

# CRUCIAL TIMES

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## CRU's Mission Statement

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

## *editorial*

We can probably all relate to the experience of having to rely on a human service, such as a doctor, hospital, tax agent, bank or school. At these times we can find that the power rests with the agency and that our voices are small. We can find that our choices are limited to what the agency determines as being on the menu, and that the agency requires obedience to its rules. In disability and aged human services, having the uniqueness of our individuality recognised is particularly at risk. The issue is that we like control over matters that affect our lives and particularly those matters that we would consider to be in the private domain.

Writers in previous editions of CRUCIAL Times have analysed and exposed the impact of both small and large bureaucracies on the lives of the people they serve. This edition of CRUCIAL Times looks at one of the things that will safeguard against the bureaucratization of people's lives: **the nature of the relationship between server and served.**

Regardless of their rhetoric, it is unlikely that any human service can be perfect. There are, however, things that services can do at an organisational level to minimize the impact of organisational processes and structures. And while it is easy for an individual worker to feel totally overwhelmed by the constraints of the organisation, there is still much that can be done by each individual. In this edition, Michael Kendrick reveals some of the ethical decisions that form a foundation for developing a more positive and authentic relationship, that which he calls 'right relationship'.

This edition includes some illustrations of right relationship in action and what happens in its absence. When any two people come together, a 'space' is created by the attitudes and mindsets of each; by what is said, by what is not said, and by the agendas of each. We are usually not very conscious of this space, but we know intuitively whether it is good or not. The articles by Lisa Bridle, Sally Barone, and Sue Tuttle explore what happens when system or service meets citizen. They provide clear challenges and ideas for those who provide a service, in terms of what happens in the space between worker and citizen. It is in this space that there is an opportunity for the power differential to be changed. In this space, hope must be created. And it is in this space that ideas, energy, and enthusiasm for a better life can be either created or destroyed.

In the power struggle between the human service system and the people receiving the service, it is most often the service recipients who miss out on having their voices heard and the power and authority in their own lives recognized. Mary Kenny depicts what life would look like if people truly had authority in their own lives, while Vivien Twyford provides suggestions for authentic consultation to enable such a vision to come to fruition. Morrie O'Connor, reinforcing the importance of right relationship, tackles the challenges of choice and control in the lives of people with impaired decision-making capacity, whose choices could lead to harm to themselves.

Right relationship is a powerful tool in buffering the impact of technocratic processes and the weight of bureaucracy. Most importantly it gives us hope, by reminding us that no matter who we are, and where we are placed, no matter how strong the institutional agendas or how overwhelming the issues may seem, at an individual level there is *always* something we can do.

Jane Sherwin

## A WORD FROM THE PRESIDENT

The philosopher Kant said that all objects are means to ends, but humans, that is all humans, are ends in themselves and, as such, are entitled to unconditional respect - all human beings. Kant rejected all forms of racism, discrimination and exclusion. He once said that whenever he noticed outstanding moral behaviour on the part of servants, he stopped to pay a silent tribute and would have bowed openly if prevailing customs had allowed him to.

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 labelled 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.

At CRU we are sustained by the realisation that there aren't many "right answers" to be had at the moment. Certainly, our history and historical successes, while a guide to our values, do not contain a change agent's Rosetta stone that can unlock success for the current generation of workers and committee. Sometimes having to juggle multiple agendas and needs at a time when clear direction and strategy are not easy to come by can be very challenging, even stressful, for both staff and committee. What sustains us when we are confused about the right thing to do is a deep sense of goodwill, a willingness to engage in honest dialogue, to talk openly and honestly about the tough stuff and to focus on the quality of our relationships with each other.

In many ways the current context presents greater challenges and opportunities for people of goodwill to make a difference. I am prepared to continue to "Be Excited"...if you are.

Mike Duggan

# Right Relationships:

## With and Between Family Members

*Lisa Bridle is a social worker with a background in community development who has recently joined Community Resource Unit as a consultant. The birth of her son, Sean, eight years ago prompted Lisa's exploration of the meanings of disability and parenthood. In this article, Lisa suggests that the idea of "right relationship" is key for families too, not only in how services relate to families but also for relationships within the family.*

There can be no doubt that many people with disability have not historically enjoyed what we could consider to be our birthright as human beings, what we would hope every human baby came into the world already endowed with - unconditional love and enduring and accepting relationships within family. Luckily we live in times when parents are not routinely encouraged to reject outright their newborn with disability. But sadly we do still live in times where relationships between babies, children and even adults with disability, and their families are "done damage".

This "violence" to the relationships between people with disability and others occurs in many ways, including: the way parents are told that their child has a disability, in how people with disability and their families are consigned to "special" services and roles, in the ways parents are encouraged to be therapists, medical case managers and "carers" rather than parents, and the way families are encouraged to abandon their family member or describe their family member and family experiences in wholly negative ways in order to access services.

Even before services intervene, the relationships between parent and child can be precarious. Most of us who become parents of children with disabilities lack prior relationships with people with disability, so initially we see our children through the prejudices and stereotypes society has schooled us in. While our intimate connection with our family member is the antidote to those stereotypes, there is much which happens to families which continues to damage, rather than restore or make right those relationships. And even when we have moved past those bad beginnings we must find ways to nurture our sons and daughters in communities in which we might find only grudging and conditional acceptance, if not outright hostility and lack of welcome. These experiences can easily have the consequence of creating further damage.

Loving someone who is accorded so little value in the world - someone so conditionally "there" - is excruciatingly painful and hard. It is common to feel constantly "on guard". Continually struggling for what others take for granted, such as meaningful work,

regular schools, friendships, and support to live a reasonable life, can erode your sense of optimism and hope. The clarity of seeing the world as it (at least partly) is, as a place of injustice and rejection, can wear you down, cause deep scars and make you battle-weary. Sometimes you can feel so tired and overwhelmed that you are tempted to give up on parts of your vision of a full and rich life for your family member. It is frighteningly easy to find oneself compromising not only one's vision, but also the integrity of family relationships.

It is however helpful to remember that the world is not just a place of exclusion and prejudice but also a place of beauty and wonder, relationship and possibility. Due to the courageous examples of parents who have gone before, we live in times where it is possible for families to dream about lives of value, richness and quality for our family members. We can dream of lives richly embedded in community, even if it is hard to realise those dreams. Despite our best efforts, our achievements are fragile and the dominant culture remains strong, even seductive, in its ideas about the "proper" and "realistic" pathways for people with disability. It is one of our most urgent tasks to find ways to ensure the obstacles and setbacks we will inevitably face do not have the final word.

Achieving "right" family relationships may be crucial in partly answering the question of how we maintain our vision and how we nurture our capacity to stand firm in pursuit of that vision. It feels to me that, as a starting point, family members need to acknowledge both our vulnerabilities and our strengths. "Witness" - standing with a person with disability in a totally committed way - does not come without risks and costs. We need to recognise, rather than ignore, that it is uncomfortable (and often worse) to be outside the mainstream, to have what we would consider "commonsense" - like the idea that our family member belongs at the heart of community - held up as irrational, fanciful and impossible. This social marginality associated with passionate love and commitment for a marginalized or oppressed person is a potential source of emotional pain but also of healing, of possibility and strength. bell hooks argues that marginality isn't wholly negative. It is also a site for resistance - a place of radical openness.

Radical openness strikes me as one of the transforming gifts of parenting a child with disability. Our hearts feel "bigger", more open. With the vulnerability of an open heart, comes strength, passion and even boldness. Our experiences of standing with our family member at the margins often provide us with clarity and purpose, they are "assertiveness training boot camp"; they keep us on track about what really matters. We need to remember and celebrate the positive transformations in us because remembering these, not just the battles, will help us stand with our family member, rather than succumb to, or collude with, the dominant culture.

It may be useful for us to keep connected to those transformative experiences that nourished us in the past.

For me one of those experiences came in the first 48 hours of Sean's life. Sean had been whisked away to intensive care and I was dispatched to a far off ward to recover from a general anaesthetic and surgery. In the first day I was wheeled past Sean and given a Polaroid photo but spent the rest of the day fielding visitors and trying to make sense of the news of his disability. The next day I visited Sean but only to touch him through the wires and apparatus of the ICU. It was only on day three that a kind nurse suggested I could actually cuddle my baby and I started to feel that I could begin to "reclaim" him from the hospital. For the previous 48 hours my head had been bursting with the label he had been given, his "diagnosis". Around it swirled in my head "what does it mean to have Down syndrome?" But as I held Sean I felt suddenly calm. There was a lot of sadness in the calm but I felt a strong sense of "rightness" with the world. Here, in this small baby, in the body of my son whom I had carried and known for nine months, was the answer. Sean would help me to learn all I needed to know...and it would be fine.

Over the eight years of Sean's life I have not always been able to hold on to that sense of "rightness" and calm but it is also true that I have never revisited the disorientation of those first days. Given the damage done to family relationships, we need to find ways to build and nurture our "witness" with our family member. I am still learning to do this for myself but I feel certain that as family we need to always, always see our sons and daughters, brothers and sisters with "family" eyes. Even when we are quite commonly thrust into complex roles, as "therapists", as "carers", even as "advocates", we must make sure that our role as a member of a family is never compromised and that we do not allow our "gaze" to be contaminated by the gaze of those who see our family member as a "problem", a "challenge", a "case", or a collection of deficiencies.

I think part of right relationship within families is also for us to claim our right to our share of fun and enjoyment within our families; to have time for celebration, lightness and a regular, typical life; not just for our family members but for us too! If we believe that disability does not define our family member then it should not define either their life or our own.

And we need to seek, and argue for, services which DO NO MORE DAMAGE. These services would encourage and support us to be parents first - and last. They would reflect to us a view of our family member as someone of value and worth and help us to hold to this view. They would support us in having authority and ongoing involvement in the lives of our family member. They would be a buffer to the worst excesses of community exclusion. They would most definitely help us to dream and imagine full and better lives and I hope that some might walk with us on the long, exhilarating (but also possibly exhausting) journey to achieving our dreams.

Lisa Bridle

# The Role Of Personal Integrity In Upholding "Right Relationship" In Organisations

*Michael Kendrick has a passionate interest in the provision of quality services to people with disabilities and is well known for his work on leadership, quality, advocacy, safeguards, and the promotion of community living for people with disabilities. Michael's writing speaks to the power of individuals in developing an ethical relationship with the people they serve, despite the prevailing attitude of their organisation.*

The ethical character of the relationship between formal services and the people they assist can often be very problematic. Organisations of all kinds can too easily end up treating the people they serve poorly, and may even grow to put their own needs ahead of those they are supposed to put first. Relationships are often damaged by ethics that are devaluing and disempowering, and that become embodied and institutionalized in the formal roles and structures of services. Even good people may inadvertently help reinforce and legitimize these embedded negative ethics unless they are mindful of carefully choosing pathways that uphold "right relationship".

Choosing the right pathway begins with the recognition that there needs to be a fundamentally respectful and ethical relationship between services and the people they assist, i.e. "right relationship". Secondly, it requires that such individuals recognise that they can personally embody right relationship ethics in how they relate to people, even if the systems of which they are part behave in a quite contrary manner. Thirdly, it requires that such persons be willing to bear the cost of upholding right relationship ethics; positive ethics held without commitment cannot possibly provide a counterweight to deeply embedded negative ethics. Should these kinds of orientations take hold in the practice and culture of an organisation, it then becomes possible to imagine an internal process in organisations in which the people in them try to draw the organisation back to a "righter" relationship with the people they serve.

Consequently, it is important to look at what can still be done with "right relationship" *despite* the organisation's overall state of either ethical indifference or perhaps torpor. What is possible under such unfavorable conditions depends a great deal upon the kinds of decisions taken by individuals, more than upon those taken by the organisation itself. These can be entirely individual decisions or they can be decisions taken by small groups of persons deeply committed to supporting each other, but not necessarily backed by officialdom itself. In this regard what will be described here are decisions that can transcend official thought without necessarily opposing it. Many might suggest that such decisions are universally untenable when the real difficulty is that they are untenable for some rather than others. These decisions are most certainly quite difficult and require commitment. However they have the value of being both possible and desirable in the face of adverse conditions. The kinds of actions people can take, and decisions that individuals can make, regardless of their organisation's stance include:

- To extend to the people served by the organisation, a level of respect, decency and actual useful service that would stand a reasonable test of ethical and beneficial treatment;
- To consciously withdraw from engagement in and endorsement of any devaluing and degrading practices that may be asked of people who may work in that organisation;
- To consciously take the position that one will principally remain loyal to the people served, even though one will always strive to give the organisation its due;
- To take the view that, while the organisation may well be entitled to one's best efforts as a dutiful employee, this does not in any way extend to the task of being seen to publicly uphold its deceptive self-representations;
- To recognize one's own extensive shortcomings, ethical lapses and the like, and to resolve to ameliorate these such that the role model one asks others to follow is mirrored in one's own conduct. This is not meant to suggest that the person must be an exemplar, but rather that the person resolves to remedy their own matters of integrity, before asking others to do so;
- To support and uphold others who are attempting to be good and ethical;
- To persevere with one's attempts to behave ethically for as long as this may be sustainable;
- To look for suitable opportunities to challenge the organisation to become more faithful to people;

- To continuously strengthen and prepare oneself to be conscientiously and consistently principled;
- To stand alongside the people that the organisation serves such that they act as advocates, protectors and champions of people where they welcome this and where it is needed.

These decisions will undoubtedly serve, to some degree, to draw an organisation back to "right relationship". Nonetheless, they only have effect if the individuals are able to hold to them. Individuals must show fidelity to the people for whom these decisions constitute a kind of pledge or promise. If they act in contradiction of their true intent, then a kind of dissonance begins to occur that will eventually lead to an ethical collapse. Consequently, "right relationship" rises and falls with the ability of the person to act with integrity.

Once this alignment is properly understood, then it is easy to see why organisations behave so differently when they are populated and led by people with strong ethical orientations. One can see that the active ingredient of "right relationship" is people whose integrity and loyalty to people is forthright, dependable and authentic. It is also true that such commitments are often demanding and taxing for the individual, and may well seem quite unattractive to people in search of a hassle free existence. Not only do such ethical commitments bind people to act in consistent ways, it also makes them much more accountable.

These "costs" are more than offset by the satisfactions of living up to a principle, but it is important to recognize what ethical commitments might ask of people, and the sacrifices and even sufferings that may come from such obligations. If an individual were to conclude that they could not bear such distress as may come with being occasionally at odds with one's organisation and colleagues, then it would be sensible for them to only undertake obligations they can sustain. It is also obvious that a person may quite wisely decide that they cannot personally undertake a demanding regime of ethical commitments to people due their own limitations at a given point in time. They might well support and admire such ethical commitments, but recognize that they cannot meet the obligations involved.

It is also true that few people can expect to be utterly consistent in their ethical conduct, despite quite admirable levels of personal integrity. Consequently, one might quite sensibly be very cautious about equating ethical integrity with some kind of perfectionism.

This would still leave the door open for any number of good people to sharpen their ethical commitments to "right relationship" by reviewing the kinds of ethical decisions they may have made or not made, and coming to a judgment that they would like to go somewhat further. Since the outcome of "right relationship" is ultimately very dependent on these personal judgments, any effort to reflect on personal integrity will be beneficial in keeping the matter alive and in mind. Where matters can begin to worsen is where integrity is presumed to be beyond doubt, and where there is no need to question it.

We are all the beneficiaries of the countless decisions of many anonymous people who have simply decided that ethical principles matter to them, and that they will try to uphold them. Often we do not appreciate their benign presence and influence until others,

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with a different cast to their characters, come into force. It is also interesting that while we often praise such persons in retrospect, we often leave them unsupported in their struggles to find and do the right thing. Perhaps if we could develop a culture of appreciation and recognition for these wonderful aspects of many good people, we might somewhat lessen the load they carry on our behalf. "Right relationship" is possible, but not without the integrity that these good people bring.

**Michael J. Kendrick**

*[Due to space limitations this is a summary of Michael Kendrick's excellent article. The full text can be obtained through the CRU website or by contacting CRU.]*

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# THE IMPACT OF SERVICES ON A VISION FOR LIFE

Long before the birth of our children, we have a vision for them; we know them in the way only parents can. We have hopes and dreams for them based on our experiences and needs. But on a more universal plain we all share some pre-conceived certainties of what we want for our children: health; happiness; shelter; and to experience a life where love is freely given and received.

With support and love from a caring family most of our children fulfil this universally held parental vision with minimal problems. Few parents ever articulate this innate vision and many are, on a conscious level, unaware they hold it and measure their children's successes and failures by it.

When we have a child who has a disability we not only have to own and be aware of our vision for that child, we have to be able to articulate it, justify it, and advocate for it. Why?

Because although no westernised society today would attack the civil rights of a child who has a disability, our vision for our child is vulnerable and is often under attack.

Unprepared we are thrust into an existence of recognising we have a vision, keeping the vision alive in spite of all the outside influences. Visions like everything else in a parent's life need nurturing. Maintaining, expanding and modifying the vision, without compromising that vision, becomes a central theme in the life of the parents.

Our vision for Dominic is not different from the vision we hold for his siblings. For children who will both give and take from their communities, society accepts that it is reasonable to have a vision, which encompasses health, happiness, shelter and love, in a community of their choice. These people all function at a level that society in general, values. Their contribution is valued, and consequently, so too is their existence. Comparatively what Dominic is able to contribute is seen as minimal. People consider he is taking from his community. Therefore, through the loose intellectual and moral associations people make, members of his community see his existence, his contributions, and his place in his community as of less value. Our vision for him is therefore not a vision shared by the general community. Western society, I would argue, is a "value" based not "values" based society.

For Dominic to receive medical or therapy services we must be prepared to articulate, and defend our vision for him. The simple vision of a parent that this child has the same needs and wants as his peers, and that he offers a unique contribution to society, is challenged by well meaning professionals. Like most parents, I have been patronised, treated as a mushroom, an imbecile, and a person of questionable character. Fortunately, I am not easily undermined. In the worst possible scenario, I am grudgingly allowed my opinion and nothing is considered, recommended or done to Dominic without my permission. The best scenario occurs when the professional involved and I, are able to participate in an exchange of ideas and ideals, which leads to positive outcomes for all concerned.

The education system creates a particular challenge to vision through its minefield of consultations, explanations, and recommendations. These are, in my experience, all in the best interest of the education authority rather than the child or family. I remember simply stating our case to the school that Dominic had an enormous amount to offer the school community and I needed to know why they would reject that opportunity. We were convinced that their community would benefit from a relationship with Dominic. It was often a difficult line to hold: they could use all the

"This is no child with a child's face;  
this has no name to name it by;  
yet you and I have known it well.  
This is our hunter and our chase,  
The third who lay in our embrace."

*Extracted from Judith Wright's poem  
Woman to Man*

*Suzanne Tuttle, from Innisfail,  
describes herself as a wife to Chris,  
and mother of their ten children. Her  
values are based on the experiences  
of her childhood and early adult life.  
Suzanne has been involved as an  
advocate for people, particularly  
children who are marginalised, for  
over thirty years. Here, she reflects on  
vision, and the impact of services and  
bureaucracy upon the vision of  
families.*

politically correct language; they held all the politically correct concepts; and they knew their legal position and legislated rights. Our beliefs and vision were vindicated when, at the end of grade twelve, Dominic had the night of his young life celebrating his graduation with his graduating class. His peers arranged the graduation so he could attend. This was no small feat as he needed air conditioning and wheel chair access in a non-air-conditioned Shire Hall. They celebrated with him in a compassionate and inclusive manner.

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As each new threshold is approached, the vision needs to be the focus of our thinking. Post-school opportunities and support to be part of the community comes at enormous cost to families. Every assessment form to obtain services or funds requires a frighteningly negative picture to be painted of them. This filling out of forms for a panel to assess or a cumulative number to be attained, gives no opportunity to enunciate the vision. Faceless panels weighing up the unweighable leaves a pervading sense of hopelessness. Negativity suppresses hope. Our present systems to support community living are based on negativity.

Hope is the nourishment of parental vision; it may flicker very low on occasion but it is never extinguished.

"This is the maker and the made;  
This is the question and reply;  
The blind head butting at the dark,  
The blade of light along the blade.  
Oh hold me, for I am afraid."

**Suzanne Tuttle**

# Right Relationships:

## A Picture Of Life With And Without Overwhelming Bureaucracy

*Sally Barone is a mother of three daughters who became an activist in order to make a better life for her daughter with a disability. In this article Sally reflects on the role of bureaucracy in shaping her family's life, and points to a right relationship with bureaucracy.*

Why is it that when you have a disability your life is so ruled by bureaucracy that people who don't know you can make decisions about you that can determine what sort of a life you have, or even if you have a decent life? My family's experiences show how bureaucracy can do this, and also how bureaucracy can assume its rightful place in a family's life.

Our family was introduced to the disability bureaucracy when our daughter Sarah was a few months away from her fourth birthday. On the day she was diagnosed with autism and intellectual disability the doctor rang the Autistic Centre and she immediately became a client. There was no discussion, but we were quite happy with that. After all, what did we know about autism? That was also the time when we realised that there were those who knew everything (the 'professionals') and those who knew nothing (us).

This was 1981, the International Year of the Disabled Person, and we soon found there was nothing much to celebrate. A few years later, our youngest daughter was a toddler and we needed more help than the odd bit of respite could give us. There was no nice bureaucrat to ask us what would help keep our family together. No, it was an institution or nothing. No one forced us to make this decision, but nothing else was offered and our family was in danger of falling apart. Funny that the bureaucratic thinking at the time was that in order to help families you took the most vulnerable member of the family away.

So in 1984 Sarah went to Basil Stafford. We were told that we would have plenty of say in what happened to her, but of course we didn't. We were never part of any decision about who Sarah would live with and who would support her. We had no control over her money and in fact a large sum ended



up with the Public Trust. She was deemed incapable of handling her finances – at the age of 10. It was bureaucracy gone mad!

So we became resigned to the fact that Sarah's life was out of our (or her) control and her fate would be decided by faceless bureaucrats.

Until.....

One day, a day that will be forever burned in my mind, I was fortunate enough to attend a forum where a woman spoke about the life of her daughter who had severe disabilities. She had her own home, she had people around her who liked her and wanted to be in her life. How easy was that?

I thought about it for a while. There were no people, to my knowledge, with Sarah's complex needs living in their own home. Sarah needed 24-hour care. Where would the money come from?

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Funny that the bureaucratic thinking at the time was that in order to help families you took the most vulnerable member of the family away.

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Two years later there was a Criminal Justice Commission Inquiry into the abuses at the Basil Stafford institution and I knew I had to do something. That's when my circle of friends started and we began planning for Sarah to move into her own home. Although institutional reform was announced, it proved to be a rather frustrating experience, as nobody wanted to talk about what Sarah's life might look like. In fact I don't really know what was achieved in all the endless meetings. However all that came to an end when we had a sudden change of government and the doors to institutional reform slammed shut. It took a great deal of advocacy, including street marches, rallies and publicity before a number of people, including Sarah, finally received their funding.

We were very fortunate that a small community based organisation approached us and asked if we would like them to coordinate Sarah's support. We jumped at this, as it was the type of organisation we wanted, where everyone involved was part of a community. The organisation respected Sarah and our family, expected decisions to be made by us, and treated the people they served as the most important members of that community.

Six years later it is still that way. Sarah, my husband Dom and I interview every prospective worker. Sarah can't speak and communication is very difficult for her and we have to make decisions on her behalf, but we make sure that they like Sarah and Sarah likes them before they are taken on permanently. We have regular meetings with Sarah, staff, family and the coordinator where anything can be talked about. Our workers are very much a team and are expected to think about Sarah's life and how it could be better. We have had some great help from therapists employed by Disability Services Queensland, but all decisions are made by us. In the early days departmental people kept asking the organisation to make decisions and found it very confusing when they were told that it was up to Sarah and her family to make decisions, not them.'

Sarah now pays her own bills, does her own shopping, and makes decisions about what she wants to do. I do her budgeting and Sarah is able to live quite well on her pension. Because she lives alone her funding doesn't cover 24-hour support so we have to provide some extra. However we sort out how we will do this, with the help of the organisation. Even Sarah's roster is different; no eight hour rigid, immovable shifts. The roster is built around what Sarah is doing at the time, not what suits somebody else. This experience has left me wondering: why can't bureaucrats work hand-in-hand with families and small organisations to ensure the best outcomes for everybody?

As Dom and I get older our thoughts often turn to what will happen when we can't do it any more. Our dream is a network of like-minded people around Sarah who are there because they have a commitment to her and value and respect her. Whether it be socially or in a monitoring role, there will be people there to make the decisions when we can't. What we need is a 'friendly' bureaucracy: one that respects family and friends; that will see the value of networks; and that will assist people to facilitate this by providing resources, financial or human - anything to prevent Sarah being re-institutionalised as she ages. If people with disabilities and their families are to have a decent life, bureaucrats must recognise who are the decision makers, and that they are there simply to serve.

Sally Barone



# DISABILITY AND THE INCREASED RISK OF VULNERABILITY

"In June this year, the second ad hoc United Nations Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities took place in New York where they deliberated on a UN Convention to promote disabled rights. This convention, adopted in draft form by the UN General Assembly in November 2002, would commit governments to developing inclusive and appropriate government policies in order to enforce the rights of people living with disabilities and encourage their inclusion into mainstream society.

At last, the rights of people living with physical and mental disabilities have been firmly placed on the broader human rights agenda. This is an incredibly significant step because it places disabled rights squarely within the human rights monitoring and advocacy framework. It further reflects a shift in mindset that moves away from seeing people living with disabilities as objects of pity or special care, and moves towards embracing citizens who happen to be physically challenged as fully-fledged members of society. It means that people living with disabilities cannot be deprived of their rights to vote, own property, access jobs and education, and participate fully in their communities. Although people living with disabilities are afforded protection by the Universal Declaration of Human Rights these rights are often neglected or abused, especially in countries with few resources."

*Kumi Naidoo President of Civicus, a worldwide organisation promoting citizenship throughout the world.*

*Mary Kenny is a Queenslander who grew up in a country town where she was acknowledged and appreciated as a member of a family and a community. She has experienced hearing impairment since birth, and more recently has become severely hearing impaired. She has worked in the public service and private enterprise and during the last thirteen years she has worked in advocacy for people with disability in Queensland. She completed a study tour of Citizen Advocacy programs in the USA in 1996 and came back convinced that we have much work to do if we are to truly include people with disability in our communities and acknowledge their contributions as citizens of our society.*

If we think about the words of Kumi Naidoo, we are right to be concerned about issues surrounding the lives of people with disability in Queensland. When we experience ourselves being treated as commodities, products and outcomes, the odds are stacked against us being treated as human beings worthy of dreams, vision, hope, dignity and respect. We are at the mercy of the goodwill of others, surrounded by a maze of conditions and regulations that bind us to live lives that are less than satisfactory. We do rely on the goodwill of others.

Despite its name, I had hoped that the Disability Services Act would make a leap beyond services and focus on the person. As we review the Disability Services Act, I'd like to propose some alternative indicators to ensure people with disability retain their autonomy and gain adequate support to live their lives in a participative and enriching way.

So let's start with the key indicator of "relationships". Relationships are integral to who we are and how we identify ourselves as human beings: as a person, as a person of worth; and as a person of dream and vision.

It's very important that we have family relationships, but families need support; they need so many more people in the community to be there with them if they are going to be there for their sons and daughters with disability.

Those family relationships need to be supported and encouraged and backed up by freely given relationships with people in their community. Some of us have the capacity to approach someone and say "G'Day", so that they can see, "Look, I am worth knowing". But some of us need people to move towards us first, and to embrace us as part of the community.

We also need a place to come home to. We also need a sense of belonging to a group, being included in the local community, more than just being placed in a local community. We need access to the many sites where everyday life happens. We need opportunities to engage in and explore spirituality, even to belong to religious or spiritual traditions, as this is where life happens for a lot of people in our community. Our education needs to provide us with opportunities and to have high expectations of us. It needs to be focussed on gifts and the ability to help us to be good at one or more things.

We need opportunities to engage in meaningful activities. This may be work or it might be other activities that involve the use of a person's gifts and skills. We need to be able to have a sense of reasonable safety and security and we need some assurance or insurance to get all four things happening. Given my life's work, I know that it's

really essential to have very strong independent advocacy in a whole range of ways, present within the system and outside the system, to enable people to receive the support and the hope that they are entitled to.

We also have the right and the expectation that we will be viewed as human and treated with respect and dignity by everyone. We are also entitled to be dealt with honestly, to be treated fairly and not be taken advantage of. We need to be treated as an individual. We need to have a say in important decisions, and to have significant family or others who are in freely given relationships be with us to assist in that decision-making.

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We need to be able to contribute and have that contribution acknowledged and appreciated by the community. We need to be treated as more than a consumer or a user of services. There needs to be an acknowledgment that the person with a disability is a citizen and a participant in the evolution of society.

Kumi Naidoo sums up the situation so well when he writes:

"It is all very well for me, as an able-bodied person, to write about disability rights. Citizens living with disabilities must take the lead in this debate through the organisations that support and advocate for them. Indeed they are doing so with increasing effectiveness, professionalism and strategic skill. Civil society organisations representing people living with disabilities must set the agenda, and then work in partnership with broader civil society and government institutions to protect and enhance disabled rights and ensure greater levels of acceptance and inclusion for citizens in all countries."

**Mary Kenny**

# When Consultation is Truly Listening

*Vivien Twyford is the President Elect of the International Association for Public Participation (IAP2), a non-profit corporation established to advance the practice of public participation. The work of the Association is premised on the belief that the public should have a say in decisions about actions that affect their lives. Based in NSW, Vivien is the first President living out of North America. Drawing on the learning and teaching of IAP2, Vivien suggests some basic principles that might guide the use of public consultation in service and system reform.*

When trying to establish or improve the way any service is offered, it makes sense to consult with those people who are involved in the delivery and receipt of that service. Yet, if asking for input seems so sensible, why is it so difficult to do, and why do so many people feel unhappy about consultation processes and outcomes?

Some of the frequently articulated concerns about consultation are about transparency and clarity. People ask if the consultation is genuine, that is, whether the people consulted were heard and whether they made a real contribution to the decisions about service improvement. There are concerns about who has been heard, whether the right people are involved and whether the quiet voices have been heard. Many people don't feel heard after a consultation because they never know whether anyone listened to them or whether their input made any difference.

The ultimate aim of any consultation process is to improve a decision. Therefore, prior to consulting, it is important to be clear about exactly what decision is to be made, who will make it, and how this decision can be improved by input or participation from stakeholders.

For example, if a service or system is to be reviewed, with a view to improving it, it is necessary to think through clearly who will make the decision about necessary improvements to the service, and the information they will need on which to base their decisions. It is also necessary to be transparent about any budgetary or other constraints that will affect the potential changes. Clarifying what stakeholders can and cannot influence is also important as well as clearly stating the level of influence users of the service can have on the decisions on improvements.

If decision-makers have no intention of considering input from service users when considering service improvements, then they would be better not to undertake any consultation. People who take the trouble to participate in consultation processes have a right to feel that their input will, in some way, make a difference and influence the decision. So, it is vitally important that the decision-makers do three initial things:

- Clarify the decision they will be making that they seek input to;
- Clarify the process they will use to make the decision and the kind of input that they seek; and
- Clarify the influence any stakeholders, including service users, can have on their decision-making.

If these three things are clearly explained and understood before a consultation starts, this will avoid a mismatch of expectations between the decision-makers and the service users or other stakeholders. Significant problems arise when service users think their opinions and their input will be the only information on which the decision makers will base their decisions when in fact they are only being asked to comment on proposals already researched and favoured.

Other important aspects of consultation include;

- Identifying the people who need to be consulted, that is, those people who will be affected by the changes to be made to the service;
- Providing sufficient and relevant information to allow stakeholders, including service users, to contribute in a meaningful way;
- Designing and scheduling consultation activities to be accessible and attractive even to marginalised groups or individuals such as those who don't speak English, those with a physical or mental disability, those from a non-Australian cultural background and young people;
- Gathering and summarising all data collected during consultation and providing the summary to the decision-makers so it informs and assists their decision-making; and
- Communicating clearly to those who contribute to the consultation so they know what decisions were made and how their input was used to improve them.

Every consultation should include a planned evaluation process. Indicators of an effective consultation process might include:

- A more informed, more sustainable or more implementable decision, which is understood and owned by those affected by it;
- Informed stakeholders who feel included and heard during the process, and who understand the decision, even while not necessarily agreeing with it;
- Productive and positive relationships between decision-makers and stakeholders; and
- High trust levels between decision-makers and stakeholders.

It is important to gather data throughout the consultation process to assist in the evaluation and to facilitate learning and consultation practice improvement.

Consultation processes provide vital opportunities for decision-makers to learn from those with a stake in the outcome of decisions they make. However these same decision-makers need to be accountable for the quality of their consultation. Those who are consulted must learn to discriminate between effective and less effective consultation, and demand clarity and transparency in their processes.

Vivien Twyford

# VALUING PEOPLE

*Morrie O'Connor has been extensively engaged in community work since the 1970s. Morrie has worked at the Community Living Program in the northern suburbs of Brisbane since its establishment in 1987. In this article, Morrie explores some of the issues in supporting people who experience difficulty in making decisions, to have more autonomy and authority in their own lives.*

The recent British Governments White Paper on 'Valuing People' a new strategy for learning disabilities (intellectual disabilities) for the 21<sup>st</sup> 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?

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.

Morrie O'Connor