CRUCIAL TIMES

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Editorial

CRU was born in a time of change! The Disability Services Act was introduced in 1986 bringing with it great opportunity but also of course fear and trepidation for many people and organisations. There has since been significant development in what we think is possible for people with disabilities. Time has shown that this particular legislation, perhaps because of the leadership, opportunities for innovation and principles that were integral to it, heralded a period of real and lasting change that has endured. Many times we have been promised great change but not much has actually changed in the lives of people with disability. Since its origins in 1988 CRU has sought to understand the difference and to invest in authentic change.

This year CRU celebrates its twenty fifth anniversary and CRUcial Times will be 20 years old; the first edition published in late 1993. These anniversaries have prompted us to explore what we believe endures over time. As we face another time of great change and we look to the next twenty five years, what can we learn from our past? What should we invest in for the future? What are the things that endure over time? What are those things that we expect will always be required for people who live with disability to have lives that are recognisable as equivalent to their peers? What will it take for more people with disability to have lives that are the envy of other Australians rather than lives that bear little resemblance to those of their fellow citizens? What are the threats that endure and will always need vigilance and safeguarding against, for people who are perceived as different? How do we discriminate between real change and the latest fad? How do we recognise changes that are actually more in the interest of parties *other than* the person with the disability - changes that are more designed to improve the lives of the family; the workers; the service providers; the general community or the funders?

Contents

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.

In this edition we draw on a small selection of the wisdom contained in past editions of CRUcial Times and offer for your consideration some thoughts on what we think endures, and therefore what should be invested in, for the future.

This selection is not an exhaustive list by any means and nor is it intended to be indulgent reminiscing. As I read these articles I needed to double check the dates that some of them were written. It surprised me just how topical they remain and how much we still have to learn from them.

We are delighted to include a selection of writings from Mike Duggan. Mike was President of the Management Committee of CRU for twelve years and in that role wrote the feature "From the President" thirty seven times.

It is probably no surprise to you that our first article is a paper on change and leadership. Ten years ago, Lesley Chenoweth wrote that '*striving to create more inclusive communities will always involve a call for change, and leadership will always play a vital role in bringing about such change.*' She quotes Richard Louv who claims that too many of us think that being a leader is a job for someone else and that only celebrities qualify for the position. His line that "*Leaders somehow appear magically – summoned by fate, endowed with charisma, and usually good hair*" continues to be a very appealing thought even though the evidence is not there to support it. The need for intentional development of values based leaders and leadership to influence the direction of change is one of the things that we think endures.

> The need for us to develop responses that are suited to; unique to and driven by the person and those close to them remains something that endures

In 2004 Glenys Mann wrote as the mother of a then primary school aged child about the threat of the disability label (and all that brings with it), overshadowing who her son really was. The need to focus on the person first rather than only seeing their disability is a message that is still relevant today.

In her article, Lisa Lehmann, a woman who lives with disability says '*it became clear to me that the reason I encountered such empty words and inadequate support was because I was being perceived as my disability. However I am not my disability – I am Lisa first. These workers saw their role as overarching my entire life'. 'In reality I simply need some assistance with a few parts of my life. It is not complicated nor would I want it to be'*. Lisa also eloquently captures for us the difference between receiving support that is ***called*** person centred and support that actually ***is*** centred on her and what she wants for her life. The need for us to develop responses that are suited to; unique to and driven by the person and those close to them remains something that endures. Being able to perceive the difference between what something is called and what it actually does or provides, is likely to be needed even more in the future.

Even though the definition of family may change over time, the role of the family continues to be seen as a critical piece of our general social structure. Without wanting to romanticise the notion, the family is recognised as a place for giving and receiving support across the generations. Every political party claims that families are the bedrock of our society and strengthening families is part of key government policy. Michael Kendrick's one page article, 'The Natural Authority of Families' was first published in Crucial Times in 1996 and I suspect is one of the most photocopied articles from our collection. This paper is a great reminder of the natural authority afforded to family by society's systems and services – it is an authority that is not often made explicit or offered by the system but is an authority that continues to be helpful to remember and draw upon.

Developing our thinking about finding appropriate ways to support families who have a member with a disability to continue their natural and typical family role particularly as children become adults has been written about in a variety of ways over the years in CRUcial times. We have included a paper by Margaret Ward, who has been involved with the Homes West association in Brisbane. This organisation has deeply influenced our thinking about how families and services can work respectfully to negotiate what is the role and business of family in the person's life and what is the role and business of the service. We recognise the important place of freely given support, either by family or friends in our community and the need to develop our thinking in how we respect and value that, as formal support is introduced, is still relevant today and will be needed in the future.

One of the objectives from the British Government's white paper on Valuing People was "*to enable people with learning disabilities to have as much choice and control as possible over their lives*". This notion of 'choice and control' is also reflected in the National Disability Insurance Scheme and Disability Care Australia. It is very interesting to read Morrie O'Connor's paper, entitled "Valuing People" written ten years ago, where he explores and illustrates how workers and organisations can support people who live with intellectual disability to achieve this objective without resorting to operating from either an 'all freedom' or 'all control' model of practice. Refining how paid supporters work individually with each person to offer the appropriate amount of support – not too much and not too little – requires our attention now and into the future.

The notion that some kind of stable, static and enduring entity called 'the community' exists out there somewhere is a myth. Often a community does not exist for people to join or services to work with. Increasingly one of the roles of human services is to help develop communities of people who can support, encourage, live with and love one another. Ingrid Burkett is realistic about how challenging this is when organisations are subject to competition policies, administrative demands from funding bodies and privatisation and management ideologies that are contradictory to the building of community. While there are community development tools that are helpful, Ingrid believes this is less about techniques than about nurturing a spirit of community and engaging in a transformation that is both personal, professional and organisational. Knowing our history of excluding people from community, the importance of appreciating and enjoying life in community and deliberately working towards that is very relevant today and will remain relevant into the future.

This edition of CRUcial Times could easily have become a book. The more we looked in the archives the more articles we found in past editions of CRUcial Times that were pertinent in answering those questions about what has been important in the past and what we need to invest in for the future. We haven't addressed the importance of innovation, planning, analysing the bigger context within which we operate or remembering our history and the list goes on. Nevertheless, we hope that this edition will provide you with an opportunity to reflect on what is important and should be held on to; what are the fads and promised changes that won't last or be remembered; and what is likely to make a real difference in the lives of people with disability now and into the future.

Margaret Rodgers
Director

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From the President

One of the stated aims of the Community Resource Unit is to "*Inspire and encourage individuals and organisations to pursue better lives for people with disabilities"*. To work towards this aim CRU has a deliberate strategy to direct its work to a wide range of people across the disability sector: people with a disability, family members, friends and allies, government and non-government workers and academics.

This strategy has been a key feature of CRU's workshops and other events from the very beginning. At the celebrations in October last year to mark the 25th Anniversary of the Search Conference, it was widely acknowledged this conference was one of the first events in Queensland where all stakeholders had come together to develop a shared vision for the future. As I continue to learn about the history of the disability sector in Queensland, I begin to understand how much more limited in its effect a conference such as Search would have been had it ignored the voice of any of those groups.

The concept of a CRU-type agency was part of the vision developed at the Search Conference. The Community Resource Unit became a reality the following year. Since then CRU has proudly continued the tradition of bringing people together rather than having different groups meet in isolation or in specialist gatherings. Many deep, thought-provoking and hopefully life-changing conversations have been generated as a result of this inclusive policy. The opportunity to share ideas in a broad setting has been especially important for people with a disability.

The range of contributors to CRUcial Times and the scope of its content are another indication of CRU's inclusive strategy. Each edition of CRUcial Times includes articles from a diverse range of people including people with disability, family members, workers and academics. This current edition of CRUcial Times is a collection of articles from editions published over the past 25 years. It represents a range of voices from the sector, revisits themes of great importance and reinforces the call to personal leadership and the belief that Good Lives are possible. Please enjoy this historical collection and, whatever your interest in CRU's work, be motivated by our aim *to pursue better lives for people with disabilities.*

I would like to close with a quote from Margaret Mead:

> *Never doubt that a small group of thoughtful committed citizens can change the world:*
> *Indeed it's the only thing that ever has.*

Such a group were the participants in the Search Conference who had the original vision for the Community Resource Unit. They left us with a legacy that we are proud to continue.
Cheers,

Matt Stone

President of Community Resource Unit

CRU has a website, please go to: www.cru.org.au

• For more information about CRU • Details on upcoming events • Bookshop
• CRUcial Times including previous editions

Reflections from a former President

***Mike Duggan** was President of CRU from 1988 to 2010. In that role Mike wrote the feature "From the President" thirty seven times. Mike's thoughtful reflections have a way of highlighting trends and issues whilst calling for a reality check between what is said and what continues to be. Here are some highlights of his contributions to CRUcial Times.*

Issue 2. February 1995

When people eventually get to move out of institutions, it is often very similar to when a teenager leaves the parental home and protection for the first time. On one hand he or she is filled with excitement and anticipation of a new, very different lifestyle; one which encompasses freedom, choice, autonomy, etc. On the other hand there are feelings of varying degrees of fearfulness and apprehension, even intimidation. However, there are differences between the average person leaving home, and a person leaving an institution.

For instance, if the former does make a mistake, often he or she will be able to cover up to such an extent that probably nobody will ever discover it. Whereas for the person with a disability, is anything private? He or she is virtually constantly 'on show', with people almost waiting for mistakes to be made. Of course, this does great things to one's confidence!!

Issue 8. March 1997

In this changing agenda are we always thinking about the best interest of the person who has the disability? If so, why are there so many people living lives of isolation, loneliness and of having to constantly battle for day-to-day survival? Under a guise of "empowerment", people with a disability are being forced into the task of hiring-and-firing personal care workers, and of managing budgets and planning. These tasks are so demanding, that there seems little left to work on "getting a life" whatever that might mean for each individual.

People with a disability must be supported to dream (perhaps for the very first time) and to grow in self-confidence. This requires time and encouragement and the permission to make mistakes and to learn from these mistakes.

To enable a life of quality in the community, the vulnerability of people with disabilities must be acknowledged and safeguarded and their life experiences understood. We should strive to ensure that we do all that is in our power to make the community as welcoming and as inclusive as we possibly can, while developing and maintaining innovative, flexible and responsive approaches to service provision.

Issue 9. July 1997,

Inclusion does not just mean building a ramp (though in many instances it would help). Inclusion means undergoing a complete paradigm shift to one that is a social justice framework. The four main principles of social justice are participation, self-determination, access to resources and opportunities, and empowerment. Peter Westoby (a Brisbane social justice activist and author of the book, *Waiting in Line)* stresses that these principles should be driven by compassion and responsibility, and should strive to achieve:

- Equality rather than the passive acceptance of inequality
- Freedom instead of domination or exploitation
- Dignity for all rather than selfishness and individualism
- A sense of the mutual instead of a disregard for community
- Co-operation instead of competition
- The placement of social consideration over the economic
- The will to meet human needs for health, growth and development

Whilst I would be one of the first to acknowledge that there are many hurdles to overcome before we can even whisper that community living has become a reality for people with disabilities, I believe this is what we must all aim for, all of the time. By not doing our very utmost to uphold such an ideal, and seeing to its implementation in the best possible ways, we are not only betraying people with disabilities, we are actually harming our entire community, because we all belong with, and need, each other. While some are excluded, the whole community is deprived

Issue 24. July 2002

In contrast to the principles of social justice, managerialist beliefs and practices give legitimacy to the pursuit of cost-efficiency and administrative requirements as pre-eminent values… Technocratic managerialism, in particular, uses planning that is top-down and imposes performance-indicators and stringent accountability processes that leave those who are the most vulnerable even more vulnerable, more disempowered, and more marginalised. This type of approach generally leads to a rationalisation of service delivery, which in turn, leads to a reduction of direct, personalised services.

One element that will save us *all* – if anything will – is the development, nurturing and maintenance of meaningful, reciprocally giving, supportive personal relationships. We have to honour, respect, and *love* one another. This will require a shift in our thinking, our attitudes, and our values. Such a shift has to be characterised by an emphasis on the sanctity of each person and the importance of personal worth. We have to share with one another openly, honestly, respectfully and reciprocally. We must learn to respect and embrace our inter-dependency. We must learn what 'being in' community really means. We must learn how to 'be in' community

Issue 28. November 2003.

For me, this is what our work together is all about: the advancement of treating humanity with unconditional love and respect. This especially includes those of us who have been labeled as having a disability. In this day and age, I feel this unconditional love and respect is vital, perhaps more than ever before. The age of individualism, the body beautiful and unit productivity have certainly overtaken us with a vengeance. This occurrence is to the utter detriment of people with disabilities. This is precisely why we need to be counter-cultural when we think of how best we can assist people with disabilities to live fulfilling, satisfying and included lives.

Leadership and Change

From: 26th Edition, November 2000

Lesley Chenoweth *has worked for over 30 years as a change consultant, social worker and academic to further the interests of people with disabilities and families, and to encourage personalised, responsive services that support them. Lesley is currently Head of Campus and Professor of Social Work at Griffith University, Logan campus in Queensland.*

Many of our efforts in achieving good lives for people with disabilities mean that we must deal with change: we have to initiate it, point it in the right direction, survive it, sustain it and, importantly, safeguard it. Change efforts require having enough critical mass of stamina for a long haul even though individual people may need to withdraw for a while to restore energy or attend to pressing personal or family issues. And there are times when a proposed change would have negative implications for people, families or communities. How many change initiatives have been promoted as innovative but a closer analysis has revealed major flaws that would have led to negative or even harmful consequences for vulnerable people? Under these circumstances we need the capacity for discerning flaws and for resisting harmful change. Central to all change efforts, however, is leadership.

> Change efforts need different kinds of leadership that can address the complexities of systems and community.

One of the leadership challenges is to recognise the different forms that leadership may take. Change efforts need different kinds of leadership that can address the complexities of systems and community. For example, large-scale change occurs over a range of different situations, systems and contexts.

In contrast, some leaders never work in the public arena; they work invisibly, quietly making a difference in the lives of families and vulnerable people. Other leaders make incremental changes over long periods of time. Some leaders work to develop new knowledge or theory that will make a difference, and others work to make opportunities available for innovators.

Most of us carry assumptions about what ‘leadership’ is. Leadership has become such a gripping subject that it has frightened off many people. Richard Louv, a writer for the San Diego *Tribune*, and author of many books on community life in America, claims that too many of us think that being a leader is a job for someone else; that only celebrities qualify for the position; or that “leaders somehow appear magically – summoned by fate, endowed with charisma, and usually good hair”. In many organisations leadership is seen as somehow the same as management. Although good managers need to be good leaders, I would argue that the vast majority of leaders are not managers.

Joseph Rost, an expert on leadership theory, explains that most ideas about leadership reflect the values and assumptions of the industrial model of organising, which dominated the twentieth century. He says that the ideas have been “management oriented, personalistic in focusing only on the leader, goal-achievement-dominated, self-interested and individualistic in outlook, male-oriented [and we would add to that: mostly white], utilitarian and materialistic in ethical perspective, rationalistic, technocratic, linear, quantitative and scientific in language and methodology”.

Rost goes on to say that the values and assumptions that leadership needs to reflect upon are “collaboration, common good, global concern, diversity and pluralism in structures and participation, client orientation, civic virtues, freedom of expression in all organizations, critical dialogue, qualitative language and methodologies, substantive justice, and consensus-oriented policy-making process”. I think that this describes a more hopeful standpoint. Social movements such as those that strive for a better and fairer world need collaborative and transformative types of leadership. Our understanding of the world is changing rapidly, so searching for alternative approaches to the study of leadership may be in order.

Leadership is often situation specific and this is so for the disability movement. Some people possess great leadership qualities but they haven't been placed in a situation where these qualities can come to the fore. Specific situations can bring out qualities in people or groups where leadership is called for, and different situations require different kinds of capacities, skills and attributes. In a movement for change, there are many situations across different contexts and time, each calling for its own kind of leadership.

It is important for us to understand that leadership itself needs to be developed. Most people will be familiar with the famous story about Rosa Parks, an African American woman who refused to give up her seat at the front of a bus to a white man. This story is often used as an example of the power of one brave act of leadership, which set off bus boycotts and the civil rights movement in America in the 1950s. Most people assume that, in a moment of indignant resistance, Rosa sat at the front of the bus, which was reserved for whites. What is less well known is that Rosa was not acting on a whim. She had been involved in social justice activities since high school and had spent twelve years leading the local chapter of a national organisation, and just before her bus sit-down she had attended a ten-day session at a training school for leaders in civil rights. Rosa was not a spontaneous leader; she spent long years preparing for the 'fabled moment'. She had been working at the grass roots and was involved in deliberate leadership development over a long period of time.

> Specific situations can bring out qualities in people or groups where leadership is called for, and different situations require different kinds of capacities, skills and attributes.

For those who have been involved in social movements, there is an acute awareness that efforts for change take a long time, and most of the theory and research on change would argue that slow deliberate change is the most sustainable. This is also true for leadership development in change movements; it takes time. While leadership development opportunities are prolific in the business sector, for example, in the disability sector they are patchy at best. (CRU is one organisation that has provided opportunities for leadership development for at least a decade. The most impactful of these are the formal strategic programs for leadership development that they conduct. These efforts and others like them need to be supported if we are to sustain a movement for positive change into the future.)

Nowadays change is so rapid that it sometimes seems we need to be working for stability rather than for more change. As the world becomes more complex and turbulent, efforts for change become more difficult to implement. Followers are more resistant and perhaps less optimistic, and so this too will call for different kinds of leadership, and we will need to time our change efforts to the situation at hand.

The following are some principles that I have gleaned from other leaders I have been privileged to follow, from reading, from teaching others, and from my own modest efforts at leadership.

- Put people first. At the heart of our movement are people with disabilities and families. It is their lives that are ultimately affected by any efforts we make.
- Make sure the values underpinning the change are ones you agree with. Ask: will this work towards a better life for people with disabilities and families?
- Be flexible in approaches and strategy. We will face a range of situations, some of which are new and unknown. We need to be open to different approaches and try another way if needed. Leadership needs creativity and innovation.
- Sustain optimism even when things are bad. This is key in a movement such as ours. We have faced tough times with despair and it is

hard to dust off and keep going. Leadership can help sustain optimism.

- Balance caution with optimism. This is related to the previous point. We need to carefully consider what we do before we act.
- Lead by example. It is no good expecting others to do what we are not prepared to do ourselves.
- Work with others. When we need collaborative leadership, we need many others around us.

Striving to create more inclusive communities will always involve a call for change, and leadership will always play a vital role in bringing about such change.

Holding on to the Ordinary

From: 29th edition, March 2004.

***Glenys Mann** is a mother of three children and long term member of CRU and QPPD. She has a background in teaching and is experienced in supporting schools to be more inclusive of students with disability. As a PhD student, Glenys continues to be involved in the area of inclusive schooling for children with disability. She was the publishing editor of “Diving for Pearls”, QPPD’s 2011 report on parent’s quest for inclusive education in Queensland and “I Choose Inclusion” in 2012.*

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.

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.

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.

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

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 cannot 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.

Being at the Centre of my Life

From: 30th edition, July 2004.

Lisa Lehmann *is a social change agent and has been actively involved in both self-advocacy and systemic advocacy for over fifteen years. She works as a consultant in the sector and also mentors other people with disability in how to manage independent living. Lisa has been a keynote speaker at a number of national conferences, including the CRU Conference in 2007, where she spoke about her life as a woman with a disability directing her own supports. Lisa is the parent of a six year old son and is currently studying business with the plan to become a social entrepreneur.*

I thought I was in control of my life once and I was for a while. I utilised a service known for its high standard of person-centredness for about five years. However a change of management and the subsequent erosion of organisational values led to deterioration of the delivery of service.

The illusion of person-centredness persisted in that all written material continued to state that I was the employer and I was still encouraged to think I was in control. However I discovered that the managers and staff of the service I was using were having meetings about me without me. The tasks that I instructed the workers to do were ignored. Workers did what they 'thought' I needed to have done. As a result my health suffered because things were left not tended to despite numerous requests. Workers went away from my home with preconceived ideas and unfounded perceptions about my life and my friends that were not only none of their business; they were harmful to me and to my friends' reputations.

I exited myself from that service and it was during that process that all my fears were confirmed. The service providers did everything in their power to punish me for my decision and undermine my abilities and to diminish my reputation and confidence. So much for being in control!

I am always keen to learn from the things that do not work or that go wrong. I began thinking: how was I going to use what I was learning? What could I do to bring to my life the kind of supports I actually wanted in a way that allowed me to be me, totally? These questions have led me on an exciting and powerful journey and have made a number of things very clear.

It became clearer to me that the reason I encountered such empty words and inadequate support was because I was being perceived as my disability. My needs were merely related to the needs of my disability.

I am the only person at the centre of my world. Anyone who believes they put me at the centre of their thinking has misconceptions about their role in my life. There are too many competing factors. It is impossible to put someone else completely at the centre of one's life, without one's own needs impacting on the other person. The needs of the service also compete with the needs of the individual. The amount of support provided is based on budget formulae, the culture of an organisation and its ability to attract and nurture good people. It is unrealistic to think that I or other people who use such services could be at the centre of things. Too often the needs of the service and staff come to be valued more than the person themselves.

It became clearer to me that the reason I encountered such empty words and inadequate support was because I was being perceived as my disability. My needs were merely related to the needs of my disability. However I am not my disability – I am Lisa first. In reality I simply need some assistance with a few parts of my life. It is not complicated, nor would I want it to be. A significant step in living my life the way I want has been thinking about what I need and want separately from the perception of needs my disability creates, and then breaking these into easily identifiable roles. For example, I need help with my housework so now I employ a cleaner. I found her in the Yellow Pages and she is a professional. She is not employed by any disability service; in fact I am probably the only person with a disability who she cleans for.

Likewise I need help with my personal hygiene; this need also is now met through the employment of professional nursing staff. Both the nurse and the cleaner are very clear about their roles and do not try to take over other aspects of my life. They do not have a need or the opportunity to meet or discuss me – I am not at centre of their existence nor would they ever pretend that I am.

When I contrast this with what I was receiving from my previous 'disability support workers' the picture is dramatically different. They saw their role as overarching my entire life. They did not really want to clean my home, they did not see that as being their role, yet clearly that was what I employed them for, and what I needed and expected from them.

I am grateful for the lessons which have contributed to the way I live my life now. Without these insights I would still be treated, done to, and done for in my own home. I now know the difference between good service and bad has nothing to do with you being at the centre, it is totally based on how much you are valued and respected. I know I have an equally respectful relationship with all the people who play a supporting role in my life. Without this, person-centredness is an empty phrase. I am now back in control of my life, and my destiny is mine once again. This is true person-centredness to me.

The Natural Authority of Families

From: 6th edition, July 1996.

***Michael Kendrick** is well known internationally for his work on leadership, quality, advocacy, safeguards and the promotion of community living for people with a disability. He has made a significant contribution to the field as an educator, consultant, and advocate for over 35 years. Dr Kendrick works regularly in Australia and has a long history of collaboration with CRU. His book, "Letting in the Light", was published by CRU in 2009.*

With great regularity, consumers of services and their families will find themselves having to confront professionals, bureaucrats and others in roles of authority. Not uncommonly the authority of these persons tends to overshadow the authority of "small people". It can sometimes help to remember that families have a natural authority of their own which can go a long way to reducing this imbalance of power and authority. In order for this to happen, however, families need to appreciate this natural authority and be willing to act on it. What follows is a brief description of some of the common sources of authority that families can call on when they are acting in the interests of a family member.

1. The public generally recognises the primacy of families in terms of their responsibility for a person's wellbeing. In this way, families have the authority to be highly engaged because they also tend to have greater responsibility for the wellbeing of their family members.
2. Families have authority (normally) arising from knowing their family member the most fully and over the longest period of time. In this way they have the authority that arises from long term observation, insight and personal relationship.
3. Families typically care about or love their relative more than would be true of others, however committed the others may be. Not only do families usually care more but they are also expected to care more.
4. Families have a stake in outcomes. For example, they have to live with the long-term consequences of service failures to a greater extent than any other party, except the person themselves.
5. Families are expected to advocate for their own members. Not uncommonly, they are granted considerable presence in the decision-making processes affecting their family members, even where legal formalities do not require it.
6. The family is an authoritative witness to the performance of professionals and systems and may have special (though not necessarily exclusive) insight into events that take place.
7. Family members bring to their role a wide range of talents and experiences which can give them additional authority on many matters. For example, a parent might also be an expert educator.
8. Families are often best positioned to see how everything, in its entirety, adds up in a person's life. For this reason they can often see the incongruencies of different interventions.
9. Family members are often free of the vested interests which call into question the credibility of other parties. Frequently family members are granted a degree of independence which highlights their credibility and purity of motive.

While these common sources of authority do not, in the end, resolve the question of ultimate authority, they do offer families some measure of security that their views should matter as much as, or more than, others who also claim authority in deciding what will happen to a person. Because it is very difficult for a person to advocate if they hold some doubt about the legitimacy of taking on the role, these points may help to strengthen the resolve to hang-in-there and advocate for your family member.

Reclaiming Family Business

From: 24th edition, July 2002.

***Margaret Ward** is the mother of three adult children. Despite significant disabilities, her first daughter Ismena lived in her own home for ten years, with the support of family, friends and the Homes West Association. The family's involvement in Homes West is the focus of this article. Margaret is well known for her strong, visionary leadership in the Queensland disability movement. She also played an important role in the establishment of Queensland Parents of People with a Disability and CRU.*

Most families who use services have been frustrated by technocratic managerialism. They are bemused by the increasing complexity of the service system and the widening gap between the call for 'efficiency and effectiveness' and the reality of their son's and daughter's lives.

Technocratic managerialism commonly manifests itself in ongoing restructuring, increased reporting requirements, and an emphasis on management ahead of experience-based knowledge and wisdom. Families work differently. Their ways of solving human problems are messy and idiosyncratic, requiring trial and error, intuition and perseverance. Experience and wisdom allows them to think smarter as they get older and the tasks get harder.

> Technocratic managerialism commonly manifests itself in ongoing restructuring, increased reporting requirements, and an emphasis on management ahead of experience-based knowledge and wisdom.

There have been some successes in bridging the gap between the service system and families but those successes have been few. Those services that have been successful have shown it is possible to work respectfully with families and shield them from the demands of technocratic managerialism or whatever fad is fashionable at the time.

The March edition of CRUcial Times offered some strategies to service providers who want to work in similar ways. Here, I am offering some strategies for families.

Embrace the natural authority of families.

If you are unsure of your authority as a family member, I suggest you make two lists on a sheet of paper. In the first column, list all the people who have been constant in the life of your son or daughter for the last ten, twenty, or thirty years. In the other column, list all the people who have come and gone over the same period.

My guess is that your first list will be short, naming your family members. There may be others, if you are lucky, and perhaps a few faithful friends or 'extended family'. This list is valuable because these are the people who can even <u>begin</u> to claim some authority in your son or daughter's life. The other list will be enormous and frighteningly irrelevant.

Michael Kendrick wrote a short pithy, piece called *The Natural Authority of Families*. I suggest you obtain a copy from CRU and stick it on your fridge. In no time you will be clear, realistic, and authoritative and you will need to be if you want to take back what is, and always should have been, Family Business.

Reclaiming Family Business.

I believe that there is 'Service Business' and 'Family Business'. Service business is the business of providing services; and Family Business governs how, when, why, and what level of service should be provided for a family member. Family Business is also the following:

- Daring to dream the seemingly impossible;
- Thinking lovingly, passionately, and intuitively about your son or daughter's life;

- Protecting the sacredness and privacy of family customs, culture and history;
- Espousing your son or daughter's beauty, gifts and talents.

And when your son or daughter cannot speak out for themselves:

- Ensuring that service providers meet his or her needs.
- Naming what is a good life for your son or daughter;
- Stating clearly what is negotiable or non-negotiable, what is acceptable or not acceptable.

If you are spending all your energy trying to get services to do the right thing, being pleasant to service workers who disregard you, or generally trying to find out what-the-hell is going on, you have lost control of what should be yours – Family Business.

Getting it back is tough. Keeping it once you have it back is also tough. However, families are doing it all the time and services, once they let go, realise that it works better when families have a say in what services do. Services also discover that when families signpost the way, there is a sense of continuity, fewer situations that turn into crisis, and less waste of time and money.

> I believe that families do best when they join together. When you find your allies, listen to them – they may save you a lot of time and heartache.

Stick to your message.

Once you are clear about your authority and your vision, you will need to stick to it. All manner of effort will be made to offer you a compromise that fits better with the service system. This can be stressful because your non-compliance may earn you the name of 'trouble maker', 'unrealistic, or even 'greedy'. The well-worn rules of action are relevant here: courtesy, truthfulness and tenacity. Because a symptom of the present service system is that staff come and go quickly, this labeling is not as damaging as it might otherwise be.

It is important to be sure that your message is, in fact, what you really want for your family member. Allies and trusted advisers can help you to double-check that what you are doing is the best way forward.

Find your allies.

There are people in service systems who do want to help families; they are usually long-term players and are skilled at minimising the effect of whatever management fad is in favour. They don't break the rules but they do know how far they can bend them. There are always loopholes and windows of opportunity when change is rife and your allies can tell you about them. They will also know other families who are thinking alike and where good things are happening. They can also warn you of the pitfalls. Other families with the same vision as yours are important allies. It is here that ideas can be tested and modeled, using real experience and understanding. The synergy of a group of families is powerful and strengthening for each member. I believe that families do best when they join together. When you find your allies, listen to them – they may save you a lot of time and heartache.

Support people making change.

People with a disability, family members and workers have taken systemic action over the years to influence the service system to be more responsive to people with disabilities and their families. They sit on committees, write submissions, make deputations, and take legal action. It is very important that we support them.

It is almost certain that service systems and governments will become even more complex and technocratic over time, and that there will be ongoing changes and fads in management.

We cannot depend on some management technology, financial theory or restructure to bring sense to the service system. It will be the culmination of systemic and individual actions by concerned citizens, along with families and people with a disability that will continue to call the service system to order.

Valuing People

From: 28th edition, November 2003.

***Morrie O'Connor** has worked at the Community Living Program (CLP) in Brisbane since its establishment in 1989. He is the current co-ordinator of this service, now known as Community Living Association (CLA). In this role Morrie has overseen the development of the Association to include a range of innovative strategies and projects that assist people who live with disability and mental illness.*

The recent British Governments White Paper on 'Valuing People' a new strategy for learning disabilities (intellectual disabilities) for the 21st century states as one of its objectives, "To enable people with learning disabilities to have as much choice and control as possible over their lives".

This fairly unexceptional statement explicitly advances two beliefs; the first that people should have the right to self-determination, self-direction and self-authorship. The second, that there are limits to self-determination. However, workers often fail to synthesise these two beliefs and instead operate from an 'all freedom' or an 'all control' model of practice.

Neither of these one dimensional approaches 'all freedom' or 'all control' adequately respond to the complexity of people's lives, and the joint needs that people have for both autonomy and support to avoid harm.

To further explore this point I would like to share a number of experiences. They are everyday stories, not unusual.

Experience One:

One of the workers employed by our organisation was present, as an occupational therapist was going through an assessment with a young man with an intellectual disability. The assessment was on what help he would need to live alone in a flat. The assessment was a tick box: Can you cook? Can you budget for yourself? To these questions the young man affirmed that he was able to cook, able to budget and handle his own money. The worker from our organisation knew from previous conversations with the young man and his family that he had rarely cooked, and instead had a serious accident when endeavouring to cook, and had difficulties managing money.

Experience Two:

I was invited by a young woman with an intellectual disability to go to an interview with her. The interview was for her to receive assistance to get a job. As the interview progressed it was clear that the interviewer had come to believe a lot of errors about the young woman's previous work history. As she repeated these errors the young woman assented to them. The interviewer's plans for employment then began to be formulated around this erroneous information.

Experience Three:

One of the workers employed by our organisation was working with a young woman with an intellectual disability. She lived with two friends who didn't have a disability. Over a period of time the worker became concerned that the young woman's recurrent mental illness problems were tied to possible exploitation by her flat mates. The young woman consistently denied that any sort of exploitation was occurring in the relationship when the worker broached the subject with her.

Each of the above stories illustrates some of the general difficulties that people with an intellectual disability have in negotiating life. Were the young man and the occupational therapist talking the same language? Did it have the same meaning? Did cooking or budgeting have the same meaning for both of them? Was the young man able to share 'inabilities' with a stranger? People with an intellectual disability often experience a lifetime of failures and put-downs. It can take a great deal of self-confidence to say, "I can't do that thing". The young man really wanted the flat; did he feel that if he said he couldn't cook that he would lose it? Perhaps he was just used to saying 'yes' to people in authority, even if he didn't understand. His experience was that if you agreed with people in authority they took you at face value and things happened.

The job interviewer was very enthusiastic about the young woman's job chances seeing that the young woman had successfully worked for three years in a kitchen. The young woman with an experience of many let downs with employment agencies was buoyed up by this enthusiasm about her job prospects. Little wonder she didn't want to bring in history that felt negative and unfair. She had worked in a kitchen for almost a week (her understanding of the distinction between a week and three years was hazy). She was sacked for refusing an order from the chef, but she felt this was terribly unfair, as she didn't believe the chef was the boss and so shouldn't be able to give her orders.

For the young woman, the flat mates were her friends, they told her so. She had never had friends. They did things to her that caused her to feel angry, and depressed. She didn't even know for sure that some of the things were wrong, only that they made her feel bad. How much courage does it take to acknowledge that my only friends ever, treat me appallingly?

> Both the 'all freedom' and 'all control' approaches can be seductive: 'all freedom' because it seems to affirm people's value, 'all control' because it seems to guarantee the right decision (in the worker's or other's eyes) being taken.

The workers in the above stories have three broad options in terms of action.

Firstly, they can trust whatever the person with a disability is participating in as an exercise in self-determination. Even when there is reason to doubt that the person is fully conscious of or fully in control of what they are agreeing to. This can to the worker feel respectful, empowering of the person with a disability. However, in reality it is a cop-out and ultimately disrespectful of the person.

Secondly, the worker can see themselves in control. "This young man needs cooking skills". "Oh no he can't budget!" "She didn't work for three years, she got sacked". This approach reduces the person to object and denies the importance of people being authors of their own story. Control has been the dominant methodology of the disability sector and like all expressions of power it has a tendency to corrupt the user.

Thirdly, the worker can be honest in as respectful a way as possible. "Do you remember you told me you almost burnt yourself cooking". "I know you don't want to tell them you were sacked but I don't think they'll be able to give you proper help unless you let them know about past problems".

And this honesty may need to involve engaging in exercising 'control over' the person. "It looks to me as if they are doing a lot of bad things to you that are making you sick. If you're finding it difficult to stop what is happening, I think I have to make sure something happens to stop what they are doing". However, the exercise of such 'control' needs to be done respectfully.

Both the 'all freedom' and 'all control' approaches can be seductive: 'all freedom' because it seems to affirm people's value, 'all control' because it seems to guarantee the right decision (in the worker's or other's eyes) being taken. So, what principles of action assist in working out what to do? How can we find a different way from the vexed polarities of 'all freedom' and 'all control'?

The first is a 'commitment' to do the best possible by the person. The 'best possible' includes a commitment to the person having good relationships, a sense of personal control, freedom from exploitation, personal meaning, meaningful use of time, material requirements, personal development etc.

The second principle is to listen, listen and keep on listening for what it is that people are really saying.

Thirdly, a strong stand against 'exploitation of the person' is needed.

The fourth principle is if it seems necessary to act in a ‘control over’ way, to discuss this respectfully with the person and where possible to seek the advice of others who are committed to the person, or at the very least to seek the advice of experienced peers.

In conclusion I think of support to people with an intellectual disability in the use of decision making as a holistic process: a process that will include supporting people to take authority in their lives, a process that should include working with the person and their significant others to share authority and which may include working to have others to take authority in the person’s life.

Navigating for a Community of Relationships

From: 10th edition, November 2000.

***Ingrid Burkett** was a lecturer in Community Development at the University of Queensland when this article was written in 2000. She has worked across government, corporate and community sectors, locally and internationally. Dr Burkett is currently the Managing Director of KNODE, a social business focused on knowledge design for social innovation. She is also the president of the International Association for Community Development.*

The environment in which contemporary human services operate is more like a mangrove swamp than solid ground. It is a swamp which appears as hostile, difficult terrain where it is often difficult to find a patch of hard ground on which to stand. Swamps are generally viewed with disdain – they can be messy, unpleasant places – and yet they are now recognised as supporting the most amazing ecosystems.

The swampy environs of human services are the subject of this article in which I have contemplated how a service can work with and in a community. The map that I use to navigate this swampy terrain is informed by some of the principles of community development. It is a map which has various guide-posts which can help in broad navigation, but that has no set paths - each service must develop its own paths in relation to the directions it wishes to take.

The **first of these signposts** points us in the direction of asking what is this thing we call ‘the community’. Before a service can work in, and with a community, there needs to be some analysis of what ‘community’ the service wishes to engage with. Increasingly we hear politicians and bureaucrats referring to the roles and responsibilities of ‘the community’, as though some solid entity exists out there which can take up where the government leaves gaps in its ever diminishing safety-net. ‘The community’ which is the subject of this rhetoric is an imagined entity. The notion that some kind of stable, static and enduring entity called ‘the community’ exists out there somewhere, is a myth. This is not to say that ‘community’ itself is mythical – but it does mean that we need to be a little more specific about what we understand by ‘community’.

At the root of ‘community’ are human relationships – the different ways that people find to live with, and love one another – in informal and formal ways, through friendships, associations, organisations, interactions, and so on. The ways in which these relationships are portrayed often revolve around notions of harmony, mutuality, and closeness. What is left out of this quaint, nostalgic picture is what a real struggle relationships can actually be. Human relationships, as we all know, are filled with difficulties – they are hard work, requiring vast amounts of dedication and ongoing efforts and maintenance. This is not to say that relationships are never harmonious or wonderful, but only to say that they are filled with paradoxes: pleasure <u>and</u> pain, harmony <u>and</u> conflict.

Communities are not only more difficult than is often portrayed, but they are also more complex. People no longer live in single communities. More often, people are members of all sorts of communities, centred not just around localities, but also around identities and interests. And importantly, it should be emphasised that for many people, the fact that they have very few relationships within any of these spheres, is a major feature of their social marginalisation. It is increasingly recognised that a lack of relationships – a lack of community – is a key characteristic of disadvantage and poverty in Australia. For this reason, very often ‘a community’ does not exist for services to work with; increasingly one of the roles of human services is becoming that of building community. This means that rather than asking the question of how services can work in and with communities, services are themselves being asked to build communities of people who can support, encourage, live with, and love one another.

> Community building involves processes that are slow, small-scale, unpredictable, fragile, and often difficult – but which also can be beautiful, touching, and heart-warming

The **second signpost** in this swampy terrain leads on from where the first one ends. If one of the ways in which services can work in and with communities is to become actively engaged in community building, then how do we go about doing this? Is the building of community something we can read about in books and apply to whatever context we work in? Again, I would suggest not. For human service organisations such a process is particularly challenging because the outcomes of engaging in community building are not always clearly identifiable in the short term. Their processes may not always appear logical or ‘professional’ from the perspective of funding bodies or service evaluators who are seeking clear, objective, quantitative outcomes.

Two particular challenges exist for services wishing to engage in community building. The first is how to ensure that communities are strong enough to be long-lasting. It is a common misconception that communities, in order that they remain harmonious, should be based around commonalities. I often hear the notion that the word ‘community’ is actually a combination of the words ‘common’ and ‘unity’. Apart from the fact that this is not an accurate understanding of the roots of the word ‘community’, it is a very misleading interpretation of the realities of life in community. Building communities amongst people who are all similar (whether in terms of identity or interest or other characteristics) may seem less fraught with difficulties in the short term and yet, it is diversity, not ‘common unity’, which actually sustains communities in the long term. Just as the swamp is filled with diversity, and this diversity makes the ecosystem of the swamp sustainable, so too communities need diversity and difference – in terms of roles, capacities, personalities and interests – if they are to remain sustainable.

The second challenge for services in building communities lies in the fact that diverse communities are also those which are dynamic and ever-changing. The challenge is not to see communities in terms of achievements or outcomes, but to see them as continuing processes. This is not to say that community building happens in the dark, with no guiding method – community development has very clear methodologies and frameworks of analysis – they are methods and frameworks of how to engage in process, not how to determine or define outcomes. In engaging in community building one can be very clear about how one will go about working with people in open, democratic and participatory ways. And yet the methods of community development do not only rely on having the right ‘tools’ to create good processes – community building is much more about nurturing a ‘spirit’ of community than it is about applying techniques. Too often we hear of concepts like ‘empowerment’ or its newer alternative, ‘capacity building’, being interpreted as though they represent some kind of super tool which can be applied to ‘create’ community. It is crucial, if services are to become involved in community building, that opportunities are created for a diverse range of people to commune in spontaneous, creative and enjoyable ways that are not just exclusively related to their service functions.

The **third signpost** points both straight up and straight down; it points both in and out. It indicates that the engagement of services in the messy endeavour of inventing and creating community, presents challenges both to the outside environment in which a service exists, and to the inside, not just of the organisation, but to the inside of each person within that organisation. Engaging the process of building community means an engagement in a process of transformation – personally, professionally, and organisationally. For human service organisations I think this presents some challenges, particularly in the contemporary political and economic environment.

Services are under increasing pressure in the current political and economic environment. Financial management and accountability have, in many cases, been taken to such an extreme that I sometimes wonder how workers find the time to do anything outside of keeping statistics, and recording the cost-benefits of each activity they undertake. Most human services are working to full capacity, and yet they are often asked to take on even more work. The danger of this situation is that there is often only time for constant activity with little or no time for reflection on those activities. Further, whilst participatory community processes are now recognised as the ideal, they take a great deal of time and effort, and for many services the realities of the demands and pressures they face from the outside environment are such that this makes community processes impossible to sustain. If services are to be involved in building community this situation needs to be addressed internally and externally: through the creation of reflective spaces that are central to the workplace culture within an organisation; and externally, through the lobbying of funding bodies, making them aware of the realities of work which has, at its centre, community processes.

Building communities not only means building relationships between people but it also means building cooperative relationships between services and amongst the people within them. My map of community development makes me think of how a mangrove tree presents us with another picture of how services could work with and in a community.

Mangrove trees do not exist in isolation – nature has realised that a single mangrove tree at the edge of the water is too susceptible to the push and pull of the tides. Rather, mangrove trees exist in clusters and they link their roots in such a way that each tree connects with each other tree, the root systems intertwined, supporting the entire group of trees. The strength of the root system means that it is much more difficult for one tree to be pushed over, and together the trees support an amazing ecosystem. The contemporary environment in which human services exist is one which makes it very difficult for services to formally interconnect – they are increasingly subject to competition policies, administrative demands from funding bodies, applications of privatisation and management ideologies, and the list goes on. And yet, if services are to work with and in communities in ways which build community, then the values of interconnection, cooperation and integration are central – not just as abstract principles, but as enacted components of the work which services undertake.

Community building involves processes that are slow, small-scale, unpredictable, fragile, and often difficult – but which also can be beautiful, touching, and heart-warming. Community building is not something that can be done in isolation either by one person in an organisation, or by one service acting in isolation from others. It involves the invention of ways of making the most micro-actions reflective of the principles of participation and justice. It requires a commitment to making real, the power of creativity and spontaneity. It demands a valuing of diversity and difference in all facets of work, and is founded on a belief in the possibilities of the impossible.

Services can and do have a role to play in building community. To do so involves some very real challenges that require making conscious decisions to undertake journeys into rather swampy environments, in which plans change, maps are only vague guides, and where each one of us, whether ‘provider’ or ‘recipient’, becomes explorer and inventor of never-ending stories.

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