CRUCIAL TIMES

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Editorial

Margaret Rodgers

This edition of CRUcial Times will focus on the theme of Courage. It is not our intention that this becomes a sentimental tribute to specialness or that it reinforces any notion that disability in some way equates with burden, thereby requiring some super human response. We are attempting to offer another lens through which to view and understand the strength and resilience that exists in people; in particular the community of people we know who live with disability and those who love, care about and stand with them.

As I have read the contributions from our writers for this edition, I note they are not talking about the big, one off moments of courage – the events that we read about on the front page of our newspaper or in the bravery awards. Each of them is talking about the day to day; step by step courage it takes for people with disability to get what is ordinary and taken for granted by most people in our society. They describe lives of courage rather than moments of courage. They describe the courage required by people who live with disability to face the world each day when that world is often unwelcoming, dismissive or disinterested in all they have to offer. It takes great courage to be hopeful, generous and gracious in the face of that. It takes great courage not to give up, or, when you do, to get back up again, even when you know what the consequences are likely to be. This is the courage that is usually not recognised or celebrated and would rarely be named as courage. It is not sought and nobody feels prepared or equipped.

From a variety of perspectives, the writers in this edition describe how the people who stand with and support people who live with disability also need courage to be

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faithful over time; to continually seek new ways; to be prepared to speak up and to admit when they are wrong. It takes courage to make the best guess on behalf of a person who can't speak for themselves. Whether these supporters are family members, advocates or paid workers, there will be some big moments or points of transition when they need the courage to take a stand. There will be many more moments of ordinary life where they need the courage to stay focused and faithful to ensuring that the person they care about is healthy and well cared for.

Most of our authors balked at being called courageous or making a link between their actions or examples and the word *courage*. Some went on to talk about people they admired for their courage – people who had inspired them by standing up for something and then standing their ground. Perhaps courage is something we recognise more in other people than in ourselves as we know how unprepared and uncourageous we feel. But maybe if we can accept that we and others around us are courageous, then we can tap into a lot of wisdom, gathered over centuries and from around the world about this virtue and how it might be strengthened and developed.

The theme for this edition was chosen following a conversation evening at our office in February on the topic of *courage*. We had an immediate and enthusiastic response to our invitation and had to turn people away. Given this interest we were keen to extend these reflections to a wider group of people.

Maya Angelou says that "without courage we cannot practise any other virtue with consistency" so we hope that pausing to reflect on the virtue of courage might help each of us to recognise, celebrate and thereby strengthen the courage in ourselves and those around us.

Margaret Rodgers
October 2011

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From The President.

I can't believe I am writing a small piece to be included in CRUcial Times! It's actually taken a bit of courage to feel up to the task. My difficulty in starting was mostly because CRUcial Times has played such an important part in my development and formation over the years and partly because past President, Mike Duggan, made his contributions such an art form. As a young support worker reading CRUcial Times, I found it inspiring and challenging. It helped shape my attitudes about disability and introduced me to concepts and approaches not always visible in workplaces. I would read it cover to cover and then read it again. I have held onto several editions and still pull them out from time to time to copy an article for a parent or colleague, or to share at a staff meeting. So, with such high regard for this publication, when asked to prepare something for this edition, my reaction went something like this: First...FEAR! I can't! I just can't do that!!! Then ... DOUBT. What could I possibly write that anybody would want to read and even if I do write something it probably won't be very interesting? And finally ... COURAGE. I will do this. I will have a go. I will be brave.

When I think of courage, the image that comes to my mind is that of the student in Tiananmen Square, clutching his shopping bags, staring down a military tank. A person brave and courageous enough to stop a tank! WOW! When I first saw this image in the newspaper I was moved by the person's obvious conviction in their struggle for democracy. I could barely imagine what it would take to stand up for what you believe in like that. We may never find ourselves in such a situation here in Australia, but I know there are, and have been, many leaders in the struggle to bring about real change in the lives of people with a disability who have had to stare down tanks: the nay-sayers, the people who think it can't be done, the people who think you're crazy for wanting an ordinary life – a good life. Their courage is encouragement to me that real change is possible.

I'd like to finish by sharing a lyric from the Audrey's song *Small Things* that also speaks of courage: "The only way to find your feet is just to stand your ground". I'm finding my feet as a chairperson but I have appreciated the opportunity to contribute to CRU and its role of pursuing positive change in the lives of people with disability. The nature of our efforts may not immediately conjure up an image of staring down tanks but we do try to stand our ground in pursuit of good lives for people with disability and to help others to do this too.

I look forward to meeting and speaking with you in coming months.

Matt Stone
President

CRU has a new website, please go to

www.cru.org.au

When Courage is not Optional

__Bob Lee__ has been involved in providing services for people with disability since 1978 and has been actively involved in the promotion and training of Social Role Valorisation since 1986. In 1996, Bob was employed as the founding co-ordinator of the Sunshine Coast Citizen Advocacy Program and continues to work in that role.

In this article Bob explores some seldom heard stories of courage. Courage which might not sell newspapers, but which does challenge, protect and seek justice for vulnerable people with disability.

Commentary on the lives of people with disability has become regular fare for tabloid media which is always on the look out for eye catching “human interest” stories. A combination of confusion, ignorance, cynicism, and the overriding need to sell media means that the reading and viewing public gets frequent messages about people with disabilities as being burdens to themselves, to their families and to society as a whole. As if to soften the blow, these messages are often accompanied by the portrayal of people with disability and those who are part of their lives as heroic bearers of their unfortunate burden. Whether intended or not, this only serves to reinforce and perpetuate the unfounded belief that just to be involved in some way with people with disability requires not only special expertise, but a measure of courage not possessed by ordinary folk.

The great irony is that this insulting and damaging interpretation is completely unnecessary. There are more than enough fine examples of courage which really should be acknowledged. Let’s begin by being clear about what “courage” actually means.

Not having access to a good dictionary, I have consulted that marvel of the internet, Wikipedia, for an appropriate definition.

> **Courage** (also bravery, fortitude, or intrepidity) is the ability to confront fear, pain, danger, uncertainty, or intimidation. **“Physical courage”** is courage in the face of physical pain, hardship, death, or threat of death, while **“moral courage”** is the ability to act rightly in the face of popular opposition, shame, scandal, or discouragement.

Well that seems to be fairly clear. In my thirty years of engagement with people with disability, I can think of many people who left me speechless with their willingness to act rightly and to confront fear, danger and intimidation in their pursuit of a “fair go” for vulnerable people.

There are, for example, the families of people with disability who have resisted family pressures, medical advice, bureaucratic inertia, and social isolation to give unconditional love and support to their child with a disability. There are parents who have shrugged off intimidation and coercion to insist that their children, and other people with disabilities, have the opportunity to live typical, regular lives in their community.

There are also those ordinary citizens who are moved to respond to the needs of vulnerable people with disability in their own community. They choose to act to protect and defend the human rights of people with disability by advocating on their behalf without expectation of reward or compensation.

Those people with disability who are most isolated, and therefore most vulnerable, have lives where decisions about them are often made largely for the convenience or benefit of others. The preparedness of an independent advocate to question or challenge decisions which are not in the best interests of a person with a disability can result in some formidable reactions by those whose vested interests are being challenged.

Despite being highly regarded in their personal networks, and the communities in which they live, citizen advocates frequently experience concerted efforts to undermine their personal credibility. Typically, advocates can have their motivation, or competence, or both, questioned by those who have no business doing so. Some advocates have endured baseless accusations that their interest in protecting a vulnerable person is motivated by the possibility of financial or even sexual exploitation. Good citizens will recognise this for what it is –desperate measures by individuals or agencies to avoid legitimate scrutiny of their actions. Advocates understand that when their advocacy is obstructed in this way, there is an even greater need for their involvement. Nothing protects vulnerable people as effectively as someone who takes an interest in their lives and is prepared to ask questions when questions need to be asked. When ordinary citizens continue their advocacy in the face of obstruction, intimidation, coercion and besmirching of their reputations, they demonstrate clearly the **moral courage of acting rightly**.

While we might more readily recognise the courage of families and advocates, it is true that sometimes the courage of those most personally involved is overlooked. Time after time I have seen very vulnerable people demonstrate, often to the great consternation of others, that they are more than willing to risk the pain of rejection, humiliation and sometimes punishment, in an effort to claim their legitimate human rights.

When ordinary citizens continue their advocacy in the face of obstruction, intimidation, coercion and besmirching of their reputations, they demonstrate clearly the moral courage of acting rightly.

I have met too many people who, after experiencing lives filled with isolation, loneliness and abuse, in institutions of one kind or another, are prepared to trust that the system that abused them will finally get it right.

I have met too many people who long for the experience of family and friendship because it has always been absent from their lives. I know too many people who smilingly open their hearts to newcomers who profess to care about them, while they secretly wonder if they will ever see again the last person who said they cared.

I first met the man who taught me most about personal courage about thirty years ago. I remember his blazing eyes and his flaming red hair as his wheelchair was pushed outside into the ferocious heat of a midsummer day. He was being punished for swearing! Yes I did rescue him and in return acquired a friend for life.

Bruce was without a doubt the most courageous person I have known, even more so because his courage was not recognised and acknowledged. He knew that non-compliance, questioning of authority, and expressions of frustration and anger would only bring about retribution and punishment, yet he was willing to act on his deeply held conviction that services for people with disability should not be conditional on accepting incompetence, ridicule, humiliation, and abuse as part of the package.

Bruce experienced years of ice cold baths in winter, hours of being “forgotten” in toilets, and many more creative punishments for his resistance to the routine oppression of the institution. While he never regarded himself as a campaigner for all people with disability, he did think that those who managed services should see him as providing them with a “window” into the experiences he shared with others who did not complain. I think he was making a good point here, but I am not aware of anyone taking the advice.

Bruce did survive his time in the institution, and before his untimely death had many years of more pleasurable life in his own home. One moment in his company will always remain in my mind. We were watching on the news discussion about surveys which indicated that many Australians believed that they would prefer to be dead than to live without the physical ability to manage their own personal care. Bruce gave me his familiar wry smile. He had quickly come to an inescapable conclusion. Despite his satisfaction with his life, these surveys meant that many of those who lived in his neighbourhood were likely to believe that he would be better off dead. As usual, he laughed this off, but I could only wonder at those who live lives where courage is not an optional extra. It’s an absolute requirement for vulnerable people to have in order to tolerate the thoughtlessness and casual cruelty which often comes their way.

I’d like to end with a thank you to two great friends who taught me much about courage and disability and continue to inspire me, Ronda and Bruce. May they rest in peace.

Enduring Love!...

__Mike Duggan__ is a well known contributor to the disability movement in Queensland and has had a significant involvement in a number of community-based, not-for-profit organizations. He was a long-term President of CRU and remains on the CRU committee, as well as maintaining significant roles in other organisations.

In this article, Mike canvasses the diverse expressions of what we call courage, calls into question a number of popular notions of courage and asks us to consider what drives those acts we call courage.

Courage? I would like to get more! Can you tell me where I might buy some?

Oh dear, I would but my courage has evaporated in light of your request ...!!

Farfetched but perhaps we can start here to question the objectification, rarefaction and commodification of "courage". Because I live with a label of disability, I am someone who might be seen by some as having or needing courage. My physical disability does heighten my vulnerability, at various levels. In some respects it is my physical disability that evokes stares, misunderstandings, disdain, isolation etc from people.

But I am not my disability! And, in any case, I am not sure of some of the assumptions made about courage – or about disability for that matter! I truly feel that despite heightened vulnerability, it is my disability that enables me to understand people and get close to them.

So … Is it correct to think of courage as something we have or don't have? Is it correct to think that courage is some universal "something" that is present or absent regardless of the situation?

Perhaps courage is something that points to rather different qualities. For example:

- Is having the courage of one's convictions more about the courage or about the convictions?
- Or another example, one might display a physical bravery (seen as courageous) but have little moral courage.
- Or one might display courage in standing up for loved ones or the weak or helpless but have no interest whatsoever in standing up for oneself or one's pride or prestige – which might (rightly?) be seen as a lack of courage!!!.
- And then there is the courage displayed quite spontaneously as in jumping into a river to save someone, neither foreseen nor carefully considered but a spontaneous display of humanity;
- Or the "courage" to stand up for rights and personal dignity or moral conviction after considerable thought knowing full well that the consequences are not likely to be good (at least in the short term).

I once lived in an institution for about twelve years (who's counting?). I would say that the first few months in that institution were truly the worst of my life. What would those strange people, calling themselves sisters and nurses' aides, do to me? Why couldn't I have an orange drink first thing when getting up in the mornings? Why did I have to have a shower at 5.30am? Why? Why? But I survived this twelve-year period in that institution relatively unscarred emotionally – well, that's my story and I'm sticking to it! I quickly became able to easily distinguish the staff "goodies" and "baddies". I quickly learnt to "hide" when the baddies were on duty, and to become "more apparent" when the goodies signed on for duty.

I 'escaped' that place by taking part in a Demonstration De-institutionalization Project. On leaving the institution, I was told I had only one month to change

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my mind, before my bed was given to some other pour ‘deserving’ soul. Now, at the time, I was just doing what I believed I had to do. For me terms, such as “courage”, even “fool-hardiness” would not have crossed my mind.

Similarly, when I was ‘locked away” working in a sheltered workshop making rubber door mats and typing addresses on envelopes using my “headpiece”… What made me want to make my escape by applying for a Uni Degree, especially when such low expectations prevented me from even sitting for my Secondary Schooling Qualifications? Was this “courage” or simply “pigheadedness”? Or did I just feel: “This was my time; and that God had a hand in all of this”? I’m just not sure… but I would say “probably”!

My take and hope for courage seekers is that they might see that often it is a matter of conviction or the strength of our connection (relationship) to others that gives rise to those actions others might see as courage. What they are really seeing is not the evidence of courage but the evidence of conviction, integrity and connection or, dare I say it, love. Yes, love ultimately is not only a feeling or an emotion or an attachment, but a willingness to act.

So one should NEVER think that one is not courageous or lacking in courage as we can all love. The pressure that comes of being defined by others might box you in, particularly when you are “lacking something” such as being dis-abled. One of those boxes might come to be worn as “I do not have much courage”.

However, if it is love that motivates people and makes people ‘get on’ with life: let us look for evidence of love instead of “courage”. For example, it may be in patience and long-suffering that love is shown. It would not often be thought of that way but perhaps acts of patience and longsuffering are some of the most courageous! The point being that we can all love and be loved - not that that is not a struggle at times but it is central to our being. To display courage without principles or conviction or love would be meaningless. To be separated from one’s convictions or capacity to love through the lack of courage is to take our eye off what is really important because what is important is that we act out of love and convictions. Perhaps regardless or even in spite of the courage we feel!

Courage is thus challenged as a bit of a fake, an imposter for the real thing. Elevated as it is by social norms and mass media it has been separated when in fact any real courage that displays a real integrity of our lives grows out of our love and convictions.

Never mind if they think of us as courageous, if we know it is love that drives it!

PEACE!!
Mike Duggan

Getting Out of the Way

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

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

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

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

Choosing to be steadfast in our commitment to one person at a time and our new paradigm wasn't easy. Our funding bodies wanted shapes and numbers. We didn't have a historical stepping stone; everything that we had done and had designed over the years, our planning, our staff models, how we spent money etc. had an element of cost effectiveness to it. We basically thought the same things would bring the same benefits to each person. Other than knowing that what we were doing wasn't good enough and that we wanted to create opportunities for people to live the best lives possible, we had no idea what this change was going to mean for our organisation, our staffing or our viability. There were high levels of uncertainty and, of course, the risk of failing miserably. When we looked around us for models of services that had transitioned to individualised self-directed services which could lead the way, could help us to take short cuts and provide us with mentoring, we couldn't find them. What we found was rhetoric without a capacity for implementation. We found, including within ourselves, a consistent capacity to confuse good intentions with good results.

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

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

We have come a fair way down the path of

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

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

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

Courage & Disability & Politics

***Sue Boyce** is a former journalist and company director. She has three adult children and one extremely gorgeous grandchild. Her younger daughter, Joanna, is 27 and has Down syndrome.*

Sue has been a Queensland senator since April 2007. In this article Sue reflects on courage in politics and her attempts to influence policy and debate on disability. Her contribution prompts us to consider how we can be more effective in seeking change for people with disability – whether in our own local communities or on the political stage.

In 1956, the then Senator John F Kennedy published Profiles in Courage, a study of eight US senators who had crossed party lines or defied the public opinion of their constituents to say or do what they believed was right despite criticism and the cost to their careers.

One of the eight was conservative Ohio senator Robert Taft (1889-1953) whose many strong stands included adamant opposition to the Nuremburg Trials as "victors' justice" where the winners of World War II set themselves up as prosecutors, judges and alleged victims all at the same time.

It wasn't a popular view in post-war USA, nor was it a view that John Kennedy supported.

It takes a lot of courage to espouse the "wrong" or unpopular cause as strongly as Senator Taft did, but it also takes courage to honour that stand, as Kennedy did, despite finding it unacceptable.

It would be interesting to see how easy or difficult it would be to find subjects for a contemporary book about courageous politicians—in the US or here in Australia, in Queensland.

Courage, of course, comes in many forms. Kennedy also profiled Senator Thomas Hart Benton (1782-1858) who stayed loyal to the Democratic Party and battled on, despite his opposition to the Party's then policy to extend slavery.

I'm always bemused by media criticism of politicians for blindly following the Party political line, at the same time as virulent attacks on those politicians who display "party disunity" by publicly daring to differ.

Despite the media, and general, disdain for our politicians, I don't think it would be difficult to find plenty of courageous examples here in Australia, but it would require deep knowledge of the behind-the-scenes manouevrings in modern political parties where most of the dissent now occurs.

Of course, the eight men that Kennedy profiled were caught up in various ways in the great sweep of

19th and 20th century politics and the expansion of democracy.

In Australia, we necessarily operate on a smaller scale but there has been courage. In some cases, the actions have been popular, but costly, such as committing Australia to some wars; in other cases, just straight out unpopular such as the introduction of the GST.

Some people thought my decision to cross the floor and vote with the Government on the Emissions Trading Scheme in 2009 was courageous. At the time it didn't feel courageous, it just felt like the only thing I could possibly do.

But I know there were many good people on both sides of the political fence who held their Party's line and voted against their own conscience that day. Some are now in positions to influence policy on Climate Change. In some circumstances, 'surviving' to fight another day can be just as courageous as taking a stand. And, of course, this judgment about strategy and compromise is not just restricted to the political sphere.

> Some issues fall into the "courageous" category because, as a society, we choose to ignore them rather than recognise our very unattractive ability to give one group's needs primacy over another's

But if political courage requires acting outside the acceptable norm, it certainly hasn't extended to disability.

There is no reason to be particularly surprised about this. In the main, politicians reflect the world views of their constituents.

If much of mainstream Australia think it's a shame the institutions were closed down and that special schools are a very good thing and that more respite centres should be built, why should we be surprised that many of our politicians think the same?

The primary experience that most politicians have of disability is the attitudes of their local communities and occasional visits from constituents with problems, primarily carers, not people with a disability.

There are many good, well-meaning politicians who still display what I call the charitable "poor little kiddies" view of disability.

We have a political system that still sees the Treasury, Defence and Foreign Affairs portfolios as the most senior or "glamour" portfolios.

The portfolios of Health and Ageing and of Families, Housing, Community Services and Indigenous Affairs (which includes disability) are generally used as training grounds for young up-and-coming politicians or those near retirement.

An interest in disability, especially disability rights, is certainly no passport to political fame and glory.

In the 27 years since my daughter Jo was born, I had worked my way from individual advocacy to systemic and policy advocacy until parliamentary advocacy seemed the next logical step.

In that context, I have tried to be 'courageous' ever since I made my first speech in the Senate 4½ years ago.

I've spoken consistently about disability and from a perspective that has raised some eyebrows and—I'm pleased to say—some interest.

In my first speech I set out the wants, indeed rights, of people with disability to an ordinary life and criticised the "special people in special places doing special things" view of disability as an exclusionary one.

I've spoken on numerous disability topics since. My speech on "respite" as a two-way street, not just bricks and mortar drop-off points, went down like a lead balloon. I wasn't aware until later that the Minister was announcing funding for some shiny new respite centres at about the same time—in response to what was perceived as constituent need.

I believe one of the biggest problems in the disability sector is that we consistently preach to the already converted—our conferences and workshops are filled with people who believe what we believe about disability rights. These conversations are comfortable because they reinforce what we hold true, but attitudinal and systems change require us to face those who are vehemently opposed to our world views.

I can guarantee that there will be strong opposition to my speeches promoting truly inclusive education and criticising special schools as exclusionary. When the objections are teased out, many people are actually agreeing with me that it's the system that's failing.

So I've set out to challenge the norms and play "thorn in the side". My constant refrain of "is there a genuine representative of people with a disability in that advisory/reference group?" has led to changes on some occasions and, hopefully, better outcomes.

One of the most gratifying speeches I have made was on the topic of euthanasia and assisted suicide from a disability rights perspective. I can't find one disability rights organisation worldwide that is in favour of legalising euthanasia. So I said so, set out the reasons why people who already felt under-valued were worried, and made the case for adequate funding of palliative care as a better first step.

It wasn't exactly an avalanche of responses but about a dozen MPs and staffers emailed or phoned me to discuss this hitherto unexamined view further.

And one completely unanticipated bonus from my 'courageous' speeches has been the impetus that they have given to some of the groups I have spoken about. Women with a disability, palliative care groups, public servants working on ignored disability issues have all said: "It's so energising to know that someone cares."

Some issues fall into the 'courageous' category because, as a society, we choose to ignore them rather than recognise our very unattractive ability to give one group's needs primacy over another's: the exclusion of women with a disability from the discourse of the main women's groups tackling violence and abuse; the legality of forced sterilisation of people with a disability; the shameful health statistics for people with an intellectual disability; people with an intellectual disability or cognitive impairment 'lost' in the prison system; the financial, physical and emotional abuse of some people with a disability by their families.

Whilst none of these issues have the scale of world peace or international justice of Kennedy's book, they do carry the great themes of individual liberty and of oppression. They'll take collaborative courage—and compromise along the way—to fix.

Finding Courage

***Ann O'Brien** is a teacher and a mother of 3 boys, the eldest is 13 and has a disability. In this article she draws on her lived experience of needing courage many times during her son's life. She shares with us stories of some of those occasions that have required courage, identifying what has been helpful and detrimental in her desire to achieve a great life for her son.*

We learn a lot about ourselves when we become parents, our children somehow manage to bring out the best and the worst in us.

I am the parent of three young boys. Our eldest son is a happy young man who has cerebral palsy, is severely visually impaired and has epilepsy. My reflections on the virtue of courage come from my journey with him, my husband and our other two sons.

I have done lots of thinking about courage since I was invited to contribute to this edition of CRUcial times. My first thought was: what book have I got that I can plagiarise? There was much to read. As I read it became apparent that the courage many of those books were talking about was not some seemingly out of reach "big" courage but the courage we need on a day to day basis. As a parent of a child with a disability I can relate to this.

Our journey with our son has seen all of us make significant progress. The very early years were incredibly sad. They were dominated by visiting therapists, attending early intervention and having regular appointments with neurologists, orthopaedic surgeons and paediatricians. It was really only the arrival of our other children that took us from this largely medicalised world of focussing on deficiencies back into the real world.

Medically Luke still doesn't follow any rules. You will not find him in a text book, neatly fitting the description of a child with cerebral palsy. We live daily with the reality of Luke's vulnerability to serious illness, and hospital admissions, particularly over winter, are not uncommon. We try however not to let this reality define Luke's life. We want to provide Luke with the opportunity to make friends, get an education, have holidays – we want an ordinary life.

If I am to reflect on the place of courage in our lives, there are a number of significant decisions that we made that required us to take a risk. My husband and I and our other boys are called to be our sons ally; we are his voice; we hope we speak truthfully his hopes, desires, likes and dislikes. We hope also that we listen to what he wants his life to be like.

Three years ago we decided to approach our local state school about him enrolling into grade 5 full-time. This decision was driven by Luke's desire to be with his peers in a stimulating noisy environment. We had learnt that he is much more alert and attentive when there is a lot happening around him. It was not an easy decision. We knew many would not understand our desire for Luke to be part of our local school where his brothers attend. We put ourselves on the line and then couldn't back down until we achieved what we had set out to do. After much discussion, approval was given and Luke began grade 5 in 2009. This year he is in grade 7.

Earlier this year on school assembly he received a senior leader badge. His delight and enthusiasm on assembly was evident to everyone. Without the courage to take those first steps of enrolling him at our local school, this moment would never have occurred.

We are now working with our local high school and again I find myself looking for the courage we need to make this transition. There are times when I would like to crawl under the nearest rock and hope it will all go away, but of course that won't happen. We need to continue to advocate for him and his right to receive an education in a regular setting.

While planning for Luke's inclusion into our local state primary school we also decided to take 6 months to travel around Australia. My husband and I planned carefully and ensured that we had thought through what we would need to keep our son safe, given he has, at times, significant health issues. We were aware of the risks we were taking but decided that the experience and the benefits would far outweigh any of the risks. The reality was that we would deal with whatever life threw at us at the time.

Our trip was a wonderful time together. We saw only some of what this beautiful country has to offer, but memories of those days keep us going when times are difficult. Our son experienced all we did, often on my husband's back as we climbed mountains and explored gorges. The most important lesson learnt was about the importance of taking a risk and following your dreams. Had our son's health deteriorated or the trip been too exhausting we would have rethought our plans or if necessary come home. If we had allowed, however, those potential risks to overwhelm us, what wonderful experiences we would have missed out on.

Over the years we have made decisions about our son's life based on some very clear understandings we have learnt. These are reflected in what I see builds and unfortunately destroys courage.

What builds Courage?

- Being clear about your vision for your son or daughter's future.
- Watching and listening to what your son or daughter is telling you.
- Surrounding yourself with people who support your dreams.
- Appreciating the ebb and flow of life. Sometimes you may need to retreat to protect yourself and your family.

What destroys Courage?

- Other people's opinions – professionals, teachers, and sadly even other parents of children with a disability or family members – can destroy your courage.
- Staying too long in the disability and medical worlds which often only concentrate on deficiencies.
- Spending too much time with the "what ifs", running from our pain, wishing it was different etc.

The journey from the early days of Luke's life to now have been fraught with more ups and downs than I care to remember. But survive it we have and I am pleased to say that we do better than just survive. Life is good. Some days much better than others, but deep down we know that, if we hang in there long enough, things will change. It is comforting to know that while I may drop my bundle from time to time, I will ultimately be able to take that all important breath and keep on going.

Is this courage? I am not sure!

> My husband and I and our other boys are called to be our sons ally; we are his voice; we hope we speak truthfully his hopes, desires, likes and dislikes.