 'change' edition of CRUcial Times I hope the information, stories, articles, theories and examples of change are inspiring and motivating.

Cheers,
Matt Stone
President

Changing Mindsets

Martin Elks

Martin Elks began his career as a psychologist for the Victorian government before completing a PhD in disability studies at Syracuse University. He has since worked as a behavioural specialist and in the areas of self-determination, school inclusion and advocacy. Martin and his wife Darcy have 3 children. They have remained vigilant that their daughter Mary be actively involved and included in her community with a variety of roles including work.

In this article Martin explores the influence of mindsets and why they must be considered in any change effort. By outlining common mindsets in relation to disability he shows how mindsets shape systems, create their own legacy and define what is considered possible in the lives of people with disability.

Changing Mindsets

My mind has changed significantly at least three times in the course of my professional career. These changes include letting go of the Special Programs and Objects to be Fixed mindsets (I explain these mindsets below) and adopting Social Model and Person Centered mindsets. I also changed from an individualistic behavior management approach to a family systems and positive behaviour supports mindset. I changed my mind as a result of exposure to new ideas and new theories that made sense of my experiences and embodied a vision I could identify with. I attended workshops by the best leaders in the field and can still remember the ‘ah ha’ moment when I was first introduced to the concept of disability imagery via the rating “deviancy image juxtaposition”. The images of half-naked people wandering aimlessly across institution day room floors in Burton Blatt’s book *Christmas in Purgatory* have never left me and serve as a kind of baseline for me.

At the time I thought, very naively, that all that was needed to change mindsets was to give people the same experiences I had—surely they would see things the way I did! But I have learned that while some people change their mindsets quite readily others take a lot of convincing and some never change their minds. I have also learned that while individuals may be convinced of the need to change, changing a society’s mindset is a much more complicated process.

> ***I changed my mind as a result of exposure to new ideas and new theories that made sense of my experiences and embodied a vision I could identify with.***

What are mindsets?

Mindsets are a particular mental framework of attitudes, beliefs, assumptions and expectations. They determine our thoughts and reactions to many situations we find ourselves in. Mindsets are especially prevalent in politics. For example, politicians who talk about “asylum seekers” have a different mindset to others who talk about “illegal immigrants”. These fundamentally different mindsets lead to fundamentally different policies about how to handle contentious issues surrounding unauthorized immigrants.

Mindsets are very important because they have long term consequences. With respect to aboriginal Australians we are still living with the consequences of a colonial mindset and its policies of genocide and cultural eradication more than two centuries after the First Fleet. Whether 26 January is Australia Day or Survival Day depends very much on one’s mindset.

Fortunately mindsets do change. Freakshows are no longer popular entertainment and sheltered workshops are increasingly being seen as obsolete whereas once they were seen as a great advance. We also used to think that a continuum of services was ideal but we now realize that it is much better to live and learn in the community than have to "work your way up" to your own home after demonstrating success in learning skills in various halfway houses or home simulations.

Mindsets in Disability

There are five common mindsets in disability.

- The ***Special Programs*** mindset is perhaps the most dominant mindset, especially for people with intellectual and developmental disabilities. This mindset assumes that people with disabilities need separate "special" programs such as special schools, special transportation, special teachers, special games and special workshops for "special people."

- The ***Personal Tragedy*** mindset sees disabled people as victims of a personal tragedy that is an unfortunate consequence of being dealt a "bad hand" in life. Financial compensation and charitable works by compassionate people are what is needed to help these people deal with their unfortunate life circumstances. Seeing people as "better off dead than disabled" is an extreme but not uncommon example of this mindset.

- Seeing people with disabilities as ***objects to be fixed*** is also a common mindset. People with disability are not seen as persons but collections of behaviours that need to be improved by particular arrangements in their environment, especially by manipulation of regimes of rewards and punishments. People with autism are particularly vulnerable to this mindset and are often forced to live in strange and highly manipulated settings and sometimes subjected to harsh consequences aimed at shaping them up to have more socially acceptable behaviours

- A ***risk management*** mindset assesses each new course of action according to its potential to negatively impact on a person or organization's existing program budget, image, political profile or reputation. A new initiative is implemented only if the assessed risk is minimal or adequately safeguarded or considered to be otherwise acceptable.

- A mindset of ***inclusion*** sees people as having the same aspirations and need to belong as we all do. Disability is seen as a difference rather than a deviance and a natural and universal part of life rather than an abnormal condition to be cured, treated or prevented. This mindset believes services and supports should be developed using person-centred approaches and that disabled people should live in their community and make their own decisions about their lives.

Understanding these different and often competing mindsets is crucially important because mindsets interact with policy initiatives in ways that can expand or reduce the impact of the policy on the lives of people with disabilities.

Why mindsets are hard to change

Talking about mindsets is a lot easier that actually changing mindsets. Old mindsets may take generations to disappear and the consequences of past mindsets can last for centuries and can become deeply ingrained in society. Why should this be so? There are many reasons why changing mindsets is not easy.

- Most people think their personal mindsets are true and correct and do not need to be changed. This is not surprising since humans have a bias towards searching out evidence in support of their existing personal opinions and assumptions and rejecting evidence that may contradict these.

- Many people have a bias towards maintaining the status quo, not necessarily out of a rational examination of all the evidence but because it is easier to continue as they have always done in the past. New ideas bring risks and unforeseen consequences which can be unsettling.

- Sometimes the reasons for the continued existence of programs are not the benefits they provide to their users but due to meeting other interests such as providing employment or assisting the local economy or even simply out of tradition.

Thinking new thoughts and having one's assumptions challenged can be difficult and it can take a great deal of courage to be open-minded and willing to look at new ideas as non-prejudicially as possible.

- Changing one's mind can be hard work. Thinking new thoughts and having one's assumptions challenged can be difficult and it can take a great deal of courage to be open-minded and willing to look at new ideas as non-prejudicially as possible. New mindsets may also be perceived as embodying an implied criticism of the past which can lead to defensiveness.
- People can become cynical about change having seen new mindsets come and go but not creating the big changes that were promised. After a few such examples it is easy to see people "sit this one out" anticipating that in a few years time this too will pass, go away after the next election or won't affect me since I will have a new job by then.
- Finally, dialogue between adherents of different and sometimes incompatible mindsets can be fraught with complicated dynamics and sometimes common ground is hard to find without a lot of effort.

What it takes to change mindsets

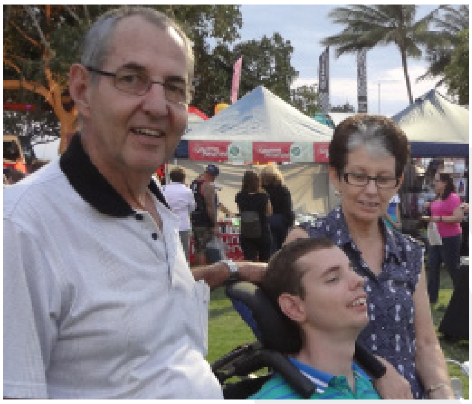
So what does it take to change mindsets? While mindsets change one mind at a time it is necessary to eventually achieve a tipping point if significant social change is to be achieved. Here are a few key aspects and processes involved in changing mindsets.

- Personal experience with disability, personal relationships with people with disabilities and education are essential. They lift the veil of complacency that surrounds and obscures injustice, prejudice, life-wasting, stereotyping, discrimination, stigma and disadvantage and how these prevent the realization of the talents and contributions people with disabilities can make.
- Over time these issues and injustices become overwhelming. After meeting others in similar circumstance to their own, people realize their private problems are shared by many in what is a systemic and widespread devaluation of people with disabilities.
- Leaders agree it is time to organize for change. This involves implementing any number of activities in a planned manner, perhaps involving protests and other disruptions to "business as usual".
- A well articulated description of the current problem and a vision of a better way forward is developed. We are working for the day when children grow up with friends and neighbours with disability in their schools and communities and think this is the way it has always been and are shocked when old people tell stories about how it used to be.
- Leaders who embrace and advocate for the new vision become highly visible. Such leaders are hard to find but are essential for change. These leaders have a sense of justice, are open to new ideas, want to do things well and not just adequately, have an idealistic vision about what could be and are willing to accept the costs involved in advocacy.
- Competent, ongoing, relevant education and training about the rationales and evidence in favor of the new mindset, especially emphasizing points of coherency with prevailing broader cultures and worldviews, are developed and offered widely.
- Clearly documented examples of the new mindset in action, especially from the perspective of people with disabilities, are documented and disseminated.
- Opportunities for open and respectful discussion of concerns, especially concerns raised by those with competing mindsets take place regularly.
- Financial and other support for former mindsets is gradually phased out as laws and regulations and funding streams change in line with the new mindsets.
- Gradually a tipping point is reached and the vision is at least partially realised.

All of this takes time but we are in the business of changing mindsets and participating in social change can be very exciting. The revolution in disability began in the 70s and continues to the present day. Contributing to this ongoing revolution with our voice and energy is one of the most rewarding and worthwhile aspects of working to improve the lives and life circumstances of people with disabilities. Theodore Parker, an American Abolitionist, said in 1857 "The arc of the moral universe is long but it bends towards justice". We are doing our part to bend that arc.

> ***We are working for the day when children grow up with friends and neighbours with disability in their schools and communities and think this is the way it has always been and are shocked when old people tell stories about how it used to be.***

Sharing life in community: the value of friends and partnerships Dianne & Greg Exelby



Dianne and Greg Exelby live in the North Queensland city of Townsville. Their son Scott was born with significant physical and developmental disabilities and they were told he would never live a ‘normal’ life. Having rejected this prognosis Greg and Dianne have worked together to ensure that Scott has the life they know he deserves.

In this article Greg and Dianne explore how the support of their family, friends, support services and community have enriched Scott’s life. Their story is testament to the value of holding a vision, choosing the ordinary and embracing the gifts available in the community.

Sharing life in community: the value of friends and partnerships

When Scott was born 26 years ago, and we were told he had Cerebral Palsy, we could never have imagined the young man he is today. We were told that he would never walk or talk, he was blind and severely intellectually impaired and that he could never expect to live any kind of a “normal” life.

We never accepted this. Part of this may have been denial, but we also knew our son and knew he was so much more than the label that was being attached to him. To us as a family, Scott has always been Scott, not Scott with a disability. This is how we have presented him to the world and we have always had an expectation that this is how he would be seen and accepted by others.

Scott has always been his own best advocate. From the time he was young, his personality has drawn people to him, and once hooked, they rarely get away. We chose, and fought for, an inclusive education for him and from pre-school to year 7 Scott attended a mainstream school. He was expected to participate in classroom activities and the teaching staff and his fellow students learned and gained as much from him, as he did from them. Scott made one particularly good friend from this time who still catches up with him on a regular basis and has never forgotten his birthday.

We were not able to find a suitable mainstream high school for Scott. He attended a special school which offered an “outreach” program in which Scott could attend some classes of interest at a mainstream high school. Through this, Scott met an art teacher and through her interest and encouragement, Scott discovered and developed his artistic abilities.

Whilst our son did have some worthwhile experiences during this time, overall we felt his secondary years were very unrewarding and unproductive. We were all relieved when it was over.

When Scott graduated from high school things changed and we saw that our next challenge was to find interesting and fulfilling activities for him to replace school. At this stage we were thinking of activities to entertain and occupy Scott, such as ten pin bowling, swimming, fishing, and music.

Without the routine of the school day Scott required more assistance from his parents, particularly his mother. Greg had to sell his business and take over work at Diane’s business. This change to our lifestyle started us on our quest to ensure Scott was living a good adult life.

In her research Diane attended conferences and workshops with the assistance of Community Connection Inc. (CCI) in Townsville. This encouraged us to broaden our vision for our son and to focus more on life and meaningful goals. Our family feel very fortunate to have been associated with CCI since Scott was 5 years old. As well as providing well matched support workers, they have also been there to support us in our planning for a good life for Scott. Importantly, they encouraged us to search for more active roles for Scott.

One of the real turning points for our son came when Diane, and three of Scott’s support people (one paid worker and two friends), attended a workshop given by Janet Klees from Canada. We were all very excited to hear the achievements of the people she works with in Canada and realised there could be similar opportunities available to Scott. We just had to find them. As a result of the enthusiasm and dedication of these people and those they enlisted, Scott has gone from just filling-in his days with activities, to become a valued and contributing member of the community.

As a starting point Scott was encouraged more and more to have a say and find his voice. This was not an easy thing for him as he had become so used to others talking for him and making decisions for him.

Our son's life is now much richer and he has much control over how he lives his life. Twice a week, Scott volunteers as a reading helper at a local primary school. Children in Year Two read to him, Scott listens to them and when they have finished, he asks them questions about what they have read. He is well respected and liked by teachers and children and has become a well-known member of the school community.

Thanks to the flexibility of CCI, we have employed artists to develop Scott's artistic skills. This has helped to give him the opportunity to become a recognised and successful artist. He has a stall at the Strand Night Markets in Townsville once a month where he sells his artwork on greeting cards and framed prints. One of his regular clients teaches at the school that Scott volunteers at, which is an indication of the natural connections he is building.

Scott had no idea of how money or shopping worked, so as a team we set this as a goal. With the assistance of a support worker, the simple activity of writing his shopping lists and then selecting and paying for his groceries has extended to a broad range of other ordinary daily activities that gives Scott control of his life. He now visits the bank regularly to withdraw cash for his weekly expenses, collects change for his stall at the Strand Markets and in turn deposits the money he earns from those markets. This is but a snapshot of the things Scott does during the week, but it shows how much he is learning and growing from the control he now has over his life.

As a consequence of these and other successes, CCI worked with Scott to prepare a slide presentation which gave Scott the opportunity to become a co-presenter with his support worker. This provided the opportunity for Scott to become a role model within the community. His presentation was created to inspire others by sharing how his achievements had been accomplished. He has presented to families and the managers of local service providers as well as organisational training for support workers from a number of different agencies.

Scott is now much more confident about having his say. An example of this is when one of his support workers took Scott to an interview with an employment agency. The agency worker was very good and was addressing her questions to Scott rather than the support worker and he was doing a good job of answering. At one point the support worker started to add to what he had said but realised Scott was glaring at her. When asked, he said he didn't want her to answer for him.

When Scott was 21, he had the opportunity to move into an accessible two bedroom unit which is perfect for him. This has been Scott's home now for three years and he has become well-known in the small close-knit street. We heard about 'Life Sharing' and thought that this would work well for Scott. One aspect of Life Sharing can involve housemates living with, and providing support and care for a person in exchange for rent concessions. When we chose this path we did quite a lot of planning to define the role of housemates for Scott. This way we were clear on our expectations and what support would be most helpful for him.

Scott's first housemates were a couple who spent a year with him until they finished their studies and moved back to New Zealand. This was a very positive experience for everyone and it provided Scott with lots of independence from us. These housemates are still in regular contact with Scott.

It took about ten months to find the next set of housemates and this didn't work out quite as well. They only stayed for five months and they relied too heavily on family to fill in the gaps. At the moment Diane is living with Scott so that he can stay in his unit which is not ideal and this creates some difficulties. This situation is only temporary and we believe this is where our son wants to be and how he wants to live, and so we hold on to the belief that we will find the way. There is no rule-book or guide to show us how to get things right the first time and not all plans have worked out. That being said we learn together and take away the lessons we need to help make future ideas work. We are trying to look outside the square and are investigating some different options.

A major part of Life Sharing is building a supportive community around Scott. This has been a great success and Scott now has friends who have offered to be the 'second person' so that he can safely go swimming regularly with his support workers. During the course of us writing this article, two other people have offered to assist Scott at the Strand Markets!

Our son is blessed with many proactive and motivated people in his life. When he turned 24, his flat mates and Support Workers organised a birthday party for him. Diane was visiting her mother and had no input to the planning. When Greg arrived he was pleasantly surprised to realize he knew only about one third of the guests. The family of one of Scott's mates provided live band music for the night and listening to Scott singing "Highway to Hell" was unbelievable.

The fun that Scott and all his friends had at that party confirmed that we have made a good start, but also that we still have unfinished work to do. Our hope is that one day what we have started with these friends, flat mates and support workers will broaden to include even more people who become an integral part of Scott's future so that he continues to live a good life.

SRV, Change, and Good Lives Greg Mackay

Greg Mackay has an extensive history in human services and has worked for a range of government and community agencies. He is currently the president of Values in Action Association (VIAA) Inc., a community organisation that promotes the use of Social Role Valorisation (SRV) as a way of understanding how organisations might best orient themselves to the people using human services.

In this paper Greg explores the history of SRV as a framework and the legacy of SRV that exists in Queensland today. He highlights how it is essential to have a sufficiently robust framework for change to ensure meaningful change is created. Finally, Greg shows how SRV offers this and much more to anyone looking to create positive change in both the lives of people with disability and the services invited to assist them.

SRV, Change, and Good Lives

Having a robust 'thinking' framework to understand how to address the needs of marginalized people helps us achieve three things. Firstly, it helps us identify our underlying assumptions and beliefs and requires us to develop a clear idea of our intentions and direction. Secondly, it helps us to identify the most effective approaches to use, thus avoiding taking up an approach that is no more than the latest fad; and thirdly it utilises an evidence base that helps turn possibilities into likelihoods. I, and many others across the world, have found that SRV ticks these boxes.

This paper examines the use of Social Role Valorisation (SRV) as a theoretical and practice framework, its legacy in Queensland and its worth as a framework for developing human service responses that are most helpful to the people at the heart of our efforts for change.

In the absence of a decent conceptual framework, people rely on habit and history. For example, how often have you found when asking someone why they do something a certain way they say that 'we've always done it that way' or 'that's how I was taught'?

Prior to the significant changes occurring throughout the 1970s and '80s in Queensland, the support provided to people with disability was restricted by outdated and limiting ideas that existed due to habit and history. The framework that counteracted and challenged these old ideas and showed a new way forward most effectively was SRV.

What is SRV?

A very brief definition of SRV is 'valued roles for devalued people'. In other words, if marginalised people want access to the good things of life and to be well regarded by others, then being in positively valued roles will help. Getting and keeping those roles will be greatly assisted by paying attention to people's competencies as well as the image they project.

Importantly, SRV is a social theory and not values-based training. In other words, it provides us with a framework of thinking rather than a set of rules. Whether or not we care to apply SRV or even elements of SRV are values-driven decisions. Of course having values that decry prejudice and a passion for all people having equality and decent lives makes for a fertile ground for SRV.

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What SRV offers

Why might we choose SRV over other conceptual frameworks for designing responses for assisting marginalized and devalued people?

First of all, SRV comprehensively addresses service design for devalued people; other frameworks tend to focus on only one or two elements of what is required. For example, rights based approaches might reduce all issues to 'rights'; person-centred planning often focuses on planning but not implementation; the social model of disability at times ignores people's vulnerabilities. Of course these are all useful concepts but are insufficient for designing well thought through responses that relevantly and potently address people's needs and desires in ways that are most likely to lead to a good life. By SRV taking such a comprehensive approach, one that considers all of the issues in providing good service response, it maximises the likelihood of good outcomes for the person.

SRV raises our consciousness about vulnerabilities and the psychological and physical hurts that come from rejection, segregation, abuse etc. In developing this theory, Wolf Wolfensberger was very clear that **people's experiences,** including the unpleasant things (wounds) done to them, influence what a person's fundamental and urgent needs might be. We can look to what is important to the person and for the person but we must also be highly conscious of the wounds they've experienced. Not being aware of wounds like rejection, discontinuities and distantiation (distancing) means they could remain unnoticed. Even worse though is where service responses focus on the behaviours arising from such wounds. This leads to behaviour management rather than responses to the wounds and the impacts on people.

The SRV framework gets us to understand the impact of service decisions and societal actions through the eyes of the most vulnerable recipients of service. In learning about SRV, we are encouraged to stand in the shoes of people with a devalued status. This then helps us understand just how service responses have impacted on the person. It also assists us avoid the overwhelming focus on things like the administrative and financial constraints in the first instance. In other words, it helps us to identify the most effective approaches to use, thus avoiding taking up the latest fad.

As we begin to design responses, SRV invites us to 'think typical', that is, to consider what is culturally valued. This assists us to develop support arrangements that clearly lead people to have lifestyles like others, and to have valued roles that are likely to provide the person with access to the good things in life. This was a core teaching of Wolfensberger, and his colleague Susan Thomas, as they developed and refined SRV.

SRV lays out a set of comprehensive strategies for both the analysis of services and the development of personalised responses. In my opinion one of the most useful and critical Wolfensberger frameworks is that of model coherency – it shows us how to most effectively construct individualised responses as well as what not to do. Model Coherency shows us the difference between the service content and service processes. We are then able to develop the most relevant and potent responses to addressing peoples' needs and pursuing their dreams.

SRV's Origins and Historical Place

By the late 60s in North America, other countries and in some parts of Australia, including Queensland, the Community Living Movement was gaining momentum. This movement was focused on people with disabilities either leaving segregated, congregated institutions or being supported to live better lives in the community.

In the same period the Principle of Normalization was developed (followed later by Wolfensberger's Social Role Valorisation), and like the Community Living Movement, its intention was to see people with disabilities living good lives in typical community contexts.

By the 80s and 90s significant change was occurring, driven by a clear vision of community living, and by people who were committed to this vision and SRV as a theory. Michael Kendrick has noted that SRV contributed *'to the shift in professional opinion towards a preference for community living, the induction into the system of dissident young people in large numbers, the family and related advocacy movements and the key role of pivotal professional leaders in service and government roles'.*

The SRV framework gets us to understand the impact of service decisions and societal actions through the eyes of the most vulnerable recipients of service. In learning about SRV, we are encouraged to stand in the shoes of people with a devalued status.

The Queensland Experience

The Queensland Government decided in the late 60s to create a system whereby people with disabilities would be housed separately from people with mental illness. The new system commenced in 1976 and the institutional arrangements were immediately replaced with, among other things, new complexes being built to house people with disability in areas across Queensland. Efforts were made to move people out of the institutions into houses in the community, mostly in groups of six.

All of this effort was based on the Scandinavian version of Normalisation, which focused on ‘as normal an existence as possible’ and ‘normal patterns or conditions of life’. Despite Wolfensberger’s North American writings on Normalisation, the Scandinavian model never incorporated thinking about ‘social roles’ and associated concepts.

Why does this early Queensland experience matter?

The Queensland Legacy

The distinction matters because Queensland chose the Scandinavian approach. Wolfensberger’s teachings about the importance of roles, which grew into SRV, were never really adopted. Perhaps the implications for doing so were just too much: too much effort, too much money.

In the mid 80s, the Commonwealth Government, through its massive change effort leading to the 1986 Disability Services Act, did use SRV as a key informant of the new service types and the subsequent legislation. The Commonwealth invested in SRV by sending many of its staff and agency staff to SRV training. The Queensland office actively sponsored the development of quite a few services and advocacy programs that were strongly influenced by SRV and by other Wolfensberger formulations.

Then, in 1992, the Hawke government, transferred responsibility for services (other than employment and some advocacy) to the States. While SRV concepts figure heavily in the State legislation, the State still resisted implementing SRV-informed approaches.

The legacy of these matters is that Queensland has a service system that ranges from quite restrictive approaches, including small congregated and segregated sites, through to services and advocacy programs that still use SRV as a key theory to inform practice.

Where are we now?

SRV remains very popular with various groups: those who were exposed to it in the days of changing from restrictive, institutionalized responses; those new to the sector who have SRV-influenced mentors; and families and people with disabilities. However it is also fair to say that many services don’t even know SRV exists. This is a worrying situation because without a decent theory to inform practice, my experience tells me there is little or no understanding of ‘quality’ apart from bureaucratic measures and nothing to guide practice except good intention. A sign of modernistic thinking is seen in assertions that nothing from the past can teach us about the present and future. Rather than being past its use-by-date, SRV as a 40 year-old theory is as relevant to the group-based building-based services and also to the creation of individualised better lives today as it was in the 1980s.

Too often I have seen responses that are influenced by the enticements of funding, the limits of bureaucratic rules, the imperative of keeping the senior echelons embarrassment free, swayed by the demands of unions and so on. SRV is the only comprehensive framework that keeps our eye on the person and their needs and dreams while examining how best to meet those needs. Its central idea of enabling people to have valued social roles is as relevant to people with disabilities, older people, people with mental health issues as it is to refugees and young people. It is relevant to a range of service and personal environments. It is simple yet complex, and enlivening yet challenging.

Robert Flynn and Raymond Lemay speak succinctly to the issue of declining change efforts: *‘It is a truism that intellectual and reform movements must renew themselves on an ongoing basis to counteract the staleness and entropy that menace them from within and the rapid changes in context that threaten them from without’.*

For those who truly want to see people with disabilities get a life like others take for granted, then it is vital that we equip more people with knowledge through theory, provide opportunities for critical reflection and development about their practice, and opportunities to gather with like-minded others.

> ***If marginalised people want access to the good things of life and to be well regarded by others, then being in positively valued roles will help. Getting and keeping those roles will be greatly assisted by paying attention to people’s competencies as well as the image they project.***

CRU’s Resource Collection holds a comprehensive collection of SRV resources. Please contact us if you are interested in reading more.

We also recommend “Advanced issues in Social Role Valorization” and “A Brief Introduction to Social Role Valorization”, 4th edition, by Wolf Wolfensberger. These can be purchased from our online bookstore.

Taking a deep breath and moving forward. Transforming Milparinka

Frank Crupi

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".

Taking a deep breath and moving forward. Transforming Milparinka

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.

> ***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.***

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.

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.

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 measureable 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.

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.

Possibility, peers and the spark of change. Libby Ellis

Libby Ellis has a long history in the community living movement. Having grown up with her brother Matthew living in a hostel and then group homes, her family made the decision to move Matthew in to his own home in a community of his choosing. Libby is the founder of InCharge, which works with people with disability and their families to create a vision for a meaningful life with possibility, potential and where people are able to direct their own support towards their own goals.

In this article Libby builds on the metaphor of a 'charge' ; "sparking a fire" to inspire a new vision of change that is more achievable and less of a leap into the abyss. She highlights the importance of connecting with others, embracing possibility and taking ownership of this new and richer way of looking at what change is.

Possibility, peers and the spark of change.

Institutions come in all sizes, but they all begin with separation. Such separation shapes the identity of the people who live in them – not just how they are seen by others but also how they see themselves and their place in the world. My brother Matthew grew up in institutions. Living away from us firstly in a hostel and then in a number of group homes. That was a long time ago and much has changed since then. We have come a long way down a path that has helped us to create a real place of belonging for Matthew – in his own home and a community of his choosing. In this article I am exploring what it took from within us, for this change to occur. It started with a 'leap of faith'.

I had an insightful experience recently around leaps. I needed to make a decision around something that felt emotionally hard and I was encouraged to try something different to my usual 'think it out' approach. Somebody close to me suggested I try a process to gain a different perspective to get me out of my head. This person has much experience helping others who have the same affliction.

The process was to externalise the decision, to help me move from my head to using my body and objects. I was asked to choose objects to represent the decisions or the problems as I saw them and then I had to place them wherever they made sense to me. Very interestingly, the decision I perceived most difficult was the one I placed closest to me. The person invited me to take a step into that place in order to feel what it was like to be there. I had perceived this step as an enormous leap, too hard to take safely really, but there it was, in front of me, only a footstep away.

I was then told to literally step in to this new space and yet I hesitated... a lot. I saw it right there in front of me. Strangely it was very scary to take the step but once I did, I knew as soon as I was there that it was the pathway I wanted. When I was ready this unfathomable leap became just a step.

What I think happened was that I stepped out of my thoughts and their supposed logic and into my gut and heart space. I felt the change I needed to make and this made all the difference. When I felt it, I couldn't talk it away - there was no going back. All the difficulties still seemed to be there, in the path of this decision, but my perspective on them changed. They began to feel less like difficulties and more just things that may (or may not) happen and just a natural part of the process.

Building the stack

This was what it was like for my family in the build up to when we helped Matthew move into his own home. Some of my earliest memories from this time involved a lot of communication within my family about what was wrong with Matthew's life. A lot of complaining, if you like. But we did it with each other as we shared the inkling that surely life has got to be better than this. During this time we were building our understanding of what it was we were not happy with. This was in the days before self-direction or personalised support and notions like 'consumer governed' or 'family governed' had not yet crossed our paths.

I also remember being present with other families at conferences and education forums as we grappled with the question of 'what could be'. The conversations started with all the things that are wrong and moved over time to better ways of doing things to not only replace them, but to make them obsolete. Piece by piece we were building a vision of a better way.

For my family the vision we were building included Matthew having his own home and a crucial element of this was wanting Matthew to not have to face strangers any more. The pain of dropping him off at the group home to a stranger who didn't know him or how to communicate with him or even take care of him was excruciating. The heart ache of that was too much. Imagining him at one moment being understood, nestled and loved, and the next moment being completely on his own amongst others, fending for himself, was awful.

Inside us at that stage were murmurings that things weren't right, but we needed an external trigger that helped us see the possibilities. All we needed was a spark to ignite us and turn these imaginings into possibilities. We needed to be exposed to the possibility that somebody with a severe intellectual disability and autism who doesn't speak could have their own home and that other people without disabilities would want to live with this person.

What happens for so many people and families is that they live in systems where others are traditionally given the role of problem-solver. This encourages families to dwell in problems and as they are encouraged to give over their power to others in the belief that those others are the ones who will create the solutions. It can also encourage them to dwell in waiting – waiting for the funding package, waiting for the next service. When people are waiting they are largely passive. It is the path of victimhood. We found this to be a bitter, soulless place to be.

SPARK

When something else comes in there – I see it as 'possibility' – then there is the spark that can lead to a shift. I define possibility as something I have not yet imagined for myself and this is always most powerfully communicated through a peer – that is, seeing that it is possible for someone like me. 'Possibility' was the kind of external trigger we needed and once we had that our imaginations ran wild. We dared to imagine him being involved in his community because we saw that others were doing it. We dared to imagine him living with someone who didn't have a disability because others had shown us it was possible.

'Possibility' has got little to do with centres or service providers or case managers or assessments. Ironically, 'possibility' dwells in ordinary things that make life great for all of us and makes us want to get up in the morning. These things are the possibilities for all people, even people who most challenge us.

IGNITION

Once we were ignited by possibility, we needed to take ownership of that possibility; see it as not just an idea somebody else had made happen for themselves, but something that could fully take its own shape in Matthew's life. We were the ones who needed to make this change. It was not the responsibility of anyone else – government, service providers, case-managers, Local Area Co-ordinators etc.

That is not to downplay the importance of collaborating with others. We had many genuine and valuable allies that helped us make our vision for Matthew possible. In fact having professionals on board helped us facilitate new breakthroughs. They were most useful when they were true allies. Allies because they had taken ownership of the part they could play in change. Their work was genuinely transformational and that's what made them good.

I also remember inviting our long term family friend, Jane, to help us. She became Matthew's first circle member when we all began talking together. I remember my mother's tenacity and strength.

FANNING THE FIRE

Once people are ignited then a fire is built. That's when we see this idea of a fire burning in people's lives so this is then about creating and tending to what you imagine. Moving from possibility to imagination to then creating that thing that you want. These are really the conditions for personal autonomy, for being in charge.

I remember when we had been overcome with the possibility of Matthew moving into his own home. I would wander the suburb where we imagined his home would be (a suburb close to my university where many of my friends and other young people lived). I would stand in front of lovely homes (not grand homes) that I thought he would like to live in and picture him there.

It is important to continue to add fuel to your own fire by keeping in touch with peers and possibilities. The point is not to light the fire once, but to keep it burning and the more people attend to a fire the longer it is going to burn. We are thinking about this idea of sustainability, of keeping something going, of keeping something alive. For this you must do another potentially challenging thing. You must be with others, especially those that can lovingly challenge you, and you must nurture those relationships. If you do this work on your own you will have a harder job keeping that fire burning.

I know that Matthew's life, with supportive networks (both paid and unpaid) around him, is something that helps other brothers and sisters to get involved and plan for the future. To feel more able to think about developing, building and sustaining these supports after their parents have died. If there aren't these networks and all you can see is you, it starts to feel again like an enormous thing you will have some-day to 'take on' – but this is for another article!

CONCLUSION

The lessons I have shared from our experiences with Matthew are relevant both on a personal level but also one much broader. The process I have outlined above is relevant to people looking to create change in systems as well as in the lives of individuals with disability.

The families of today are taking these leaps and being ignited by the 'possibilities' shown by other families. They are grabbing the possibilities – stepping in to them, feeding them and making them their own. They are building networks to fan the fire.

My hope for the future is that we can assist each other, from the space of radical change, to grow new organisations, projects and enterprises. Working with people as they do this work for themselves, so that when they take this leap, it might not feel like a jump into the abyss.