

CRUCIAL TIMES

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Contents

- 1 **Editorial**
Lynda Shevellar
- 2 **From the President**
Mike Duggan
- 3 **The Difference between the Possible and the Impossible Lies in a Person's Determination**
Anne Garton
- 5 **Resilience, The Developmental Model and Hope**
Ray Lemay
- 7 **Some Thought on Personal Engagement, Resilience and Social Movements**
Libby Ellis
- 9 **What Can Recovery Teach Us About Resilience**
Helen Glover
- 10 **Resilience: Taking the Long Way Home**
Sharon Bourke
- 12 **Exploring Creativity and Humour as Pathways to Resilience**
Kevin Follett

Editorial

Discovering The Deep Well Of Resilience Lynda Shevellar

As we move towards the end of another year it seems appropriate to dedicate this edition of CRUcial Times to the theme of 'resilience'. As we reflect on the year, we are amazed at the repetition of history. Trends and themes that have been dealt with in previous years are re-appearing. For example, congregated models of service continue to be promoted; services remain under pressure to simply 'fill empty beds'; people with disabilities are still subject to abuse and trauma and for many, there is still a daily struggle for a rich and meaningful life. We watch the same things emerge that have occurred many times previously and we hear allies asking: How can this be happening again? Does no-one remember? Do I have the energy to face this again? In this edition of CRUcial Times we have invited numerous people to share their experiences and thoughts about what helps us to be resilient in the face of such challenges.

Resilience is about facing adversity with hope: it is the process of adapting well in the face of stress, trauma, tragedy or threat. Just as these stresses and threats occur at multiple levels, so too do we need to develop resilience at those multiple levels. We need to think about creating resilience personally and within our families and socially, within our communities.

While it may sound heroic, resilience is ordinary and everyday. It is not simply a quality that some people possess and others lack. We all are resilient. However, research suggests that there are things we can do to build our capacity to face adversity. Work through the International Resilience Project demonstrates that a nurturing environment that meets people's needs for caring, connectedness, respect, challenge and structure and for meaningful involvement, belonging and power enables people to directly access their own inner resilience. It is interesting to think about the environments that many people with disabilities live in and whether they meet these requirements for respect, nurture and challenge. We may also think about our working environments, where we spend much of our time and ask whether they create spaces for connectedness and belonging.

CRU's MISSION STATEMENT

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

Margaret Wheatley, a commentator on social change and leadership, says that many of the models we use to understand our world are based on 17th century scientific thought and an imagery of machines. Terms such as needing to ‘bounce back’, ‘spring up again’ and of having the ability ‘to keep on keeping on’ are used as though we are made of steel springs or pistons. Views of organisations, families and even, individuals are based on the idea of an engine, which is destined to eventually run down. In such a model, entropy is inevitable. Instead, Wheatley challenges us to embrace modern science and the complexities and paradoxes of chaos theory. She observes that, when confronted with stress and difficulty, living organisms do not simply wind down. Rather, when they fall apart, they take the opportunity to reorganise themselves, adapt and grow.

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Similarly, in her book *Resilience*, Anne Deveson shares an image that it is infinitely more complex than any machine. She says ‘Resilience is the life force that flows and connects every living thing, continuously prompting regeneration and renewal.’ Resilience is thus a process of taking things more deeply into ourselves, so that we rise each time with greater wisdom, like a wave pulling energy in and then pushing energy out. Taking time to take care of our bodies may provide physical resilience, but to find hope, we also need to take care of our spirit and this requires connection rather than disconnection with the world. Resilience requires us to go deeper in our understanding, to meditate, read, pray, reflect, sharpen our focus, connect with like-hearted individuals or to spend time exploring our core values and beliefs. Art, music, dance, poetry and all other creative endeavours are ways of extending the mind’s mental and physical flow, interrupting our hope-less ways of being in the world. As Wheatley suggests, it is in these creative moments that we connect to the spirit and ally ourselves with life, celebrating the gift of each other and discovering the deep well of resilience within ourselves.

From the President

Mike Duggan

What is CRU? What might it represent in people’s lives? Different people will give you different answers. For some of us CRU is a ‘place of space’ — where listening, allowing and accepting (however difficult) is the ‘beginning space’ for conversations. For others of us, CRU is a ‘place of the heart’ — where compassion and support (however imperfectly) are offered. For yet others of us, CRU is a ‘place of hope’ — where possibilities and small movements forward are entertained (however briefly) somewhere in a day. And perhaps, most importantly, CRU continues to aspire to be a ‘place of courage’. Not courage in the dramatic and heroic sense, but more the courage of persistence and perseverance. The courage that it takes to put forward a challenging set of values and then in daily life to try to be somewhat true to them. For, in the final analysis, CRU has been respected and supported for a long time because of who we have tried to be as much as for what we have tried to do. An authentic ‘quality of being’ is the invisible foundation for any organisation that seeks to make a difference in the world. Perhaps ultimately CRU is a ‘place of friendship’.

As this edition of CRUcial Times is focusing on the concept of resilience, I would like to ponder ‘Organisational Resilience’. After some research, I believe that there are basically five principles of organisational resilience:

Leadership: Organisations need leaders who will set the right balance between maintaining the focus on the values and vision, while setting priorities and allocating resources and who will steer an organisation, faithful to the values and vision, in pursuit of its goals and correct its course in times of risk.

Culture: Resilience is more likely to be encouraged within organisations which build a culture based on principles of empowerment, purpose, trust and accountability.

People: When care is taken to involve people within an organisation who mirror the values and vision of the organisation, they will be more likely to be motivated and equipped to focus on priorities and work towards the goals of the organisation in the face of obstacles or disruptions.

Systems: When the values base not only informs, but really drives practice, the focus of an organisation remains firmly on the people served, while working co-operatively with government and bureaucratic structures.

Settings: Organisations with welcoming, pleasant and open environments facilitate commitment, enthusiasm and involvement and encourage and build workplace resilience.

So how does CRU maintain its resilience in the face of the many formidable challenges of its work? An important and very relevant factor for organisational resilience may rest with the commitment of CRU and the people within CRU to the following:

- To continue to be clear and vigilant about its commitment to the positive value of people with disabilities and their needs for a decent life in the community;
- To continue to make people with disabilities and families the centre of our work;
- To seek ways to make it possible for the grassroots and leadership of the community sector to be visible, focused, united and influential;
- To continue to inform and encourage people who are working to protect and promote the interests of people with disabilities and
- To seek and support opportunities for innovation and positive change.

Upholding such ideals can be a formidable task. It can be physically and mentally exhausting, emotionally strenuous and morally challenging. Identifying and working on 'cutting edge' issues in the disability field is certainly no easy task. However, when challenge and adversity are countered by organisations built on a strong values base and resilience, the very positive outcomes of renewal, strength and hope are fostered.

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The Difference between the Possible and the Impossible Lies in a Person's Determination

Anne Garton is a triathlete and a mental health advocate and is actively involved with mental health organisations. In July 2005, Anne took part in the 1,945 kilometre bike ride from Brisbane to Cairns, organised by 'A Place To Belong' to raise awareness of mental health issues. Anne's deep-seated drive and passion to fight for and advocate for the rights of people with mental illness is founded on her personal resilience. In this edition, Anne describes her journey of recovery through her triathlon achievements and speaks out about mental illness. She describes her goal to be an ambassador for mental health and to reduce stigma and fear and promote community inclusiveness.

I was living my illness. It consumed my every thought and behaviour. I was fast tracking down the road to nowhere. Locked up in hospital for months at a time — my reality was padded cells, locked wards, involuntary patient, electro-convulsive therapy (ECT), medication; forced to resign from a professional career, sell my car, move into subsidised accommodation and reliant on welfare — Disability Pension. I experienced stigma and discrimination, was called names and felt shame and humiliation when asked: 'What do you do for a living?' And I would have screamed if one more mental health professional told me to 'have hope' and 'things can get better'. How would they know? They didn't have a clue. I thought things could not get any worse. I had hit rock bottom; life seemed an unbearable agony, a living hell. I could not take any more, I couldn't cope.

During one particularly bad time, I fantasised about what I would be doing with my life if I were 'well'. I compiled a list: 'Things I Wish To Do Before I Turn Thirty'. Top of my list was 'To compete in a triathlon'. So, I simply decided to do it. It was the most difficult thing I have done. And it still is.

I began by joining a beginner's triathlon squad and learning how to swim, bike and run. Then, as now, before I can even begin to swim one lap of the pool or turn the pedal of the bike, I have to fight my mind; I have to push past the loud voices and screaming, horrific roar in my head, push past the paranoia, confusion, overwhelming apathy, terror, zero self-esteem and depression. Often tears pour down my face during a training session — it is so hard to push past the illness in order to train. But I do it; I refuse to quit because if I quit, my illness has won yet again.

Nothing was going to stop me, not even being in hospital for long spells. I spent the entire four months of the 2003-2004 triathlon season in hospital. It would have been so easy to give up and just mooch around the hospital for the four months. No way! Illness had taken everything else from me — it was not going to take this. So with permission from the doctors and nurses, I attended training sessions with my squad and raced on weekends. And guess what happened? I won the Queensland Triathlon State Titles series. In 2003-2004 I was the fastest person in Queensland in triathlon in my age-group. I had won a State Championship Series. I had succeeded in the ordinary world, despite being hospitalised and really unwell. Then I came third in the second largest triathlon in the world, the 2004 Noosa Triathlon. Once again, I raced whilst significantly unwell and on overnight leave from hospital.

In the 2004-2005 triathlon season, again I spent five months in hospital, but I raced whenever I could and managed to win or place almost every time. Despite being very unwell everyday of those five months, I trained. Many days I could barely pedal or, because my head hurt too much to run, I had to walk. But I did it everyday, I never quit. Sometimes, I got weekend leave to attend races. The doctors and nurses thought it was bizarre, especially waking me up at 4am on race days! Friends or family would collect me pre-dawn from the Hospital, drive me to race and then drop me back afterwards.

But this year, it got even better: I was selected on the Australian Team for the 2005 World Triathlon Age Group Championships in Hawaii.

My mental illness has proved to be no barrier to achieving my goals and dreams. Realistically, it could be argued I can not afford to go to the World Championships in Hawaii — the Disability Pension does not pay for international airfares. But this won't stop me. Trust me, I will find a way.

So why am I so determined and why do I refuse to quit despite significant illness? Not because I have achieved success in triathlon, but because triathlon gave me my first taste of an ordinary life, what I term 'the other side'.

For me, the 'other side' is like chocolate — once you have the first taste, you crave more and more until you want it everyday and in every part of your life. The 'other side' is the happiness and pure pleasure I

feel when I ride my bike along the esplanade, watching the sun rise over the ocean. It is the feeling of accomplishment and satisfaction after finishing a tough run. Feelings I had never had before. It is even the feeling of failure — because failure means I have a new challenge to overcome. The satisfaction of achieving something that I previously thought I could not do is the ultimate buzz.

With each small success, I started believing in myself and to recover.

With each small success, I started believing in myself and to recover. I finally accepted I had a mental illness, educated myself about my illness and sought treatment. Every day I get stronger and stronger. I can now cope and manage my symptoms much better and in a more positive way. I have had fewer hospital admissions this year and no

longer regard myself as mentally ill. I am an ordinary person; I just happen to get sick sometimes. Sometimes I lose my way, have a relapse and end up in hospital, but it is different now, because now I have hope. I know things can be different; I know setbacks are only short-term and manageable — I have been to 'the other side'. And despite the ravages of my illness, I have found something that makes me truly happy. Triathlon is my chocolate.

Postscript:

On 8 October 2005, I represented Australia in the World Age Group Triathlon Championships in Honolulu, Hawaii, despite having spent the eight weeks prior to the race significantly unwell in hospital. I had a bad race and placed 51st out of 100 women in my category. I know I could have raced much harder and faster but I refuse to let this upset me. For me crossing the finish line was the highlight of the race. I had done it — I had raced for Australia in the World Championships. My family were standing at the finish line and I was still puffing when I hugged them. Nothing beats having family at the finish line. And for the first time in many years, my family and I cried happy tears instead of the all-too-frequent tears of anguish and pain. I was a winner just for being there. More importantly, I had clearly demonstrated that disability is no barrier — anything is possible. Thanks to the support of my family, my triathlon squad, even the doctors and nurses, there I was, decked out in the green and gold Australian uniform, racing for Australia — it was magic, pure magic.

The ABC Television Network has been filming Anne Garton during the last few weeks for an Australian Story planned for February 2006.

Resilience, The Developmental Model And Hope

Ray Lemay is the Executive Director of the Prescott-Russell Services to Children and Adults in Plantagenet, Ontario, Canada. He is widely-published and has written extensively on normalisation and Social Role Valorization Theory (SRV). On a recent visit to Australia in 2005, Ray conducted a workshop in Brisbane, entitled 'Promoting Resilience'. In this article, Ray explores the concept of resilience and discusses links between resilience theory and the protective processes that enable people to successfully adapt and develop, following situations of adversity.

The surprising story of twins, Andrei and Vanya, was published in 1976 by Jarmila Koluchova, the psychologist who supervised their care, following their discovery. They had been kept locked up in an unheated basement or in a closet and were often brutalised by their parents. The neighbours did not even know they existed. When they were discovered by child protection authorities, they had stunted growth, little language, significant fine and gross motor delays and rickets. The child protection authorities assessed them as having IQs of 40 and concluded that the years of severe deprivation and abuse would leave these children with mental and physical disabilities for life. However, when Andrei and Vanya were placed in the foster care of a single woman, who provided a loving and stable environment, they quickly developed alongside their peers in the regular classroom. The most recent information on the twins is that they completed tertiary study, are married and have children: there is no evidence of any long-term negative effects from their early experiences. Koluchova believes that the simple provision of normative family life allowed the twins to bounce back and develop positively.

Koluchova's study of Andrei and Vanya created quite a stir in the 1970s and challenged the pessimistic dogma that still today animates much of human service. Is the story of the Koluchova twins exceptional or does it hint at something else of which we need to take account?

In the field of human services there seems to be a general pessimism about the outcomes of children and adults who have known serious adversity, including abused and neglected children and adults, or people who are born with or acquire significant disabilities. Human service professionals often assume that people with disabilities or others who have experienced serious abuse, neglect and rejection will not do well and develop responses and interventions based on this assumption. Yet how well might they do in life? Might they develop positively? What about their developmental potential? How might human service responses or interventions counteract people's experience of systematic devaluation?

In 1972, Wolf Wolfensberger suggested that providing people with normative levels of activity and normative life circumstances would have a beneficial impact on their competence. Indeed, he suggested that the people who would benefit most from such improved circumstances would be individuals who show the most significant levels of impairment and that even intellectual functioning could be dramatically improved. More recently, Wolfensberger described a developmental model of service based on a certain number of important assumptions about human beings. Among these assumptions, he noted that the developmental potential of individual human beings is very difficult to assess and he proposed that a person's developmental potential is only realisable in circumstances where life conditions and experiences are optimised.

The attribution of valued social roles and the experience of the good things in life will help an individual bounce back and liberate his or her developmental potential.

In addition, in 1988, Wolfensberger proposed that people with intellectual disabilities have a number of what he terms 'common assets' that are, by and large, repressed by their current, often degrading life circumstances which may include dehumanisation and brutalisation. The same seems to be true of people who have other disabilities or who have experienced severe trauma. It is not so much the disability or the trauma that represses positive development, but rather the continuing devaluation that they experience along their life paths. This train of thought suggests that a person might overcome much past adversity by simply experiencing typical or indeed valued life experiences and conditions (the good things in life), with all of the attendant roles and activities.

Longitudinal studies of cohorts of children growing into adulthood and middle age have generally confirmed that early difficulties in life, vulnerabilities and risks are generally overcome in later years. Eminent researchers and theoreticians have consistently identified resilience as a key factor in overcoming adversity. Indeed, psychologist, Martin Seligman, states that the general consensus is that there is no single childhood event that predicts future adult outcomes and Albert Bandura concludes that psychological theories generally over-predict psychopathology. One important longitudinal study documents how children who were born into significant disadvantage have done much better than anyone would have predicted. This study has been following 837 children born in 1955 on the island of Kauai. The men and women of this cohort identified that the informal support and advice they received from friends, families, colleagues and others was of far greater importance to their development than any support, advice or treatment from professionals, such as social workers or psychologists.

Similarly, resilience researchers, Ann and Alan Clarke conclude that it is the simple improvement of life circumstances and life experiences that leads to remarkable improvements in developmental outcomes. Resilience researcher, Ann Masten, defines resilience as 'good outcomes in spite of serious threats to adaptation or development'. She comments on the ordinariness of the phenomena suggesting that, by and large, resilience is the result of ordinary magic: 'Resilience does not come from rare and special qualities, but from the everyday magic of ordinary, normative human resources in the minds, brains, and bodies of children, in their families and relationships and in their communities'. This is quite in keeping with many de-institutionalisation studies which find that, in the medium term, after individuals with intellectual disabilities are moved from institutions to community residences, they generally exhibit marked improvements in adaptive behaviours. Many of these persons, mid-life and despite intellectual impairment develop new competencies.

Not only is resilience research and resilience theory consistent with our day-to-day experience, it is also wholly consistent with the developmental model as it is explained in Social Role Valorization Theory (SRV). Many individuals who are the subject of much devaluation and wounding resist heroically. Resilience research documents that ending adversity on the one hand and improving life conditions and experiences on the other, go a long way towards moving people back onto positive developmental paths and towards achieving their potential, irrespective of age. Thus, the attribution of valued social roles and the experience of the good things in

life will help an individual bounce back and liberate his or her developmental potential.

Resilience should be the expected outcome and all our interventions should be animated by hope.

The story of the Koluchova twins is not about two remarkable children – a rare exception to the rule that the experience of adversity inevitably will have negative long-term effects. Rather, it is much more hopeful, hinting that we need to take seriously the assumptions of the developmental model: that all human beings are capable of remarkable resilience and stories like Andrei and Vanya's should not be viewed as anomalies but rather as the expected outcome of intervention. When Social Role Valorization Theory underpins the application of formal and informal measures, we can predict dramatic increases in competency and important developmental progress for the person, regardless of their disability. No matter what, we cannot presume to know the limits of a person's developmental potential. Resilience research and resilience theory should inspire our positive expectancies for individuals and push us to create the opportunities required to maximize developmental potential. Resilience should be the expected outcome and all our interventions should be animated by hope.

References for this article and a bibliography of works published by Ray Lemay are available on request from CRU

Some Thoughts on Personal Engagement, Resilience and Social Movements

Libby Ellis lives in Sydney with her husband, Sebastian. She currently works in the advocacy unit of The Cancer Council of NSW and has also worked for disability advocacy and environmental organisations. In this article, Libby considers how her own personal resilience has assisted her not only to take an active and strong role within her own family's commitment to achieving a good life for her brother, but also strengthened her engagement to broader social movements and activism.

Optimism is not in believing that things will turn out well, objectively,
But in believing that one can face things, subjectively, however they turn out.
Optimism is not in feeling good,
But in feeling that good has a chance to survive.

Optimism flows not from defeats and bitterness or victories and joys of the past,
But in being here now, knowing that the past has strengthened you...

Burton Blatt: *In Search of the Promised Land: The Collected Papers of Burton Blatt*. 1999.

I wonder sometimes what keeps me going, right now especially, because I am not doing so well. I once had a lot of energy with which to face and I believed at the time, to change things; perhaps even to change the world. During my initial post-school years I had many hard times; organising protests, feeling frustrated that no-one seemed to care; I have even been arrested and faced the criminal justice system. It was only when my family began our efforts to assist my brother to come back to us and to move into his own home, that I discovered real struggle. I term this 'soul hardship'. This hardship has come about because many of our 'helping systems', our cultural discourses, our social and political institutions work against people with disabilities really pursuing the good life. We live in a disabling world that insists it is about 'enabling people'. This conceit is the first part of the struggle and its impacts have been deeply wounding.

At times it has been very difficult not to wither, become bitter or angry or feel overwhelming sorrow. Sometimes I have begun to plumb the depths of those feelings which can turn some individuals, groups and communities towards violence.

When I feel these tensions of 'soul hardship', I also know that to survive I must counter the hardship with something and in my soul lies hope. How could I justify vanquishing hope when all that will remain is hardship? I know my family must continue in our struggle and I never underestimate the power of hope; for me it is absolutely based in lived experiences.

My first mentor and inspiration, my mother, laid a strong foundation for critical thought. I learnt from her that in the world beyond my immediate experience, many people could not share the ordinary and everyday. Later at school, I was outraged when I learnt that twenty percent of the world's population owned eighty percent of the wealth. My Dad too had a role to play, especially his interest in his garden and the natural world. I went to my first protest march about saving and protecting Kakadu National Park with my Dad.

My mother especially spurred indignation in me, but she also tapped a curiosity about the world beyond my peers and in turn, doubt about the way things were.

Social movements have been very good at generating indignation among some of the population some of the time and using this indignation to spark and even, create important change. I think they could create a stronger connection with the wider community if they also tapped into people's curiosity. I alienated rather than connected with the wider population in my younger years, and it was easy to say that this was because no-one cared. However, I now believe that it is much more powerful to assume that the vast majority of people do care and that

everyone wants to be of use and to have meaning in their lives. These are the in-roads to people's curiosity, along which social movements must journey in order to create commitment to their cause.

I feel I have grown up in a period of war. In the words of one great artist, Gil Scott Heron; peace is not the absence of war, it is the absence of the rule of war, the threats of war and the preparation for war. I remember leaving school petrified on the day the U.S.A. bombed Libya; how would I get to my family if war started? Then I thought of my brother, Matthew, who could not run; where was he, who was with him, how would he get to be with us in a time of crisis? At this time and for so many years, Matthew had lived apart from us in a hostel and then in a series of group homes.

This sense of Matthew's 'heightened' vulnerability (heightened, because as humans we are all vulnerable) has remained with me since. I have discovered that he is less vulnerable when with people who love and care about him and who look out for him. Paradoxically, this kind of safety gives him opportunities to take risks and discover more about himself.

I have seen enough good come about in my brother's life over the last several years to know that the path he is on, even though it is the hardest path is the right path. He is safer now. He has been invited to live with others and share their lives. He has beautiful letters from friends and support workers in his treasure chest. His warm, understanding responses to his friends and family humble us about the limits to our knowledge. He looks in the mirror now and smiles at who he sees reflected there.

We have to keep identifying those keys that enable people and that unfold identity. Otherwise we either stagnate or weaken our capacity for resilience in the struggles or journeys we are on.

Recently, I saw a young man speak at a conference using facilitated communication. This was only a recent discovery for him and his family and he had much to say. This moved and inspired me once again; this young man demonstrated that human beings, all of us, are ever-changing. We have to keep identifying those keys that enable people and that unfold identity. Otherwise we either stagnate or weaken our capacity for resilience in the struggles or journeys we are on. These many and varied — even amongst some terrible times — moments of pure joy are what keep me fighting for change.

I once thought that revolution and revolt on a grand scale was the way to change the dynamics of power. Now I see that significant change begins in these smaller scale revolutions, which can change dynamics of power. When we include people with disabilities it implicitly changes the definitions of things that we value highly — beauty, competence, intelligence, productivity, independence, to name a few. These smaller scale revolutions have led to discoveries about myself and have led me to reflect that this might be an important key to understanding what blocks others from making change.

I keep fighting, because as another mentor of mine once said, to do otherwise would be a cop-out, a disservice to all those people through history who persevered through extraordinary odds. To stop is not the rational option; it's the irrational option — what would happen if everyone stopped? Perhaps women would still not have the vote, we might not be able to access free healthcare or to have our employment rights and responsibilities upheld in law. These are liberties that were not always there and they were not just handed out to people. Somebody fought for these liberties and people continue to fight for them. No, to despair or succumb to feelings of hopelessness is ultimately to lose myself.

These sorts of experiences have provided the personal and global discoveries that re-energise me and help keep me going. I am fortunate to have my family with whom these hardships can be faced and to have met and married a man who deeply understands these challenges and how it feels to be at the edge of an abyss sometimes. None of these struggles could have been borne if it was just me. This is the power of collective action.

What Can Recovery Teach Us About Resilience?

Helen Glover *has had a personal and professional interest in recovery and recovery-based practice for a number of years and has concentrated her practice, research and training mainly within the field of mental health and psychiatric disability. Her work is strongly informed by the lived experience knowledge base of those who have recovered including that of her own recovery from mental illness. In this article, Helen discusses the impact of living with mental illness as people move towards their personal recovery.*

On a recent overseas lecture trip, I was asked a question I had not considered before: What was it about me that knew I could recover from a mental illness? I had not previously considered my ability to recover as anything unique. After some reflection, I replied that I did not think I had ever surrendered totally to the idea that having a mental illness was my permanent future. Such a simple question reminded me of the dark times, when it probably appeared to all, even to myself, that I had surrendered and that my future was one of institutionalisation and treatment, limited opportunities, lost roles and responsibilities and that this was unlikely to change. Even in those dark times, deep within me something struggled against that hopeless vision.

How do some people overcome the experience of serious adversity such as illness or disability, yet others cannot? Is it strength of spirit, self-determination, a willingness to fight or an unwillingness to surrender? Perhaps it is the range of supports, resources or professional help that people have or even their own intelligence and insight. All these suggestions have been offered as reasons why some find a recovery space and others do not.

Recovery in itself has much to offer our understanding of resilience. When we understand the meaning of 'recovery' from the lived experience of those who have struggled and triumphed over illness, distress or adversity, we glean its meaning to be far more than simply returning to what was previously. Looking back at my journey of recovery, I notice a different person to the one who lives life today. There are many gifts in the process of recovering; I have learnt about my strengths and vulnerabilities, the light and dark sides of my stubbornness and determination and my ability to sit with distress. I would not have had an opportunity to refine and develop this understanding without the experience of

adversity. Resilience is borne out of the ability to tolerate, understand and transform from adversity. My mental illness has given me far more than it has ever taken away.

Recovery is an active space. Recovery does not simply happen. It cannot rely only on external factors such as support, doctors, case managers, hospitalisations, medications or therapies. Recovery requires individual effort, similar in determination, courage and conviction, to the physical effort of an elite athlete. When first diagnosed with a mental illness, I thought that I would find my recovery space by turning up for a doctor's appointment or taking some pills. I did not realise that I had to invest in the process and actually contribute the parts of me that were going to make the journey. Unfortunately and sadly, I doubt that others, especially health professionals, actually expected me to contribute to my recovery process at all.

...journeys always have something to teach us and contribute to our sense of discovery.

I have come to understand the effort of finding my recovery space through five major journeys, which I also recognise in the recovery narratives of others. I have named the journey the 'star of recovery', the points of which are Hope, Personal Responsibility, Active Sense of Self, Discovery and Connectedness.

The journey of **Hope** involves moving from a space of hopelessness and despair to one of hope. Hope knows that illness is not permanent, that dreams and aspirations can be realised and that the limitations of illness and disability do not define our future. Hope values the role our spirit has in the recovery process. The journey of Hope invites others to journey with us, to hold our hope for us when it is difficult to hold and to have the courage to return it to us to hold again.

The journey of **Personal Responsibility** is one of moving from the idea that others take responsibility for me to one of me holding and retaining responsibility for myself. This is a challenge for many as it is embedded within most helping and caring professions to do for another when they experience distress, pain, illness or disability. The risk of doing this on a constant basis is that because the helping and caring professions often contribute to a state of impotence, we learn more about our

inabilities rather than our many abilities. It was only when I began to reclaim responsibility for the direction of my life that I appreciated the active role of recovering; it would be difficult, if not impossible, to maintain a recovery space while someone else is holding responsibility for us.

Engaging an **Active Sense of Self** involves moving from the passive space of human service systems, which, ironically, confirms that there is nothing that is needed from me to contribute to my wellness. My attributes such as stubbornness, determination and courage are not honoured and are rendered redundant and I quickly lose sight of them. It is not until I realise that these very things will restore my recovery, that I find ways to familiarise myself with them again.

The journey of **Discovery** is much more than developing insight and awareness. It involves finding meaning and purpose in the journey, doing more of what works and less of what does not work; learning from past experiences and incorporating that lesson into the present, acknowledging that journeys always have something to teach us and contribute to our sense of discovery.

It is common that long-term illness or disability contribute to a sense of disconnectedness; disconnectedness from self, from family and from community. The journey of **Connectedness** is about moving from an identity of illness or disability to one where I can fully appreciate all my roles and responsibilities; where I can participate in life as a full citizen and not through the powerlessness of illness. I actively seek support just as I value the support I provide to others. I no longer remain just a recipient of services but actively contribute to my community.

Recovery cannot be given or manufactured by others, yet the spirit of recovery can be hampered or damaged by others. To support a person's recovery it is imperative that we have an undying belief in the person's capacity to recover; that we work as if recovery is a reality, although we may never have the privilege of witnessing it; that we provide an environment where a person can utilise personal resilience to activate recovery and that we never impede a person's recovery.

Many people find a recovery-space despite the obstacles. It is paradoxical that it is often the very people who experience adversity, who persistently demonstrate their ability to overcome adversity. It is people who have lived on the edge of life, those shunned, rejected, judged and who have nothing but their own resilience, who can teach us the most about the nature of resilience.

Resilience: Taking the Long Way Home

In this article Sharon Bourke shares how to build strategies and strengths to assist us to move forward with a strong, purposeful vision for the future lives of people with disabilities. Sharon currently works on the Pave the Way Project, which is exploring ways in which families can be supported in their efforts to safeguard the future for their family member with a disability. Sharon believes her real learning comes from sharing her life's journey with her children, two of whom were born with significant disabilities. Their gifts and the challenges continue to be an inspiration for her.

Resilience is born from the journey itself. For many families and people who have disabilities, life can sometimes appear to be a struggle. Yet, most people learn to resist, grow strength, learn to endure and emerge strengthened by working hard for an 'ordinary life'. Resilience is the ability to weather the struggles of the journey and keep on 'keeping on'. We do this because, in our hearts, we believe there is no lesser option.

While resilience is often invisible, I also believe that resilience is a fundamental part of the human condition. When I consider the people with whom I share my life and others who have offered me the privilege to be a part of their lives, I have observed that resilience sometimes seems to be like buying the ticket to ride the roller-coaster and just hanging on.

Resilience is best recognised when looking back. As is the case with most of the important things in life — friendships, love, pain, joy — it is not during but after, on reflection, that we can find the essence of what it was all about. True wisdom is learning to take time during the experience to reflect so as to be able to alter the experience by deliberate actions.

Friends and strong relationships

When we choose to be around like-minded people with whom we do not have to explain what is in our hearts, our capacity and energy are increased and our resolve is strengthened. Families throughout the state are working quietly in their own communities building good and decent lives for themselves including those members who have a disability. Families have to work harder in the current climate and seldom get the opportunity to stop and reflect. Yet at the Inspirit Mamre Family Conference in September 2005, when families gathered together in Brisbane, we saw families stepping up to challenges, using initiative and creativity to find solutions and

demonstrating hidden reserves of power, energy and wisdom. Parents will trust in the opinions and actions of other parents. Isolation may be broken down when people come together and develop respectful relationships and share strategies that work for them. At this conference resilience was demonstrated in many different ways.

Recognising the gifts

Magic happens when families are given an opportunity to focus on our sons and daughters and really see their gifts, talents and courage. Families speak about the thankfulness they feel because of the changes that their sons and daughters have forged in their lives and in their community and their world. Many of us have been sold a myth that our sons' and daughters' disabilities define who they are. This myth is perpetuated by departments and funding arrangement where we are asked to focus only on those aspects of people that are deemed to be deficient in order to receive the elusive funding package. Families know in their hearts the value of these gifts. It is these gifts that feed our capacity, our resilience.

Having purpose

It is important to remember to be true to yourself and your children. Families can and do grow stronger, more resilient, when they are confident in their own actions on behalf of their sons or daughters. Families do have the wisdom about what a meaningful life is. It might be timely to remember that we are human beings not human 'doings'. Our worth is determined by who we are not by what we can achieve. We can build communities where seeing and understanding that 'being' is more than enough.

Knowing

Resilience is about resisting those who would confuse us with notions of separateness, deficiency and exceptions to human realities. Families need to be steadfast in knowing what are the true questions, what is important and in what and who to place their trust. Life often involves striving to ask the right questions and building the trust of chosen others in our life to support our knowing — questions such as: How will this action bring about a better life? Would I like to be treated in this way? Who else has some responsibility here? If I believe this person has equal worth to me, why would I consider a lesser option?

Fun & Celebration

Families I have known who are strong and who survive and continue to strive really know how to have fun despite times of extreme hardship or heartache. Sometimes, 'being here still' is the only real win of the day. But for many of us, we know and understand this is a substantial win.

Keeping a sense of humour, recognising the absurd in the everyday, and being able to laugh together often helps people to endure. The practice of reflection allows us to see the wins and to celebrate with others. It is contagious. Celebration is a tonic to our spirit and creates energy to continue.

Kindness

Individual acts of kindness do make a difference. Like celebration, kindness grows. When we focus on the kindness of others or practice it ourselves, it grows in our community.

Hope

Resilience is not seated in despair, anger and frustration. It is not achieved by focusing exclusively on the past, on sins or indiscretions, hardships and pain, although it would be foolish to ignore the existence of such things.

History has taught us that restructure and reform do not automatically bring struggle to an end or lead to better lives. Superficial changes of titles and letterheads, glossy brochures and community consultations will not guarantee better lives for people with disabilities and their families and sitting back and waiting for change achieves little. Resilience is framed by optimism and action. Resilience is nurtured by hope. I have seen reason to hope. When families gather and where people bring their gifts to the community — different opinions, cultures, skills and different ways of 'being' — we grow stronger. Families continue to bring courage, energy and wisdom into the lives of their sons and daughters. In turn, those sons and daughters are growing strong and contributing their gifts to the community. It is easy to hope for a stronger community when I look in the faces of people and see a trust and belief in goodness and see such resilience of thought and actions.

Magic happens when families are given an opportunity to focus on our sons and daughters and really see their gifts, talents and courage.

HUMOUR AS PATHWAYS TO RESILIENCE

Kevin Follett *trained as a social worker and works in the Department of Social Work at the University of Queensland in Brisbane as a research assistant. Other articles in this edition name humour as an important component of resilience. Kevin has a strong interest in the expressive medium of comedy and humour as a way to develop personal growth and knowledge. In this article, Kevin makes the link between humour and resilience more explicit.*

Human beings are innate story tellers. We make meaning out of our experiences and create stories to help our understanding, to guide us and to give shape to our lives. The stories we create within ourselves or with each other, give shape to a context or a framework through which we then interpret our lives.

Some believe that the art of story-telling is the exclusive domain of the gifted, creative and talented among us and that there is no room for ordinary people to explore and interpret alternative pathways of understanding, expressed through creativity and humour.

The word creativity itself often evokes the response 'I am not talented enough' and an increasingly dominant story in our culture is that we have to be really good at something before it can have any value. Most of us, whether we realise it or not, use creativity in many aspects of our daily lives for solving problems or juggling our responsibilities

For most of our lives, we are conditioned to think in terms of polarities: something is right or wrong, good or bad, black or white. When we limit ourselves to this binary thinking, we restrict the freedom to explore possibilities or alternatives. Stepping outside of binary thinking can enable us to explore options outside of our existing map of the universe. Possibilities that arise from a place of freedom can be more powerful than simply responding to past conditioning or external factors.

Story-telling through comedy has a naivety and innocence unencumbered and free of the rigid constraints that most of us call reality. The comedic reality is elastic, changeable, flexible and full of possibilities.

With comedy and humour, we are able to play; we do not worry about outcomes, getting it right or projecting a positive image. We can playfully celebrate our foibles, shortcomings or neurotic behaviours. In an alternative universe of comedy, self-

and celebrated. The wisdom we acknowledge in humour is that to begin a new undertaking, learn something new, or go beyond what we know or can control, requires an acceptance on the part of ourselves to look foolish and to ignore the critical voices.

A liberating insight that inspired my own ability to be creative was the wisdom given to me by an experienced comedian, who said: 'don't try to be funny! Do not try to project an image or force people to laugh'. Natural comedy works best when we use our own personalities to create a character; trying to be someone other than who we are is striving behaviour.

While all of us have the ability to be creative, we all are unique in our giftedness. Some of us have the ability — whether dormant or actualised — to be great artists, musicians or entrepreneurs. This may or may not lead to recognition and success as success is popularly constructed. Striving, for the sake of an external reward, can actually hinder creative insight and lead us away from an appreciation of our giftedness.

Resilience lies at the heart of humour. Audiences will laugh most at failure, humorously portrayed. Resilience is the ability to bounce back from failure. Failure can inhibit our willingness to try new things and to play with alternatives. Failure can mean that we were unable to achieve a particular outcome or that a situation did not live up to our expectations. In some other contexts though, such as entrepreneurial cultures, failure is acknowledged as an important part of the learning process. When failure is embraced in comedy it can be transformed into something expressive, artistic and insightful.

The fuel of humour is the ordinary, day-to-day aspects of our lives. As a general principle, comedy takes the mundane and the ordinary, pulls it apart and endows it with significance. Humour is one of the ways we explore our daily lives and create meaning for ourselves. Humour allows us the freedom and spontaneity to play with our reality, to celebrate our willingness to laugh with and at ourselves and to gently recognise our foibles and follies. The mask of comedy is distinctive — every person can hide behind it, yet recognise him or herself behind the mask. Comedy and humour create a new context with an alternative set of rules that take us safely into realms beyond the known or the familiar, where we have the freedom to experiment without being driven by the critical voices that inhibit creativity. In this creative space, when we begin to learn from our histories and hope for tomorrow, we stretch and mould our core of resilience.