CRUCIAL TIMES

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MARCH 2004 Issue No. 29
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editorial

The poet Scott wrote of 'the sickening pang of hope deferred'. Such is the experience of many in the disability sector.

Many people believe that little has changed in the lives and opportunities for people with disabilities. Bureaucracies are bigger and more complex. They appear more powerful. An abundance of rules and policies intrude on the private lives of people with disabilities. There is more funding but there is still only a limited menu of what can be bought with that funding. Programs that allow flexible use of money are being curtailed. It continues to be difficult for parents to enrol children with disabilities in regular schools. Unemployment or sheltered workshops still await school leavers with significant disabilities. Adults with disabilities are still moved around Queensland to fill beds in group homes.

> We encourage, instead, a hope that brings lightness. Such hope gives buoyancy to dreams and ideas.

The temptation is to give up hope, to speak of lost dreams and resignation, to forecast little improvement in the social conditions for people with disabilities. However loss of hope has drastic consequences. Energy and creativity become depleted. People feel isolated, powerless and helpless. Actions for positive change seem pointless. People are driven to desperate measures, such as the dumping of family members on the steps of government departments; acquiescence to the dominant congregated segregated service models; submission to the ill conceived ideas of content free managers; assent to the quick-solution orientation of bureaucrats and politicians.

Let us dwell on what hope is left to us. There is naïve hope that government will deliver all of the answers and all of the money we require. However this sort of hope gives away the power that ordinary citizens have to find solutions to issues that occur in ordinary families and communities.

Such hope rests on two false assumptions. Firstly there is an assumption that money is the answer to all problems, when in fact it is only part of the answer. There is also an assumption that other people have the solutions to our struggles and that we must wait for approval or assistance from someplace else. Our history shows many examples where it has been ordinary people who have led the way. For example, in the 1950s it was families who established schools for children with disabilities. Likewise, in the 1980s it was people with disabilities, families and community sector members who established personalised services.

Another hope available to us is fickle hope that sees us lurching from one fad to the next, seeking quick fixes to complex human issues, such as the mass adoption of individual planning. Such fads are often based on simplistic analyses of problems and provide only short-term assistance.

We encourage, instead, a hope that brings lightness. Such hope gives buoyancy to dreams and ideas. It is a balm to the rejection perpetuated by fellow community members, a salve to the rocky path of needs assessments, funding guidelines and accountability processes. Fervent hope helps us seek relief from all that works against the human spirit. Such hope is fuelled by the voices of the vulnerable and is driven by a sense of injustice. Inspirational hope nurtures dreams and wishes, and an ardent commitment to a changed and just society.

Too often, all this feels like elusive hope, and it is for this reason that we must all find those people or things in which we can place our faith. We can find it in ourselves to be more courageous. We can seek alternative theories and advice to bolster our practical responses. We can recognise the life sapping nature of corporate culture and find the alternative ways for human services to be.

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.

editorial cont.

We can engage in acts of resistance even when we feel at our most powerless. We can resist the pressures to move away from seeking ordinary and valued lives for people with disabilities. We can choose not to close our hearts and minds to the struggles of people with disabilities, families and dissident workers, all of whom seek better ways. We can listen with our hearts and minds, not just through the filters of society's stereotypes. We can connect with like-minded others, and also provide encouragement to those who think differently.

Seeking hope, courage and the will to endure for the long haul is also a journey of the soul. Those who are in the lives of people with disabilities, seeking changes in our service systems and in our wider society, find themselves looking for ways of sustaining this vocation. Writers in this edition of CRUcial Times share with us their journeys of hope, and provide some insight into those things that have nurtured and sustained them.

Shelley wrote a message for us all when he said: 'No change, no pause, no hope, yet I endure.' We all need to find those things that will sustain our commitment to change and our faithfulness to the voices of the vulnerable.

Jane Sherwin

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From the President

What are we here for and how do we stay true to that? This is probably the most fundamental question of life. Each and every one of us would have asked this question of ourselves, reassessing life constantly as we travel along its highways and byways. Each time we attempt to address such a rudimentary, yet complex concept, we are also questioning the *why* and the *how* of the way we live our lives.

How do we stay clear about what is essential and who is at the centre of what we do and how we live our lives? I propose that love is the indispensable ingredient in all of the questioning about life, faith and hope. Central to this quest is being able to love ourselves humbly. Once we are able to love in this way, we can then love each other humbly. Words such as these make us feel uncomfortable. Dominant societal values also work against this: stringent individualism is certainly not encouraging of our opening ourselves up to others. It is certainly not until we are able open ourselves up to others, making ourselves vulnerable to others, that we will find the central core and meaning in life.

I firmly believe it is imperative that we acknowledge to which faith we are referring. For me, I am only able to refer to a faith that espouses the unique worth and sanctity of each and all persons, no matter what. We must keep the faith – we must stay faithful to our calling in life. When we do this, and not until that moment, will we find hope erupting in our hearts.

Mike Duggan

HOLDING ON TO THE ORDINARY

Glenys Mann

__Glenys Mann__ is a mother and long term member of CRU and QPPD. She has a background and an interest in teaching. Through her recent work with the Down Syndrome Association of Queensland, Glenys has been supporting schools that are including students with Down syndrome. In this article Glenys reflects on what it has taken to achieve an ordinary life for her son, Jack.

Ten years ago or thereabouts, before I had barely a moment to welcome my new son, the precious moment of his arrival into the world was clouded in dread and whispers. With the sun barely risen on his first day, this enchanting boy was wrapped in fear, examined by strangers and handed back to me with words that made my heart tighten in alarm. I can remember wondering whether life would ever feel normal again. In fact it took me quite some time in my ignorance and confusion to realise that the world still turned, the sun had indeed continued to rise in the mornings, that I loved this little boy and he loved me back.

When Jack's two older sisters were born there was no need to give a thought to how their lives would unfold. It went without saying that they would be welcomed joyfully into our family, teach us a thing or two about being parents, play, fight and grow together, go to kindergarten and then to the school down the street. They would make a few friends, learn something useful for and about life, and hopefully be happy – well at least some of the time! So what did I think would be different for Jack? Why would I doubt that the trappings of their life would look different for my new son? Why wouldn't he have an ordinary life, just like everyone else?

I suppose from that first moment, the wheel had started to turn and I did not have to be a super-mum to sense the danger. Those early months of my new baby's life seem so obscured by the words 'Down syndrome'. They had a life of their own and not content with that, threatened to take over our lives as well. I thought back then that I did not know much about my new son, so I listened to what others knew of him. I doubted him, I doubted myself and I certainly doubted the possibility of an ordinary life.

Miraculously, in the midst of the storm that raged in my head, there was a centre of stillness in Jack, this delightful little boy who was my son. In spite of everything, there was the same wonder that a new baby brings and the same relentless demands. It was in the world of the ordinary: the feeding; the nappies; the holding; and the play; that Jack himself, by the very nature of his being, steadily challenged the thoughts that raced around my mind. He was a little baby, my son. No more, no less. With that understanding, came a promise of who he was rather than what others had projected he might be.

Now, here we are, ten years later. I still may not know much, but I have spent a lot of time with Jack and a lot of time thinking about his place in the world. His life has unfolded in much the same way as his sisters: through the local kindergarten and now in Year 5 at the school down the road. These days I only sometimes doubt him, myself or this ordinary life that we are having. But the words 'Down syndrome' continue to loom large over his head and I am still confused and frightened about what that means to people. I am confused because, although I believe he is a valued member of his school, his place there was not automatic and is not guaranteed. It had to be worked for, asked for and granted by the powers that be. It is still not his right. The conditional nature of Jack's belonging is a heavy weight to carry and when I see how warmly he is welcomed each day, how much a part of the school life he has become, it puzzles me why this conditional acceptance remains. It seems bizarre that something as simple as wanting an ordinary life can become in reality so difficult and stressful.

I am frightened because there are still so many who, in their belief that they know what is best for my son, would steer us away from this ordinary life we are having; those who believe he needs special programs, special teachers and kids like him. Their promises can be very appealing and this is what frightens me most of all – that I start to believe them. Sometimes 'ordinary' seems too hard and doubts do creep in. Fear takes over: fear that he does not fit in; fear that he will not have friends; fear of what he can not do and that who he is will not be good enough.

And then, miraculously, in the midst of these doubts and fears, these endless words and opinions, I stop and I see Jack, and again I can feel a centre of stillness, of knowing. In spite of everything, I can feel the wonder that my child, like all children, brings. Once again, in the world of the ordinary – the homework, the play, the friends, the learning, the growing – Jack himself, by the very nature of his being, continues to put up a resistance to my doubts and fears.

And I realise that holding on to an ordinary life is not my real challenge. My greatest test will always be to let go of the special. In knowing this, I reject the messages the world tries to give me and once again hold on to the promise of who he is – a boy, my son. No more, no less.

Not Waiting: Creating

Margaret Rodgers

__Margaret Rodgers__ has a long involvement in the lives of people with disabilities and their families. In this article Margaret draws on her current work with Mamre Association's 'Building Informal Networks' project. The project emerged in response to separate requests for assistance from five men and their families. These young men wanted to get on with their lives; move out of home, and make friends. Mamre is committed to working slowly and individually to explore the possibilities.

In his book, 'A Bunch of Poesy', the Cartoonist, Michael Leunig has a cartoon entitled 'How to get there'. The directions for 'getting there' are as follows:

Go to the end of the path until you get to the gate
Go through the gate and head straight out
towards the horizon
Keep going towards the horizon
Sit down and have a rest every now and again
But keep on going. Just keep on with it.
Keep on going as far as you can.
That's how you get there.

My work to build informal networks for five young men from the Mamre community in Brisbane emerged from their desire and the wishes of their families, that they be connected with other people. They wanted the opportunity to have friends, close relationships and to get on with life. These are hardly outrageous hopes and yet are often out of the reach of people with disability. Most people would agree that having strong, supportive networks around people can be a great starting point for other things to happen, but many people are left wondering how that can be done.

I think, that in our efforts to assist people with disabilities that we care about, a Leunig style framework like the one above is much more helpful than pretending there are Ten Easy Steps or that there is a recipe somewhere.

In fact, embracing this quest means letting go of certainty and straightforward answers and muddling along until you find the right answer for that person, at that time. Using Leunig's directions on how to get there, I want to share with you some of what I have learnt.

Go to the end of the path until you get to the gate.
The important word is 'go': start now; do not wait; it is never too early and it is never too late to begin dreaming and scheming with this person about how they can live their own life or perhaps a fuller life. If you have been waiting then work out what you have been waiting for.

Many people wait for funding. Paid support will continue to be an important component of life for many people, but funding will never buy friendship, belonging, intimacy or commitment. These are things that money can not buy which means they can be worked on at any time. It is always an interesting exercise to do a stock take on the resources you already have, both paid and unpaid, and to think about how they might be rearranged.

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The gate is a good place to stop for a moment. If this is your job and you do not even know the person or if this is a relative and their life is so tied up with yours that it is difficult to know where you stop and they start, then do not go through the gate. Wait at the gate until you are confident you can truly appreciate and represent the fullness of the person and the gifts they have to offer, and believe that they have a unique life of their own to live. You have to believe they are entitled to live their own life and not simply fit in to the lives of others. If you cannot do that; retrace your steps and find someone who can, or wait at the gate until the right person comes along.

Go through the gate and head straight out towards the horizon.
Once you've gone through the gate and made the commitment to the person, another important task in figuring out ‘how to get there’, is to spend some time working out where 'there' is or could be. This may involve the finely tuned skill of listening to a number of voices at once without forgetting what you also know to be true. Listen carefully because some voices are practiced, articulate and seductively logical. Others are hesitant, afraid, unclear and can initially seem unreasonable. It is not a simple or quick process to find a balance between a person making their own decisions and choices, and the vulnerability that comes with disability. When you have heard what people want, it is good to be able to talk about it clearly because it may be your job to ask other people to help make it happen.

Find out who enjoys this person: ask about the people who love them, believe in them and see the best in them. This is not about finding people to fix the person; it is not about gathering people to be clever about another person’s life. They are not unpaid workers in the disability field. It is about inviting them to share a part of life’s journey with the person and being open to having the person share their life journey with them.

> Eventually you have to create
> and invent and muddle through
> to find something new and
> unique to this person.

Ordinary people are interested and are sometimes just waiting to be asked. Ordinary people have a lot of information about ordinary life and relationships. There are people who know about budgeting and bank accounts and how clean a teenager’s flat is likely to be. They have a good sense of what is not really important and what is downright unfair.

Find a way to give these interested people the information they need about what is happening and what the person needs and an invitation to be involved. There are lots of ways that others have found to do this, but you will need to work out what will be best for the person you are supporting and their family. In some situations, having people work together as a group is very helpful, but this does not work for everyone.

Keep going towards the horizon
You can learn from others and listen to what they have tried. There is much literature on helpful approaches, such as person centered planning and circles of friends, but eventually you have to create and invent and muddle through to find something new and unique to this person. There is no computer program to shortcut this process. This is not a case of someone having the answer and refusing to share it with you. Listening to one more overseas speaker or reading one more book will not take away the need to eventually just start working it out.

Sit down and have a rest every now and again
If you try something and it does not work, have a rest and a think and then try something else. Celebrate what has been achieved. One of the networks that I know keeps notes of their gatherings and progress because they expect things to change for their friend. They think this change might be slow and subtle, and they want to be able to look back and see how far he and they have come.

But keep on going. Just keep on with it.
Build and work and think and plan for the long term. If there is a group, make sure someone has the job of keeping the group working together over time. Get organised. Have guidelines about how you will work together. For some families an important reason for building these networks is to have people who know their son or daughter well, before a crisis occurs or they are too old to keep on doing everything.

Keep on going as far as you can. That’s how you get there.
Keep on going as far as you can and go as deep and as broad as you can. Go into the excitement and fun and the pain and frustration of a real and ordinary life. Just keep on going. If you think you have arrived, well perhaps you need to go back to the gate and wait there for a little while, and my wish for you is that you never get there.

‘A Bunch of Poesy ‘by Michael Leunig
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Hope

through a Meaningful Life

Connie Young

__Connie Young__ is a resident of Mackay with many roles, including wife, mother of eight children, member of the first Disability Council of Queensland, member of the Guardianship and Administration Tribunal and being active for over twenty years in local disability organisations and issues. Here Connie shares with us the story of her daughter, Eileen, and their quest for a rich and fulfilling life.

On a quiet Monday afternoon in early January this year my husband Jim and I received a phone call which brought shattering news. Jim's two elderly sisters had been involved in a serious car accident and were both in the Princess Alexandra Hospital in Brisbane. Within two hours Jim and I were leaving home in Mackay, facing a 1000 kilometre drive to be with other family members. I begin with this story because the events of that day serve to illustrate very clearly how far we have progressed along the path of setting up an independent, safe and happy life for our daughter Eileen.

Eileen has physical and intellectual disabilities which require her to have twenty-four hour care on a one-to-one basis, yet we were able to leave Mackay that afternoon after only three phone calls, and without any anxiety for how Eileen would fare without us. How we got to this point has been a long and quite often arduous journey. This journey is not yet complete, but it steadily points in a clear direction, and has not been allowed to wander along sometimes beguiling detours.

Eileen's story began thirty-two years ago on a cane farm beside a small country town. Our baby prospered until, at about nine months, we observed all was not well. A trip to Brisbane revealed that she had epilepsy, little sight, some spasticity on the left side and an intellectual disability. This was a great shock but strangely enough we did not think that we would not be able to cope. We believed we were fairly intelligent parents, with a lot of parenting skills, and that as a family we would work to develop this child as we had her brothers and sisters.

We were directed to the Spastic Centre in Brisbane and began quarterly visits there. We obtained home programs which assisted us in teaching Eileen to sit, stand, crawl and walk. For five years this was the only support available. Looking back now and observing the merry-go-round on which some families find themselves, I think we are grateful that there was so little available. We took our baby home, immersed her in the rough and tumble of family life, gave her lots of love and got on with the business of raising her as we had with her brothers and sisters. The other children developed many ways to get Eileen moving. They expected her to do things and as a result she reached many of her milestones.

> We took our baby home, immersed her in the rough and tumble of family life, gave her lots of love and got on with the business of raising her as we had with her brothers and sisters.

At a time when children with disabilities were not included in kindergarten we pushed the boundaries and enrolled Eileen at a local kindergarten. This was not without difficulty. Eileen's father, who was recovering from a heart attack, was required to accompany Eileen each day as her aide, to help meet her personal needs and to help her to fully participate in activities.

When kindergarten finished we were offered a placement for Eileen at special school. Integration and inclusion were words we had no knowledge of. As a result, Eileen entered the world of disability and wasted many years in this setting until she finished her formal schooling at the age of twenty.

While Eileen was finishing her formal learning, mine was beginning. As I learnt about Social Role Valorisation and advocacy, I began to dream of what could be possible for Eileen when she left school. What Eileen needed was an ordinary life, a life just like other young women of her age; a life in which she had independence, a home of her own, friends, and meaningful occupation.

However Eileen needed good support, so my husband and I set up a service for seven young people with high support needs for whom there was nothing available. Each person had individual goals and was to be supported on a one-to-one basis. We were assisted in our efforts by supportive community organisations, sympathetic government officers and, eventually, by a grant. Eileen was living at home and we used her allotted thirty hours a week mainly for community access.

After some negotiation with Queensland Housing a purpose-built home became available. Despite extensive efforts we were not able to find house-mates for Eileen and she did not have funding for paid support to live alone. However the house was ready. So Eileen commenced using the house for some days and overnights. In this way, Eileen had the best of two worlds: she was happy to go to her own place and equally happy to return home to us.

We held to our plan that Eileen would never share her hours of support no matter what. When the service we had established no longer met our expectations, we moved on. We felt the service was turning into the old familiar story: that the individuals were not the prime focus; the needs of the service and its staff came first; and family simply was not in the picture.

We developed a plan which is still working well today. The new service we have holds Eileen's funding. It is accountable to Disability Services Queensland and acts only as our pay-master. My husband and I are the registered employers and take care of all matters relating to staff. We have work place agreements with our staff and we hire, fire and train our staff personally. We do all the administration connected with being an employer, so practically all of Eileen's funding goes to direct support.

We handle no money and seek no administration fees. The plan has continuity. Eileen's sister acts for us when we are absent from home, and she will accept full responsibility when we are no longer able to do so.

The funder does not smile on what we are doing and expresses fears as to its sustainability, but it is working for us. Eileen has a home of her own, furnished well using the savings she has accumulated while living at home. Our aim was to give Eileen a valued place in her own community – a community which no longer knew her after many years of segregation in special school. Although we still struggle with seeking friendships for Eileen, she has many valued roles in her community.

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She is an employer, a house-holder, a member of an aerobics centre and a recognised church member. She is involved in the lives and families of her support workers, many people know her and she is very visible in the community.

Will this be enough to ensure her safety when we are not here? I think we have enough trust to believe there will be someone there for Eileen who will continue to build on the foundations we have laid. We know that the good relationships between family and support workers will be ongoing and that Eileen's good life will continue.

SHARING RICHES

Malcolm Hunt

Malcolm Hunt *is founder and co-ordinator of the Co-Listening Network, a compassionate listening and community connection organisation. Malcolm believes that ordinary people can be the catalysts for great change through deep listening. In this article Malcolm suggests that it is in recognising and sharing people's strengths, including our own, that we find hope.*

It was three weeks before Christmas. I had accepted a position as manager at an aftercare home for men and women facing mental health challenges. 'Aftercare' was a misnomer. I still remember the churning feeling in my stomach as I walked up the stairs of the very large old Queenslander for my interview, and was met on the porch by some of the people who lived there. There was an air of hopelessness and helplessness, and a heaviness that pervaded the building. I was overwhelmed by requests for cigarettes, coffee and money, and the question, 'Are you going to stay here?'

I stayed for three years. Thirty-six people, who had spent thirty to forty years in institutionalised life, were leading lives of quiet desperation in somewhat questionable conditions. These gentle folk drifted through the building like grey spectres. By well ingrained habit they congregated four times a day at the office door. There they received medication and their ration of cigarettes and coffee money to use in a coffee dispenser, which had been installed in the dining room 'for the residents' convenience'. The challenge to build a good life for these people was enormous and soon the weight of hopelessness began to press heavily upon me.

Christmas went and monsoonal January arrived with its sauna-like weather. I had come to sit on the porch with four of the people to watch the torrential rain burst like a waterfall through the eroding guttering. Tom looked at me with excitement and I sensed something wanted to burst forth in him as well. 'How did you come to this place, Tom?' I asked. For the next hour Tom told me his story. There was moisture at the corner of his eye when he said: 'You know, you are the first person here to ever listen to my life story.'

This small revelation moved me to hope. Tom taught me that I had the gift of listening. Soon the porch of that old Queenslander took on new meaning, as it became a place to share stories.

One morning arriving at work ahead of a busy schedule, I found that one of the staff members was off sick. This created a problem, as we needed to take someone to hospital for some important tests. Lilly had waited for months for this appointment and could not afford to miss it. I was not in a position to take her myself. As I was contemplating this with some exasperation, I remembered how during our time on the porch together, one of the people had told me of his passion for buses and trains and of his detailed knowledge of bus and train timetables. Dan had told me that he often went out during the day by himself, catching trains and buses to various destinations. Would Dan have the confidence to take Lilly to the hospital? His face lit up with delight when I asked him and he began to recite the bus times and connections to the local hospital. Lilly felt very comfortable going with Dan and both prepared for their journey.

At the end of the afternoon Lilly and Dan returned home beaming. Dan had not only accompanied Lilly by bus to the hospital but stayed with her in the waiting room, keeping her company and sharing coffee and cakes with her afterwards. Dan had a gift: the precious gift of travel companion that had lain hidden within his story.

We live in a society with a strong focus on problem solving: find a problem and solve it. Much of our education system is geared towards problem solving, thus we enter adult life problem-focused rather than strength-focused. British politician Benjamin Disraeli said,

> *'The greatest good you can do to another person is not just to share your riches but to reveal to him his own.'*

On the porch of the old Queenslander I had found the riches of many of the men and women who lived there: gifts hidden beneath the debris of their past, buried beneath the diagnostic labels, stereotypes and ignorance. Elsie realised her gift of music and could play some of the great classics on piano. Edmond found his gift in painting and went on to win an art prize. Ronnie revealed himself to be a gifted baker when he made cup-cakes for himself and his fellow house-mates. To find these gifts we need to listen – really listen. Quaker writer Douglas Van Steere suggests that deep and compassionate listening to another unearths the riches from the soul,

> *'To 'listen' another's soul into a condition of disclosure and discovery may be almost the greatest service that any human being ever performs for another.'*

SELF-SUSTAINING ACTIVISM

Jill Jordan

One of the most important issues in pursuing social change, no matter in what field, is how to sustain the work we do, and how we keep hope in the face of what might seem like insurmountable hurdles. Maleny resident and community activist Jill Jordan talks about some of the challenges she has faced in being a long-term change agent, and reveals how she sustains herself in the face of ongoing challenges.

My mother always told me to get a proper job, railing at me in the mid-seventies for giving up a salaried position as a psychologist for the uncertainty of working for my community. At that time, I had made the decision to leave all my props – a husband, the city, and a career and good salary – to come and live in Maleny, a tiny rural town in the hinterland of the Sunshine Coast of Queensland in order to lead a more sane lifestyle. Maleny was like most country towns: on its last legs with the decline in natural resources, and the increasing pressure of outside markets on commodity prices.

Although I did not have a proper job, I have been able to make my living as a consultant. At the same time I have been able to pursue what I believe to be my role in life: to assist with community empowerment, both by providing a role model and through community capacity-building. Increasingly, this work involves helping groups to work together better, at both a government and a community level. And my slightly erratic paid work means that I can continue to assist in the development of new and innovative strategies in my home community of Maleny, thus keeping my practice fresh and current.

Throughout this time one of the biggest challenges for me has been in my optimistic nature. Until recently, I have always focussed on solutions. I now realise that sometimes people simply want to be heard in their grief or hardship. Similarly, I have grappled with the challenge of bringing along those who travel relatively slowly; not leading so far in front that people cannot follow.

The leadership role has presented a challenge throughout my life. I have had to toughen myself against the tall poppy syndrome that is said to be an integral part of the Australian psyche. I have never been comfortable with being put on a pedestal. It has been a maturational process to sort out what is genuine praise and to accept it gracefully, to know what constructive criticism is and to learn from it, and to recognise what are merely the negative components of others' opinions about me and my work. As I come into the last phase of my working life, I have also realised the importance of mentoring younger people, and am spending much of my time in this role, although I still find myself occasionally in the role of initiator where there is a change strategy that needs to be instigated.

Related to the challenge of leadership are the threats to my values and my integrity in the face of thinly-veiled promises of status or popularity for compromising these qualities. Linked to this is the need to set very firm and clearly articulated boundaries, in order not to stretch myself too thinly. For someone with excellent health and boundless energy, this can be a real danger which often does not reveal itself until middle age or after.

The final challenge for me has been to face my fears relating to all these issues and to continue to talk, even with those who would seem to be my detractors. This, I am sure, will be an on-going struggle as long as I live.

The most sustaining belief I hold is that I am fulfilling my purpose, and that the work that I undertake is good work, or work for the greater good. This provides me with abundant energy to bounce back after a set-back. It gives me an underlying resilience.

The second belief that sustains me is remembering that the majority of humankind is not motivated by evil intent. Even when people display negative behaviour, they are still doing the best they can in life. However I am also a believer in the consequences of action – karma, if you like – which assists me in checking my own negative behaviour at times.

On a more practical level, I take regular, frequent breaks away from my busy schedule. In these times, I usually spend a lot of time in nature; the beach being my particular relaxing environment. This enables me to come back to my demanding life with renewed energy. I am also sustained by having a wonderful support network: men and women who love and encourage me, especially when I feel afraid, or overwhelmed. Without them, I could not work as effectively as I do, and probably my motivation would not be as great. Here my challenge is being able to ask for their support when I need it. It is true that strong people tend to have trouble showing their vulnerability, even to those closest to them.

Finally and importantly, another aspect of sustaining myself is remembering to acknowledge and celebrate the successes in the work, rather than just getting on with the job. Maleny is noted for its celebrations, too!

On Being Brave and Bold When Neither Comes Naturally

Beverley Funnell

***Beverley Funnell** works within the Queensland Office of the Public Advocate, with a focus on improving laws, structures, policies, service practices and attitudes that have an impact on adults with a decision making disability. Beverley has been actively involved in reform processes in both Wales and Australia since the 1980s. Here Beverley reminds us all of some of the human qualities needed for social change efforts.*

I have never believed I was called to work in the disability area. I have always thought I was just lucky. I accepted my first job in the disability area from a mixed perspective of curiosity, challenge and desperation – I needed a job to support myself while overseas. Why I have stayed in the area for so long is another story. I have found that, for me, a general commitment to the rights of all human beings requires a particular focus; a focus on disability provides an avenue of expression if I am to achieve anything more than a sense of outrage. Circumstances led me to the disability area; the injustices I discovered hooked me in. Whether that constitutes a calling I cannot say. Nevertheless I am here and since there is more than a lifetime's work to be done I will stay for a while longer.

During my twenty-four years spent working in organisations that are associated with serving people with disabilities, I have had the privilege of being involved in a number of reform processes. Those times were characterised by great optimism and hope. Being brave and bold at those times was not too difficult. There was company. There was good leadership. Ideas were abundant. A retrospective reappraisal might suggest that I was not brave at all, merely taking the opportunities that were presented by historical circumstance. Perhaps courage, like other human attributes, should only be judged within its own context.

The optimism of earlier times is not so evident in our current environment. Optimism still resides in quite a few hearts and minds but at a social policy level, concepts such as hope, love, acceptance and decent lives rarely rate a mention. In the corridors of power reference is rarely made to a positive vision of good lives for people with disabilities. 'Values' has virtually become a forbidden word. In the past, there have been periods of great optimism about the possibilities for people with disabilities. This cannot be said of the present. Instead, we have a great deal of attention being given to issues of civil containment, physical restraint, and 'managing the problem'. We have the highest level of funding ever, but reference to a developmental approach for people with disabilities has virtually disappeared, while record keeping, protocols, regulations and reporting exist on a scale hitherto unknown.

Official rhetoric is moving further and further away from the reality of people's lives. Being brave and bold is not so easy these days. Defensiveness is the hallmark of the day. Polite people with closed minds are found everywhere. On the other hand those waiting for the next bright idea or new technology are still with us. These are the fad or trend followers. Along with a detector for injustice, we therefore need to cultivate antennae for hyperbole, and rhetoric without substance.

Without an understanding of the lived experience of marginalised people many good ideas, potentially sound approaches and methodologies can become perverted.

Perhaps one of the most damaging of management fads has been the promotion of the content free manager. Without an understanding of the lived experience of marginalised people many good ideas, potentially sound approaches and methodologies can become perverted. Scarce resources can be so easily wasted. Other fads we have not finished with yet include: individualised funding (contrasted with individualised approaches); person centred-planning (contrasted with person-centredness); community engagement (contrasted with listening to people); quality assurance (contrasted with providing a quality service that meets needs); and carer recognition (contrasted with providing real support to families).

In many quarters there is a deafening silence about the conditions in which some marginalised people are living. When these are pointed out it is usually viewed as someone else's responsibility. Leadership informed by values, ideas and hopes is scant. Being brave and bold is required as much now as it ever was, perhaps even more so.

A note of caution is also required. Being brave and bold for its own sake is as dangerous as promoting change for change's sake. Some people act as though speaking out aggressively is the test of being bold and brave. It may be, but it can also be singularly unhelpful. It may make the spokesperson feel better but will it advance the interests of vulnerable people?

I suspect that we often confuse principles with practice. Recognising a bad idea, policy, or practice and naming it for ourselves is one thing; what we then do with it is critical. Being brave and bold can often mean waiting for and recognising the optimum moment or conditions. Naming issues does not always need to be shaming, except perhaps as a last resort. The use of humiliation and shame does not usually produce the best kind of change. I am aware that in our culture, despite all the rhetoric to the contrary, there is great discomfort with critique. This does not mean we should not provide critique but we need to be smarter about how we do it.

Most of us realise that the struggle for better lives for people with disabilities is unending. Phrases like 'the long haul' may appear somewhat over used, but the truth remains. We do need to hold on and we can hold on. We can learn from each other, we can be open to new people and their ideas, we can struggle to understand the other person's point of view, we can find common ground.

Should courage and boldness be tempered by wisdom, and if not tempered by our own then by someone else's? If we are in the business of critiquing others then let us remain open to advice about our own behaviour. Over-active egos can often motivate our actions, sometimes accounting for an excess of boldness at the expense of real courage and thoughtfulness.

Remember that however politely or nicely you convey your message you will rarely be thanked for doing so. What will help us to be brave will be our determination to stay focussed on why we are here at all and who it is we seek to serve.

Falling into Love

Christopher Brown

***Christopher Brown** taught social work for over 25 years and now combines the part-time teaching of companioning and counselling, with the journey with people through their deeper life issues. Christopher also spends time at Stillpoint, a centre for personal and spiritual growth in Toowong, where the focus is on assisting people to find their still point in the midst of a turning world. Here, Christopher reflects on what it takes to maintain an open heart for others.*

For all of our strivings to place ourselves lovingly in the service of others, we can often encounter our own limitations and a sense that our actions have not always been consistent with our deeper values. Despite our best efforts, we often feel like we have failed to be in authentic loving service.

We are unsettled by the deep cries of anguish of those to whom we strive to open our hearts. We struggle to bear witness to their pain. Our best strivings require conscious commitment, a disciplined will, careful and rational choices, honesty and a sense of purpose, and we often fail to maintain this. We become overly preoccupied with particular aspects of our work, too easily fatigued, impatient with the failings of our colleagues, angered by our organisation, and even frustrated with what we perceive as the slow response, even resistance, from those we strive to lovingly serve. We are seduced by contemporary emphasis on outcome driven services and evidence based practice. We distract ourselves with busy-ness to keep at bay the inner doubt that we are entertaining contradictions and are not keeping faith with our inner most truth.

My experience of living with contradiction came to a head for me one day when I was out walking and came across a person who was homeless. I was trying to clear my head so as to finish a conference paper, ironically on the theme of ‘Opening Our Hearts, so as to be in Solidarity with People of the Edge’. The man’s presence adjacent to my walking path irritated me. I would have preferred to walk by him unnoticed. I resolved to offer him a small amount of money so as to minimise contact, and to be on my way as quickly as possible; after all, I was very busy. I still remember with embarrassment the way his head dropped and he said in a muffled voice, ‘I don’t accept money’. I had just witnessed stigma – and it had occurred at my own hands.

I wanted to develop an open heart, particularly to those at society’s edge. However I also had an urge to protect myself from the stranger. I felt guilty for such contradictory impulses. Yet, when I attempted to make amends a strange and unexpected thing happened. As I mumbled an apology to the man, he said to me, ‘No. Today you have been the Good Samaritan.’ In that moment, I met paradox.

Paradox is when the *but* in our thinking changes to an *and*. It means holding the tension that I am both open-hearted *and* self-protective. This is not a weakness; it is to name what is most real. It is to gently carry open-heartedness in my left hand, self-protectiveness in my right, and to humbly wait until the point of healing emerges.

> *When our response to others remains just an activity of the mind, we are in danger of being captured by ideologies and even by false images of ourselves in’ loving service’.*

In my experience with the person who was homeless, humbly acknowledging the desires for both openness and self-protection created the shift from contradiction to paradox. It allowed me to continue to offer myself to the service of others without having to carry the tiring illusion that I was whole within myself. I discovered that I had more in common with the person who was homeless than I had first realised, and that in fact I was not fully ‘at home’ within myself. And perhaps it was this knowing, and his acknowledging this struggle for me, that enabled him to call me ‘good’.

In coming face to face with my contradictions, and through being held there I opened up space within myself for inner most truth. Contradictions can crowd into my life, noisily filling up my inner rooms with their loud banter. I cannot ignore or banish these conflicting tensions, as life itself is contradictory. But if I hold this paradox, this tension can be reconciled within the deeper inner symbolic rooms of heart or soul. As the poet Rilke encourages in his ‘Book of Hours’:

Whoever reconciles the many
contradictions of his life,
gratefully gathering them into one symbol,
expels the noisy crowd from his abode
and in a different kind of festive mood

receives you as his guest on gentle evenings.

Acknowledging and holding paradox creates an inner silence, serenity and gentleness. This inner silence encourages me to let go of my strivings, especially my more frantic efforts to extend my capacity for loving service. It invites me instead to attend more closely to what is directly in front of me. It encourages me to work from a far less self conscious self, and to look more gently and lovingly at what is before me; at what is real.

When our response to others remains just an activity of the mind, we are in danger of being captured by ideologies and even by false images of ourselves in ‘loving service’. We are encouraged to invest in outcome driven service, yet to base our efforts only on tangible outcomes can lead to a loss of hope, especially in our current times when little seems to shift for all our good and highly conscious efforts. Worse still, we become increasingly immobilised by our contradictions. We can try to hide them, but that usually means blindly projecting them, along with our failing commitments, onto others.

Human consciousness extends well beyond mindful activity. Its highest levels have to do with love. If consciousness has to do with love, and what we are seeking is loving service, then it is also relational. It is at the one time being tough minded and tender hearted. At its peak it is something that we fall into rather than access through our own strivings. And the places we fall into gently hold both our love and our contradictions in wholesome paradox. This dimension is far more mysterious and yields little to direct analysis and linguistic expression. Maybe it is more in the realm of poetry. One brief poetic glimpse comes from long ago through the lament of St Augustine,

Too late I came to love thee, O thou Beauty both so ancient and so fresh, yea, too late
I came to love thee. And behold, thou wert
within me, and I out of myself, where I made
search for thee.

With the highest levels of human consciousness reinstated it becomes possible to be more fully myself. I am able to offer more of my being, along with my un-wholeness and my contradictions, in the service of others. Part of the task of loving service is to hold contradictions, both my own and those of others, in the more gentle place of paradox, gathering them into a deeper and symbolic inner place where there is space for reconciliation, and where they can become the source, not of judgement but of healing.