CRUCIAL TIMES

Community Resource Unit Inc.
Unit 1, 414 Upper Roma Street
BRISBANE QLD 4000

SEPTEMBER 2007 ISSUE 39
Ph: 07 3211 5700 Fax: 07 3211 5711
Email: cru@cru.org.au Website: www.cru.org.au

Editorial

Changing Hearts and Minds

Sharyn Pacey

Violations of human rights occur on a daily basis despite the United Nations (UN) Declaration of Human Rights almost sixty years ago and subsequent UN declarations on the rights of minority and disadvantaged groups.

Claiming rights for certain groups within society which have historically been denied their rights can be a long and difficult process. Slavery, for instance, was abolished two hundred years ago, however segregation continued and it was not until the civil rights movement of the 1960s that the rights of African Americans were fully recognised in law. Yet in the forty years since the civil rights movement began, we can observe that this rights strategy has done little in terms of changing social conditions: black Americans remain marginalised, the majority living in conditions of social adversity; their individual needs remain fundamentally overlooked.

A rights-based strategy such as that which underpinned the civil rights movement seeks to combat violations of human rights by enshrining rights within the law – a vital step in the political process towards addressing societal inequity. Yet as a strategy for achieving cultural and social change it has had little impact in addressing prejudice. Legislating to combat discrimination simply does not change the hearts and minds of people within society or lead to better lives for those within our communities whose lives have been blighted by prejudice, ignorance and fear.

This rights-based strategy for the rights of people with disabilities made significant inroads in the political process in 2006, when the United Nations adopted its first convention of this century, *The Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*. Welcoming the convention, the then Secretary-General of the United Nations, Kofi Annan, observed that the needs and rights of people with disabilities had been overlooked for many years. The convention recognises the rights of people with disabilities to be afforded the opportunities to participate in and contribute to society. However, this is not the time to sit back and admire this significant accomplishment. At the same time as the rights of people with disabilities are being recognised, trends which run counter to the ideals expressed in the UN convention are gaining favour in modern service delivery.

One such trend is the global trend towards the reinstitutionalisation of people with disabilities – in particular, people considered by others to have 'challenging behaviour' – in group homes, nursing homes or in some instances, segregated placements in institutions. This trend is based on the premise that some people need to be restricted in order to protect themselves or those around them. Further, it is claimed that in this environment people will learn the skills to facilitate living in community, despite the fact that this learning will occur in settings which are isolated and disconnected from community. This not only obstructs social change, it continues to violate the basic human rights of people with disabilities, fuelling prejudice, ignorance and fear within community and acts as a barrier to key features of the community living movement – the participation and contribution of people with disabilities in community.

This reinstitutionalisation trend is a modern interpretation of older models of service, often referred to as the continuum models. In a recent essay which discusses deinstitutionalisation, American researcher Stephen Taylor suggests that the continuum model of service and the least restrictive environment continuum are flawed concepts in that they both obscure the debate about where people with disabilities who require intensive levels of service and support belong. The continuum model argues that at one end of the continuum the most intensive services and support should be offered in the most restrictive models of service, such as institutions, group homes and nursing homes. At the other end of the continuum, the least intensive services and support would be offered in the least restrictive models of service, such as living independently within the community. The individual needs of each person would determine where they would be placed along this continuum, and as a person develops his or her individual skills, the opportunity to progress along the continuum is a possibility.

Taylor argues that in such a model, a person who lives or could live in the community and whose support needs increase would therefore be required to move into a more restricted environment as a condition of receiving more intensive levels of service and thus would forfeit the right to live in community. The question becomes not whether the basic rights to freedom and community participation for people with disabilities should be restricted, but to what extent.

No doubt, the necessary systemic change **will** occur as individuals and families seek redress through the judicial system when their right to freedom and community participation has been violated. Legal and political challenges to the status quo **will** occur over time and may strengthen and improve the systemic responses to ensuring the human rights of individuals with disabilities are not infringed. However, once established, the continuum models of service are not as simple to dismantle as they were to set up.

A rights-based approach, while it may challenge the system, will have a minimal impact on social attitudes. Challenging attitudes requires a different strategy. We discriminate with our hearts and minds and a strategy of social change is needed to change the hearts and minds of our neighbours, our school communities, our colleagues and employers, our social acquaintances and friends, and our communities and societies.

People do not behave better towards others simply because this law or that regulation tells them to do so. People behave better towards others when their conscience is pricked; when they are challenged to question their own values; when they experience first-hand or witness some form of discrimination or bad treatment of others; when they can relate this to themselves or the experience of others; and when they **care** enough to want to act in conscious ways to improve the lives of people with disabilities.

Having strengthened the rights-based strategy with the UN convention, people with disabilities, their families, friends and allies can look forward to real systemic change. However without real efforts to strengthen the community living movement and build real social change by changing hearts and minds, the UN convention could be a hollow victory. Systemic change supports and in turn is supported by strategies for social and attitudinal change. The community living movement is a social strategy which has the potential to change the hearts and minds of all us within society and to transform the inner lives and real lives of people with disabilities and their families.

Contents

From The President

Many people with a disability who rely on the support of workers to live their lives will almost always experience at some point that the worker will have much greater power – particularly social power – than the person with a disability. This power not only provides workers with access to resources, the ability to influence others and access to decision-makers to get what they want done, in a way that the people served, possibly will never have, but also restricts the control and authority that a person with a disability exercises over their own life. When people with a disability are seen as unequal partners, they are less likely to be seen to hold the same rights as others in society.

This power is institutionalised in our culture, in our thinking and in our social structures. It is institutionalised in our own individual and shared prejudices about disability; it is institutionalised in the built environment; it is institutionalised each time a person with a disability is unable to join with others and be welcomed wherever they might be; and it is institutionalised in our relationships and especially those where control over the daily life of others is assumed, or advantage of vulnerability is taken or when people are abused or exploited.

This is what spiritual leaders, social activists and philosophers across time have named oppression – the systematic mistreatment of one group of people by another group of people or by society as a whole; with institutional power as a means of asserting that mistreatment.

For those who work in the service of people with a disability, if nothing else, the essential core of the service role is ultimately to better understand what it takes to deeply support the personhood and common humanity of our brothers and sisters, friends, neighbours and fellow employees who live with a disability. Judith Snow, a Canadian disability activist and a person who has thought about these issues at length has said that: '.... until the concept of disability disappears and is replaced by a society that is structured to support everyone's life, relatedness and contribution – until that day my life and opportunities and the lives of every other person who carries the label 'disabled' depends on the goodwill of people in the human service system. Goodwill is no substitute for freedom' (1997).

For most people with a disability, prejudice is a far greater problem than any impairment; discrimination is a bigger obstacle to 'overcome' than any disability. This prejudice starts from within each of us, and finds its collective expression in many forms. Instead of being marginalised, people with a disability must be embraced and welcomed into community. Without access to community, they cannot participate in the 'fullness of life'. Helping people to participate in the 'fullness of life' and be who they are, to believe in themselves and to belong, starts with each of us. To this end it is the responsibility of each and every one of us to work toward creating the conditions and awareness that drive out the active subjugation of people who have a disability in our society today.

To do this, we must cultivate within ourselves and constantly encourage in others, the growth of an attitude that sees people who have a disability as having a capacity to contribute to the life of our community. Often the talents of people with a disability are ignored despite the obvious fact that, like anyone else, people with a disability enjoy a wide variety of amazing gifts and talents. It must be acknowledged that people who have a disability, like most other people who have been marginalised by society, are often accused of having nothing to contribute, particularly by proponents of western consumerism. However, one of the main contributions of people with a disability is that of challenging and confronting societal norms, practices, and beliefs.

We should promote the belief that as people who have a disability are competently assisted to step forward into community life, other community members can and will ultimately welcome people into roles as friends, co-workers, mates, neighbours, worshippers, team mates, or group members. Finally, we should imagine ourselves as the vital agent of change we can be; become a role model for our workmates and other community members. Take every opportunity, wherever we find ourselves sharing space and time with others, to lead by example.

We can only hope that each of us might feel sufficiently inspired to go forward more ready than ever to engage in some new forms of active resistance to the attitudes and influences that leave people with a disability 'living the life apart'.

PEACE!
Mike Duggan

Reflections From The General Assembly Of The United Nations

Kevin Cocks *is the Director of a systems advocacy organisation in Queensland. He has always been interested in issues of social justice focusing on human rights for disadvantaged people, in particular for people with disability. In 2005 Kevin was awarded the Human Rights and Equal Opportunities Commission (HREOC) Human Rights Medal. In this article, Kevin shares the experience of attending the United Nations in 2006 as part of the delegation from Australia to participate in the ratification of the* Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, *a legal framework for people with disability to understand, aspire to and realise their human rights.*

Shortly before 8pm, New York time on 25 August 2006, the chair of the United Nations Ad Hoc Committee, Don Mackay said these magic words: 'I see no objection therefore the Convention is adopted *ad referendum*'. The floor erupted with people rising in unison, applauding, whistling and cheering; it seemed to last forever. About eight hundred people representing over one hundred and sixty countries or states, as they were called, had been participating in the eighth session of the Ad Hoc Committee meeting; from my observation, more than half of the delegates were people with disability.

The President of the UN General Assembly, Jan Eliasson, said in his address to the Ad Hoc Committee: 'on my way down to the conference room I already knew history was being made; to be here and to witness it will make it all that more memorable. This is the first convention of this magnitude for this century'. He told Ad Hoc Committee delegates that they were conveying to the world: 'the message that we want to have a life with dignity for all and that all human beings are equal.'

The formal ratification of the *Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* took place in the General Assembly of the United Nations in January 2007 and the Convention was opened for countries to sign on 30 March 2007. Australia was one of eighty-two countries to sign up on that day – a record number of countries to sign any convention on the first day.

A civil society is a society that universally embraces its citizens regardless of culture, gender, political, economic and social status, religion and sexuality and recognises that its citizens are connected by a common lived experience. A civil society identifies and acknowledges the structural barriers that marginalise, isolate and oppress people with disabilities. A civil society is committed to promoting and protecting the human rights of people with disabilities.

The *UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* provides a legal framework to dismantle structural barriers, which directly and indirectly lead to the systemic discrimination of people with a disability. Discrimination denies us having equal opportunities: to fulfil our destinies as valued citizens, in family life, in neighbourhoods, in community life, in the political and economic arenas; to realise meaningful relationships and identities and to be mothers, fathers, lovers, sisters, brothers and mates.

As with all legislative frameworks there are compromises and thus, limitations. As history has demonstrated, however, until you have legislation that recognises and sets out to eradicate prejudice and discrimination, then prejudice and discrimination will continue unchecked.

The most significant aspect and accomplishment of the drafting of this Convention is the commitment of all delegates to design a human rights framework that would send the message to the world that to deny a person with a disability his or her human rights is now a matter for public concern and resolution and can no longer be dismissed as a personal dilemma to be resolved by the individual.

The Chairman of the Ad Hoc Committee that negotiated the treaty, Don MacKay (New Zealand) stated that: 'the new instrument marked a shift in thinking from disability as a social welfare concern to disability as a human rights issue'.

Those at the eighth session, who influenced and finally witnessed the adoption of the Convention, were at the end of a journey that began thirty-five years ago: Why did it take so long? It has been argued that the resistance to such a convention was due to the belief commonly held by governments and policymakers that the rights of persons with disabilities were already guaranteed by other human rights agreements. In reality, however, persons with disabilities were deprived of those rights and were among the most marginalised and vulnerable people in most societies.

As a delegate at the Committee I must confess to experiencing an overwhelming sense of the magnitude of this event. Shortly before and for many minutes after the adoption on 25 August 2006, it dawned that we were making history; there were so many emotions running through my body that a few of them escaped down my cheek. This is the first Convention of this century, and it was completed in four years – the shortest ratification process ever. The last Convention to be ratified – on the rights of the child – took ten years.

Jan Eliasson further noted in his address this comment from the Prime Minister of Sweden, who said: 'my government will be judged by how well we treated our most vulnerable citizens'. This Convention provides a framework for people with a disability and their families to clearly measure, both on a qualitative and qualitative level, how well governments are treating their most vulnerable citizens.

In an address to the Franklin Delano Roosevelt International Disability Award Ceremony held at the United Nations in New York, Kofi Annan called for us to remember that: 'equal participation requires not only dismantling barriers, but creating opportunities. Let us stress that societies that neglect the integration of persons with disabilities deprive themselves of the valuable contributions such individuals make.'

Human rights as articulated in this convention will not be fully enjoyed by this or perhaps the next generation of people with disabilities. However, this convention provides a platform for a prospect of improved quality of life for future generations of people with a disability and improved opportunity to live life as full citizens of their respective countries.

CRU Committee Members 2006-2007

Mike Duggan .... President
Alf Lizzio .... Vice President
Glenys Mann .... Secretary
Julie Stuart .... Treasurer
Leanne Burke .... Committee Member
Kellie Baigent .... Committee Member

CRU Staff

Lynda Shevellar .... Director
Kay Marks Richardson .... Education Program
Sharyn Pacey .... Information Program
Adriana Taufik .... Office Coordinator
Carmen Beyers .... Part-Time Administration Support
Kathleen Fleming .... Part-Time Administration Support

CRU Associates

John Armstrong, Michael Kendrick, Fiona McGill
Peter Millier

Rights Issues In Human Service: Signposts On The Pathway To Community

Fiona McGill *works as a teacher of people who work or are studying to work as support or welfare workers. She previously worked as a service manager. In this piece, Fiona discusses the nature of autonomy, empowerment and rights and the importance of recognising how and when to provide support and encouragement to others.*

The efforts to draft and implement specific rights for disadvantaged and marginalised people in the '70s and '80s in Australia and other western countries was the result of the recognition of the importance of securing a legal safeguard for people who had been victims of various kinds of abuse and discrimination and were vulnerable to abuses of their citizen and human rights. These laws paid homage to the United Nations Declaration on Human Rights and later the United Nations Declaration on the Rights of People with a Disability. They represent high points in our collective consciousness about the importance of stating clearly our beliefs about our common humanity and obligation to recognise each other's humanity.

Specific rights for people who have experienced disadvantage and discrimination are important as they make it clear that *even these people* must not be treated unfairly, despite the fact that the community (evidenced by their behaviour) thought it was fine before. Specific rights acknowledge that particular people have been systematically disadvantaged and even deliberately badly treated, which means, they now need the protection of laws that state very clearly that such treatment is no longer to be tolerated and that people might need extra support to overcome the previous violations.

'Special' rights, such as anti-discrimination and equal employment legislation, and Mental Health Acts and Disability Services Acts speak to the history of abuse suffered by particular groups: the lack of attention to their basic citizen rights such as: obstructing the right to vote of indigenous people; a history of medical and financial exploitation especially for elderly people and people with mental illness; or a history of 'invisibility' in the community, which affects gay and lesbian people in particular. These 'special' rights represent one plank in a pathway to a better community. But it should not be assumed that rights alone will create or ensure that better community: rights are important for community consciousness but they will not necessarily change what happens to you in your everyday life.

Many people who use human services find their lives contained, controlled and constrained by bureaucracy and administrative requirements. In this context, rights, advocacy and empowerment more commonly mean having access to a complaints process to complain about your service. In a community where human services cosset the 'different' for us, rights become narrowed to the small world in which people are able to move and the small issues that they are able to be involved in. Vic Finkelstein, an enthusiastic supporter of a Rights ideology and the 'Social Model' of disability describes social services as: '…a pernicious influence in maintaining the boundary between disability and normality, just at a time when disabled people are challenging the artificiality of this and other boundaries that constrain our….lives.'

This brings us to the notion of 'empowerment'. The process of seeking a greater sense of control and power to act on one's own behalf is an important adjunct to the legal framework that recognises one's equal humanity by the provision of rights. We take this need for granted with our children. To feel the support and encouragement of those around you, perhaps those with more knowledge and skill than you, is the hope of all young people growing up. To experience your own growing capacity to act on your own behalf is the striving of every teenager.

Efforts designed to increase a person's sense of empowerment are important where there has been a history of a lack of personal power; an assumption of 'eternal child' or poor decision-making capacity; an assumption of incompetence and dependence; or where there has been attention only to basic physical or survival needs.

To be empowered is to be licensed, authorised and enabled. It is the process not the outcome. It is allowed by one's community. It is dependent on the environment around you and your capacity. It does not happen because it is government policy. Empowerment begins in a community where there are supportive people; mentors and role models; infrastructure; educational opportunities; employment opportunities; and when the more pressing demands of survival have been met. Empowerment begins for a person who has influence over others; competence in some crucial skills; self-determination; confidence; access to knowledge and education; and access to enough money and time. It does not happen as a line item on an 'Individual Service Plan'. It also does not happen to you in isolation from your community and it is not a panacea for the faults and inadequacies of that community.

Many people do not have the where-with-all to seek empowerment or engage in the enacting of meaningful rights and may need support and encouragement to move towards a future of greater autonomy and independence. Support and encouragement to engage in challenging and demanding activities provides all people with an expansion of their abilities and a more meaningful life.

The ways that we help young people engage in life are usually through those ordinary relationships of support that we take for granted in our community. Sympathetic and interested adults take an interest in the lives of their children and in others, including relatives, friends' children and neighbours. In the service world, however, we may find such relationships limited, truncated or non-existent. We might resort to artificial relationships of support such as advocacy or circles or social networks of some kind that seek to replicate the community support that might otherwise have provided a scaffold on which to build an individual life. These relationships, while artificial, are often necessary steps to assist on that path to community.

For people who may lack capacity in crucial areas or at certain times, we may need to limit their rights and autonomy through guardianship or other types of court orders, in order to provide them with the necessary assistance; for example if someone with mental illness is not able to make reasonable decisions due to psychosis. Indeed, our duty to them and others may, at times, involve taking away someone's rights: an example of which would be medical guardianship for a person with an intellectual disability.

We might think of rights, empowerment and autonomy falling along a continuum from autonomous self-control to having our actions governed by others. We move from personal power and influence, to support and assistance for us to enact our capacities, to the need for someone to act for us, to the curtailing of our capacities to keep us or others safe.

In supporting the decisions of someone who needs assistance, we must be mindful of their position on the continuum. We need to ask ourselves: what sort of help do they need? How much help do they need? When do they need help and when not? How should that help best be provided?

Empowerment and autonomy are not fixed. They are not objects that can be dispensed. In supporting the growing autonomy of any individual, we must move with them, through the ups and downs of their life providing what help we can, as and when it is needed.

Making The Most Of Autonomy And Choice

John Armstrong *is one of Australia's senior trainers in Social Role Valorisation. He travels extensively both throughout Australia and internationally teaching, consulting and conducting evaluations. He has much contact with families and support workers and gets to see the trends in services that impact powerfully on people's lives.*

Ideas for *how* to support people frequently come from our culture. Our culture provides a language about how we should behave and therefore how best to 'support' others in our services.

In recent decades the notion of exercising choice has attained ascendancy over many other long-held and important qualities for citizens to exercise; so much so, 'choice' is frequently thought of as *the* single most important ingredient in a secular and 'progressive' society. Fuelled by consumerism, having or exercising choice is now seen by many people as more important than the quality, content or context of the choice. Foolish choices no longer exist; the illusion of autonomy can easily be met by the action of choosing, irrespective of its impact.

Thus the exaggerated emphasis currently given to choice-making is almost wholly driven by ideology rather than a considered examination of its likely results.

Yet in some respects it should not be surprising that by living in this culture, whether paid or unpaid, supporters of devalued people seem to interpret their role in a similar fashion; to 'provide choices'. This support provides choices to disabled people with little consideration of what it is the person is actually choosing or the likely impact such 'choices' will have on them.

Choice is part of a much larger concept of autonomy. Autonomy is the moment by moment freedom we typically have as adults; to change position, get a drink, take a nap, grab a banana, watch television, get to work on time, or visit the bathroom. Autonomy implies the responsible exercise of free will. The degree of autonomy one might exercise depends on the role and context one is in. Some social contexts, for example being a passenger on an aircraft, do not permit a great deal of freedom, but do require a great deal of compliance.

Choice refers to the considered selection of a relatively superior option over another option, having anticipated and compared the likely outcomes of both selections. The process of weighing up the relative merits of predicted outcomes between (at least) two alternatives is challenging enough for most people, and especially so, if a person has a cognitive impairment or limited experience.

When carefully considered, choice consists of several factors that must be acted on together, much like an aircraft that requires the two actions of lift and thrust in order to fly. Each force is dependent on the other; if one fails, so does the other. In the case of choice, opportunity and capacity are the required forces; if either is missing, beneficial outcomes fail to materialise. In some situations a person may lack both an opportunity as well as a capacity to make choices.

Rather than choice being seen as something one has, it is more helpful to think of it as something one develops. The content of a choice is brought into relevant perspective, rather than the fanfare of merely choosing. Plane crashes occur whenever there is a failure of either lift or thrust. What happens when there is a failure of capacity or opportunity?

A lack of autonomous <u>opportunity</u> has pervasive long-term impacts: lack of confidence, fear of the unknown, little knowledge of the broader culture, continued dependency on others, fear of failure and insecurity. In other words, people become and remain less capable and are likely to be seen as childish, dependent and incompetent. Without opportunity a person cannot develop capacity; the lack of opportunity to be self-determining is simply crushing.

A lack of <u>capacity</u> typically means that people have a hard time perceiving the true nature of the options and accurately predicting the consequences of one selection over another. This can be due to deficient abilities to fully deconstruct events and predict outcomes – something young people may have difficulty with. In other words, the distinction between cause and its resultant effects is not always fully appreciated, leading to faulty problem-solving and poor judgement. The implication is that people will typically require feedback about the likely impact of their choices given that such choices may have been made on incomplete, unnoticed or distorted information. Supporters who unconditionally promote choice-making under these conditions are also failing to predict and pre-empt the disasters that are likely to happen – perhaps because their ideology surrounding choice leaves them blinded to the above realities.

Opportunity without capacity-building often leads people to do one or a combination of three things: select what they have always chosen; select things that make others happy; or select the last option offered. This can produce an illusion of choice-making that may not only fool many observers, but also keeps people locked into a very narrow range of experience; they are neither having real opportunity to explore new things, nor are they growing in capacity. They and their supporters just live an illusion of 'choice', which becomes a proxy for expressing real autonomy and decision-making in one's life.

Of particular importance to the question of capacity is the person's ability to be responsible for the implications their decisions have for themselves and others – including any negative repercussions. Responsibility is a significant milestone that marks maturity, purpose and self-discipline. It also signals the person's capacity to delay gratification, to make sacrifices and accept one's role in meeting the needs of other people. These things too have to be chosen and speak to the real nature of autonomy as self control and mastery; the capacity to control one's immediate urges so that long-lasting beneficial outcomes can be achieved. Examples of such choices are things like practicing a skill until mastered, to *not* eat something to maintain one's health, to allow others to do things that please them or meet their desire, or to suspend one's own comfort to do things that essentially serve and benefit others.

No wonder when these qualities are missing, that falling for what is in fact an illusion of 'choice' is tantamount to abandoning people and conveniently blaming them for the results they produce, often with the mistaken assumption that the 'consequences will teach them'. There *is* a 'dignity of risk', but there is no dignity in seeing people make mistakes they cannot foresee, nor see any connection to their original decision, destined to repeat the error and not know why these awful events are happening.

An additional perversion is the promotion of assertiveness, often named as empowerment or 'self advocacy'. Such approaches can arouse an adversarial attitude and an obsession about one's own rights and entitlements, which do not encourage people to remain or become openly friendly or unselfish; qualities that are much more endearing to others and encourage one's broader acceptance.

Perverse approaches such as these are likely to create further wounding as well as a lost opportunity for developing real capacity and successful relationships.

Some unintended and unforeseen outcomes of our choices can become detrimental or even life-threatening. Wisdom partly refers to the capacity to foresee consequences well into the future and to take appropriate pre-emptive action. Success, in its many forms, results from such foresight and the ability to shape one's own actions accordingly. Cultures have typically admired individuals with such capacity. Today our culture is captivated and amused by the lack of wisdom expressed by certain celebrities which sometimes inflicts inevitable misfortune, even catastrophe.

Clearly, mastery of the self and self-restraint result when wisdom is combined with good conduct. Without concerted efforts to assist people obtain such mastery, many devalued people will end up simply 'dying with their rights on' because they have been given the opportunity without the investment in capacity. Such neglectful approaches – when 'supporters' fail to respond to the impending calamity and misery which poor decision-making creates in people's lives – are a true expression of devaluation.

In contrast, true independence is the mature exercise of responsibility; real love and concern is shown in the willingness to assist people see things they may not realise are there. Duty of care is a useful construct for thinking how an average person might respond to a given situation; it fundamentally suggests an ordinary requirement to act with good intention towards those in one's care. We all know that some people are not very experienced and require assistance to get through the complexity of ordinary and sometimes daily life decisions. Let us be equally as clear about our 'duty of care' to ensure that the people we support receive from us the same type of opportunity and investment in capacity to make good choices and decisions.

The Value Of A Rights-Based Argument In Building Social Change

Michelle O'Flynn *is a long-term member and former President of a parent-led systems advocacy organisation in Queensland. Michelle is a strong, determined advocate for the rights of people with a disability. Drawing on her own experience, she discusses the role of redressing issues of discrimination by legal challenge as a necessary step in the broader context of social change.*

In 1993 there was a great deal of concern about the enrolment of my daughter at the local primary school. Her enrolment was accepted because she had a 'right' to enrol.

In order to ensure her experience of school was the best it could be, we agreed many compromises with the school. Yet, no amount of good will on my part, no matter how much time I volunteered at the school, it soon became evident that this was not going to change the attitude of those who were determined to see my daughter removed from the school. The inevitable result was that my daughter was excluded from school on the basis of her disability.

We soon found we were not in any position to bargain; the position of the education department was fixed – the choices were exclusion, special school or nothing.

The level of conflict was raised to a point of no return; so we made a big decision – to take our case to the Anti-Discrimination Commission.

This was the time for a rights-based argument, but definitely as the last resort.

We lost the case, but this does not change our view that our decision to use the court system was correct. Of course, it was disappointing that our daughter's right to be in the class was seen as an unjustifiable hardship to the rights of the school and to the other students. If we were to try the same case now, I feel confident the outcome would be very different. As more cases are heard, the levels of awareness and knowledge surrounding issues of discrimination are increased, both within the judicial system and for the general public. The more visible public stance of the Commission in Queensland about promoting the rights of people with a disability has also served to enhance this awareness and in turn, has influenced public understanding and attitudinal change, increasing the social acceptance and appreciation of people with a disability.

Nowadays, despite the likelihood that students with a disability may indeed exercise their right to be in the regular classroom it still remains doubtful that a rights-based argument will ensure their right to receive an education. Educating all students requires, among other elements, the introduction of mandatory skill development of teachers to teach all students, using adaptive curriculum and teaching methods tailored to each and every individual's learning needs. Rights-based arguments certainly have their place, but are not the answer to everything. If we had won our case, it is possible that the attitudes of some teachers might not have changed and our daughter might have experienced very negative and neglectful schooling. However, I do not believe that people with disabilities should wait for attitudes to change.

Without action to push change, it will not occur. The issue of discrimination against people with a disability is no different to racial discrimination or vilification. While the laws of the land might not tolerate or accept such bias, this does not imply it does not exist. However, it has become less socially acceptable now that laws have been made to protect people from such discrimination. Our rights must be supported by legislation and in mandatory practices. In recent history our society has come to accept imposed laws which we now accept as sensible and necessary; compulsory seat-belts in vehicles and drink-driving levels are now accepted as common responsibilities. In many countries including Australia the newly-introduced anti-smoking laws will become the norm.

We all have our rights; but does this mean we are all treated as we should be by all people in our community? The expression that 'you can die with your rights on' is as true today as it was twenty years ago. Rights cannot guarantee your safety, freedom, education, health, protection or a valued position in society. Devalued people, such as the young, the old, the poor, indigenous or immigrant, able-bodied or a person with a disability, are frequently treated poorly by the community, government departments, systems and business regardless of their rights.

Our basic commonalities of humanity are threatened daily by the perceived rights of others to choose. Choice regarding the gender and physical attributes of unborn children, the right to die, the right to conceive, the right to have whatever cosmetic surgery one desires, are all choices that are threats to an unconditional acceptance of the human condition. With this constant drive for perfection, we are all in jeopardy of being unacceptable to the young, the beautiful, and the powerful.

Rights may not guarantee anything, but without the opportunity to demand them and to argue for them to be honoured, then all would be lost. The ever-growing number of arguments for rights and their implementation is what lends impetus for change.

The outcomes of anti-discrimination complaints are dependant upon the often variable level of knowledge and awareness of issues by those who sit in judgement. Indeed anti-discrimination cases are often settled out of court, with binding agreements not to disclose the type of settlement whether this is monetary or an agreement to abide by certain conditions and terms. Regrettably when the parties refuse to comply with such agreements, no further action is available to enforce the agreement. This is true also for UN conventions and treaties. Until such time as UN conventions and treaties as well as local, national and international anti-discrimination laws are made strictly enforceable there will be those countries, states, communities and individuals that will resist whatever decision or agreement is imposed, all the while mouthing all the stale old excuses and bias that have existed for hundreds of years. Only enforceable legislative codes will persuade these recalcitrants and even then they will need to be dragged kicking and screaming into enlightenment.

Clearly no-one should wait for change to occur; we would not only die with our rights on, but we would all die waiting. One only has to appreciate how quickly the Berlin Wall fell once the groundswell movement of 'solidarity' became unstoppable. In South Africa, after years of apartheid, the push to end it did finally arrive. These were long and hard-fought battles in political systems in which some people had rights while others did not. What made the difference and led people to demand their rights and equality, was a groundswell movement of solidarity and understanding and a shared and fearless commitment to change by everyone; those who had no rights and those who did.

So I believe that when the collective community voice that is strident and clear, vigilant and insistent rings out across all aspects of society, there will be some hope that the longed-for right for a decent life for people with a disability might be won.

Rights Talk:
An Allergic Reaction

Christopher Newell, AM *is Associate Professor of Medical Ethics in the School of Medicine, University of Tasmania. He is a person with disability and publishes and speaks regularly on matters associated with the situation of people with disability.*

It is a strange confession from a disability advocate with many years of experience, but I must confess that I am developing a severe allergy to 'rights talk'. How can this be so? After all, I can remember back to the International Year of Disabled Persons in 1981 and have long been involved in advocating for human rights for people with disability. So why is it that I have become particularly nervous even just hearing the word 'rights'?

Such concerns are precisely because of how the 'rights' word is used. Too often, it is not in the context of a communitarian account of human rights, whereby all of our claims to basic goods are embraced and the state or government and society have a responsibility to all people. Rather, 'rights talk' occurs increasingly in an individualistic 'me, me, me' society. This disconnected focus on 'me' all too often can threaten the dignity or inherent worth of people with disability as 'us', as affirmed by the Universal Declaration of Human Rights.

A recent outbreak of my allergy occurred recently while watching *Four Corners*, an ABC television documentary, which interviewed ageing Australians who claimed a right to die when they developed disability. Impairment was so bad, they suggested, that they should have a right to die. There is nothing new in this argument. Yet how could *Four Corners* present such a program without in any way exploring the implications of such an argument for those of us who acquire disability, in the womb, at birth or as young people? It left me breathless, requiring more oxygen than normal.

Such a self-centred, individualistic account of rights ignores the fact that many of us live with disabilities that are said to be so abhorrent to society that we should be given a right to die. This account of rights directly contradicts the right to live; a right hardly acknowledged in society for people with disabilities.

Likewise, the increasingly shrill claims of reproductive technology, genetics, and some parents to 'a right to a healthy baby' makes for a good seven-second media sound bite but leaves unexamined the implications for marginalised people such as those of us with a disability.

Initially, the 'right to a healthy baby' seems such an obvious, even innocuous claim, that is, until we explore the way in which that claim is used to justify a variety of forms of screening and the practice of eugenics. The incidence of Downs Syndrome is now actively targeted in pregnancy screening processes, as are an increasing number of other genetic conditions, suggesting that to live with Downs Syndrome or some other condition is so abhorrent that you have a right not to exist.

The list of conditions where life is unacceptable seems to grow exponentially as the language of choice, therapy and science masks eugenics in the everyday.

Even the account of 'rights and responsibilities' leaves me chilled to the bone, especially when utilised by government departments. Usually the list of responsibilities is far greater for those who are marginalised and powerless than the few scant resources and opportunities granted by the state in the name of rights. All too often these days, 'rights talk' can lead to further marginalisation rather than talking of rights founded on inherent worth and dignity including the fundamental responsibilities of the state towards its citizens.

The biggest sadness is when people with disability use 'rights talk' to claim individual, superficial desires as opposed to fundamental human needs. Indeed, a right to choice is important, however, too often this is formulated in a way that isolates rather than cements us together as members of the human family. Often, it revolves around a self-centred motivation that largely ignores the human rights of all people. A significant degree of community development is required in the disability sector to challenge this notion of the right to choice.

Indeed, implicit in many of the claims to euthanasia, technologies of genetic screening and disability abolition, and even government programs for those who have enough manifest suffering, is an underlying account of disability as inherently negative and burdensome; something to be avoided.

All of this narration of 'rights' stands in stark contrast with an account of human rights, whereby all people have inherent worth and dignity by virtue of being human. From that account of human rights flow claims to shelter, family, education and all of the other basic goods of life necessary to live and thrive as a human being. As part of this we recognise that we are more than disconnected individuals claiming rights in shrill ways, but members of the human family. Such a communitarian account helps us to come together, just as occurred in 1949 when the Universal Declaration of Human Rights was signed, to recognise the abhorrence of the denial of the dignity of any person and to signal the way in which we can act together as human beings to address that injustice.

In a 'me, me, me' society of individualism, where advertising focuses on purchasing choice and destiny, and political manipulation focuses on individual greed, is it any wonder that increasingly we claim a right to just about anything? Is it any wonder that I have developed a severe allergy? Too often for me as a person with disability, 'rights talk' turns into my right not to exist; as someone viewed as sub-human with an inherently undesirable life. It is time we move beyond rights as individualism, to reclaim an account of universal dignity as we reaffirm an account of human rights based on the worth and beauty of all people.

This periodical is part of CRU's Information Program. CRU publishes the periodical CRUcial Times three times per year. We believe that generating, sharing and disseminating information will lead to grass roots change in communities.

Contributors from CRU's wider network are invited to explore issues relevant to authentic change in the lives of people with disabilities, their families and the people who walk alongside them.

CRUcial Times complements the projects, developmental and educational work that CRU engages in, by providing perspectives on current issues and concerns.

CRUCIAL TIMES September 2007 **ISSUE 39**
ISSN 1323-2231

Printed by: **ABC Printers**