CRUCIAL TIMES

Community Resource Unit Inc.
Suite 5B, 19 Lang Parade
Auchenflower Brisbane Q 4066

March 2005 Issue 32
Ph: (07) 3870 1022 Fax: (07) 3371 3842
Email: cru@cru.org.au Website: www.cru.org.au

Editorial

Contemporary Understandings of Autonomy, Empowerment and Self-Determination

Jane Sherwin

In life in general, notions of autonomy are biased toward people who are capable, competent and independent, so it is no surprise that people with disabilities are not naturally given high degrees of control in their own lives. This situation is not a recent one; it has been present in society from the days of Aristotle. He and his colleagues described who could be valued as autonomous individuals. Those who were dependent were not regarded as fully human and so therefore could never be fully autonomous. The historical underpinnings of these terms, then, work against the interest of people with disabilities.

Today, notions of autonomy, empowerment and self-determination in the lives of people with disabilities have positive intentions but are actually slippery terms. People think they know what they mean, but there is no single agreement about their precise meaning. They also encourage relatively superficial thinking: that they are goals unto themselves. Instead, what is important to note is that these goals and processes are actually about enabling us to find and nurture the spirit and potential within each of us.

Broadly speaking, when the terms autonomy, empowerment and self-determination are used in the disability sector the goal is the crafting of a meaningful life. The key expressions of this are to have one's own home; to have income, that is not necessarily confined to employment; and to live a life where one has a say over one's support arrangements. Even deeper than these outward appearances of autonomy and self-determination is the fundamental journey toward self-expression and identity.

In this context, the articles in this edition discuss the notion, and the experience, of empowerment. Three things contribute to the experiences of people with disabilities in terms of power. The perceptions held about people with disabilities have largely been based on cultural stereotypes such as: eternal children; sick; incompetent; menaces; and objects of charity and pity. These terms are examples of how a person with a disability is perceived as 'other', and therefore as powerless. Their messages are projected onto vulnerable people, and this in turn, affects their view of themselves and their capacities or lack of them. Secondly, these potent messages are also projected, consciously and unconsciously, onto families and service workers, affecting their day-to-day interactions. Thirdly, systems, services and environments use processes and practices that perpetuate the experience of people with disabilities as being the less powerful party in these systems and environments. When a person with a disability attempts to exercise more power in their relationship with a service, for example, it is far too simplistic to say that the answer lies in workers and systems listening better, or that people with disabilities/families need to be more assertive.

In addition to these experiences, there are endless examples of the perversion of notions of autonomy and self-determination that have led to a person being worse off as a result of making unwise decisions, and sometimes such situations have even led to the death of individuals. It also needs to be acknowledged that there are thorny ethical and practical issues: parents and workers wonder how people with cognitive impairments can be liberated to make their own decisions.

There are however two ways in which empowering processes and practices can be facilitated. One is in the kinds of relationships and interactions that occur between the person and the personnel in the system or service. Key questions to enquire of these interactions include: Is the assistance provided to someone a necessary help, or is it unnecessary and therefore dependence-building in nature? Is each individual who receives the service treated the same way as every other person who receives that service, with expressions of individuality denied? Or alternatively, is each person approached as someone unique in personality, preferences and life history, perceived as a hopeful and thinking individual who is trying to effectively deal with this world, and understood through attention and empathy?

The second way in which empowering processes and practices may be facilitated is found in terms of the organisational processes. The experience of people with disabilities in Queensland, when viewed in the light of analysis from the research literature, shows that truly empowering processes are likely to include the following:

- Authority is respectfully held by the individual person over the staff in that person's life;
- Individual budgets (this could include individualised funding but is not limited to that process);
- Rules that are highly flexible in relation to how the money is spent;
- Reasonable levels of accountability;
- A body that acts as an intermediary between the person and the funding source to look after legal, financial and human resource matters, so that people with disabilities and their families can focus on managing their support arrangements and their own lives;
- The presence of people who facilitate the creation of a vision for the person's life. Such people are independent of the funding body and even the service, so that there is no conflict of interest;
- A wide range of services and support arrangements ensuring that the person does not have to buy supports from an existing narrow menu of support types, especially where the dominant service forms are large, congregated and segregated; and
- Support provided by service workers who are competent, and who are, in turn, valued and supported by the service employing them.

In the end, 'empowerment' is a mindset: it exists both consciously and unconsciously in our hearts and minds, and guides us in our daily interactions with people who are vulnerable. Without this mindset, any movement towards self-determination will continue to be frustrated.

Contents

> *"Empowerment [means] the power to define one's own life situation and needs, to make and control one's own life decisions independent of service convenience, to engage in unpaid relationships, develop community ties, and participate as a full member of the community, to direct disability supports towards meeting individually determined needs and to be treated as a valued consumer with input into the operation of service organizations"*
>
> *David Hagner & Jospeh Marrone, 1995*

From the President

Mike Duggan

Empowerment is really the process or principle of people taking back power that has been denied to them. For many people with disabilities, this means exercising power in their lives for the first time. The process of taking power from someone or transferring their power to another person or entity is complex and not easy to define. In order for a person to exercise power, they need to gain information about themselves and their environment and to be willing to identify and work with others to bring about change. I suggest (perhaps through bitter experience) that transformation in the lives of people with disabilities must include a transition: from a sense of themselves as helpless victims or clients to an acceptance of themselves as assertive and competent citizens.

When we ponder the concept of ‘empowerment’, we need to consider the concept of ‘power’. Power operates insidiously and unconsciously, as well as overtly. The unfair use of power invites resistance and struggle, at both the micro and macro level of society. In terms of disability, resistance occurs at the micro-level by challenging what is done to disabled bodies and at the macro-level by challenging disabling social structures. Michel Foucault points to the importance of movements of resistance, and to strategies for emancipation. Since the late 1970s, people with a disability have been more vocal. Collectively they started defining themselves and their condition as something of which to be proud, as a means of challenging the subjugated – silenced or denigrated – knowledge of disability and its consequence for them.

In their book ‘Leisure, Integration and Community’, Peggy Hutchinson and Judith McGill note the way in which empowerment has become a buzz idea for human services. Human service workers are now talking about ‘empowering’ people, as if they are able to actually ‘give’ people power in their lives. Yet power is not given to people nor is it earned. The existence or transference of power happens as a result of a constructive, meaningful activity that leads people to be more informed, skillful, and aware than they previously were.

Ultimately, it is impossible for us to discuss empowerment without trying to define power. Power is inherent in practically all social and political relationships. It is often claimed that having power is essentially possessing the ability to control powerful resources in order to get what you want, despite resistance. Powerful people, then, are those people who possess the resources of power in our society: roles, wealth, social prestige, property, various kinds of knowledge, leadership roles, control of jobs, and control of information and media. The presence of these resources alone is usually enough to deter others from posing a challenge to their power. Powerlessness, on the other hand, can be understood as the absence of these resources and the inability to secure them.

Community groups, on the whole, are inclined to hold a somewhat different perspective on power. They believe that power should not belong to any one person, and seek change through mutual group action. They believe that, together, they can create the power to bring about change, and that power exists whenever people cooperate with one another.

The following are some thoughts on power and empowerment as they relate to the lives of people with disabilities. They are taken from the works of Hutchinson and McGill, Hershey, and Owen.

- Empowerment is a lifelong struggle for personal and political awareness and greater consciousness.
- All people experience powerlessness at different periods and in different areas of their lives. People with disabilities, however, are more vulnerable to sustained feelings of powerlessness.
- Individual people understand their own needs better than anyone else and therefore must be given the chance to articulate these needs and act on them. All individuals can build on their individual capacities and strengths.
- Power is not given to people by professionals. Power comes from meaningful activity that supports people to be more informed and aware than they were before.
- Certain factors, such as opportunities for dialogue and partnership, contribute to the process of empowerment and these things need to be understood by those who consider themselves to be allies and supporters so that they do not act as obstacles, but enablers to the process of empowerment.
- People who are given the chance to be involved in planning and decision-making will become more empowered.

These are some important ways that individuals and groups might take back, or give back, personal power to where it rightly belongs. For people with disabilities, empowerment has a long history of ups and downs. There are periods of gradual growth and change, interrupted by down-periods that are often related to inappropriate or inadequate supports and services. It is essential that in thinking about the process of empowerment, we move beyond personal change in our lives and act at a broader level of social change.

Now I Can Please Myself

Christine Pampling

Christine Pampling lives in Toowoomba. She is a sought-after guest speaker in her local community, having presented her personal story to sporting clubs, government forums, local community groups, and conferences. Her life experiences are presented with particular focus on her transition from hospital to community. In this article Christine reflects on what autonomy means in her life.

‘I will never get out of here.’ This is what I said to myself when I lived in the psychiatric hospital. I was there for forty years, and I always tried my hardest to get better, but the tablets didn’t help. In hospital I had given up on everything, I had lost hope of ever getting out. I just did not care about myself.

In 1997 I talked with two Volunteer Friends about Project 300, a government scheme to discharge people from psychiatric hospitals so that they could live in their own place, with help from support workers. I talked to Richmond Fellowship and they told me I could have eight hours support each day. That is why three of us, Rachel, Jill and I, moved into a house together, so that we could combine all our support to cover twenty-four hours a day.

To begin with the support workers would come out to the psychiatric hospital to see me, to help feed and care for me. I always wore a crash-helmet because my body would shake so much I would bang my head on the wall. At meal times the hospital nurses would want to take my plate away before I was finished because I was so slow, but the support workers would not let them. The support workers took the three of us out of hospital to shop for things we would need in our house. When everything was ready we all moved into the house at the same time.

We were pretty scared to begin with. We did not know what we should say to our support workers and whether they would talk about us behind our backs.

When I first came out of hospital it was hard for me to do anything properly because I was always shaking. I could not control my hands properly – nor did I really care. It was hard to eat a meal or even to smoke. In the hospital, they had a special plate for me with sides on it, a special cup, and a special spoon with a very thick handle. When I moved to my own home I began taking steps to control my shaking. Now I eat with a knife and a fork, I can drink from an ordinary cup or glass. It is easy for me now. I go down town with support workers to have a meal and I do not have to be careful or worry about spilling things like I used to.

It has been really good since I have been out of the hospital and living in my own home. I can now do most things by myself: get in and out of bed; dress and undress myself. Years ago I could not do any of that by myself. I always had to have one of the nurses help me. I could not do a thing. Now I am quite independent and I have everything I want: my own bed; my own wireless; my own tape-recorder; my own shower; we even have our own computer! Rachel and Jill and I pay our own electricity and telephone bills and we have our own bank books. One of the support workers does the budgets. I have got my own dog and cat, and they sleep with me. I think they are wonderful. I feed my dog Milo too much really, but I would do anything to give him a life. I can keep these animals, and no one can take them off me. They are part of my life.

We can choose our own support workers, and they are on three months probation to see if they turn out the way we thought they would. If not, then it is: ‘Bye bye’

Since coming out of the psychiatric hospital I have been bowling regularly (until I got sick of it). I have worked for the St Vincent de Paul Society and also at a nursing home. Lately I have been making craft to decorate our home and to sell.

I go to Clubhouse every Tuesday and Friday. Clubhouses are member-run mental health rehabilitation facilities. Many of the people who go there have been at a psychiatric hospital and now they are living in the community. I have been working there for about three years. I enjoy helping to prepare the meals and cutting vegetables. I like going there because there are lots of people who are lonely.

Richmond Fellowship supports me to travel to Murgon whenever I want to visit my mother. I have met my children again, and have twelve grandchildren. I even stayed in a motel in Murgon for my 55th birthday. It was really good. My sisters and family came to the motel where I stayed.

Nothing is like I expected. And now I am just happy, because I can do anything I want. Now I can please myself.

Understandings of empowerment: Little clarity but good intent

Greg Mackay

Greg Mackay has had significant involvement in disability issues for over thirty years in a range of roles. He is currently Chair of the Brisbane Social Role Valorisation Group, called Values Action Assoc. Inc., and is a PhD student at the University of Qld. He has worked in the government and non-Government sector. Since writing this article he has taken up the position of Director, Centre for Social Justice, UnitingCare Queensland. Greg explores how the concepts of autonomy, empowerment and self-determination have emerged, and some of the problems associated with these concepts.

It could easily be said that each person wants and needs to be part of the social world. This need is something that people with disabilities have had to continuously strive for using their individual and collective energy. Numerous concepts are used, often confusingly, to describe this struggle: empowerment, autonomy, independence, interdependence, choice, right, self-determination, self-governance, human agency. This article explores a little of the history and beliefs of several of the concepts at the heart of the struggle.

For a long time people with disabilities have been seen as 'other', as people apart. Furthermore some individuals came to be seen not merely as people apart but as non-people. Such beliefs led inexorably to people being set apart from others within society. From the mid 1800s, these beliefs gave rise to the establishment of institutions. Such initiatives, along with latter efforts to improve service delivery, have been shrouded in a cloak of good intention since that time.

By the 1970s the Community Living Movement had arrived. Largely fashioned from the theory of Normalisation, it was used to show how institutional responses reduced people's dignity and cut people's connections with ordinary society. The notion of inclusion arose in the following two decades. This included a rejection of support arrangements that saw people with disabilities preparing for work and community living, but rarely actually gaining real employment or belonging to community. Importantly it was out of this period that citizen advocacy and self-advocacy arose: self-advocacy for those who could speak for themselves; and citizen advocacy that was targeted at the most vulnerable citizens who were not, at least not fully able, to speak for themselves.

In the 1990s social movements variously known as the community living movement, the independent living movement, disability rights, and self-advocacy all contributed to the rise of concepts of self-determination. Self-determination is said to consist of five principles. The first principle is 'freedom', including deciding where and with whom to live, how to earn money, deciding on relationships, and so on. The second principle is 'authority', including a person having control of his or her own funding. The third principle is 'support' through the unique arrangement of resources by and for the person. The fourth principle is 'responsibility', for example the use of resources wisely and in a cost effective manner. Finally, the fifth principle is 'confirmation' whereby individuals must be part of public policy changes to support self-determination.

Along with self-determination there arose ideologies of consumer direction, autonomy and empowerment. All of these generally work towards changes in the design of human service systems, and have an influence on how people with disabilities are perceived. All then, have a part to play in creating better lives with, and for, people with disabilities. However, problematic interpretations and odd notions accompany each of these concepts and can confound the very best efforts of all involved. Two concerns are outlined here: firstly, dependence versus independence; and secondly, individualism and choice.

A person's desire for a say in his or her own life is often narrowly framed according to the dichotomy of dependence-independence. It is common to talk of people being dependent on services, family, or friends. It is also common to hear of a person striving for independence from those same services, from family, and even from friends. Unfortunately this way of talking emphasises one-dimensional, dichotomous thinking which can be limiting and unhelpful.

Additionally, notions of 'dependence' and of 'independence' tend to be used and understood as absolutes. For example, a person is seen as being either dependent or as independent, although it takes just a few moments thinking to realise just how dependent each of us is on others for so many things. In the extreme it would be nonsensical for any of us to claim to be truly independent in the absolute meaning of the word. We all rely on others to varying extents to meet our needs, from our emotional needs through to practical matters such as the production and distribution of food. Between these two extremes of dependence and independence lies the more constructive notion of 'interdependence'. Without cooperating and relating with others we are less able to do many things; we are less able to be. Interdependence *is* the human condition.

How then does interdependence inform self-determination, consumer direction, autonomy, and empowerment? This requires recognition that in being autonomous and in choosing our own lifestyles, we rely on others for various forms of assistance, but we are also principally able to exercise our own direction, with minimal constraint by others. This is true for all of us; interdependence should not be one thing for the general population and another, more restrictive matter, for people with disabilities.

The second concept that can confound the very best efforts of anyone is that of 'individualism' and 'choice'. Clearly modern day perversions of individualism that lead too easily to unfettered choice have been fostered by the notion of consumerism.

Our society currently places high value on the achievement of individual interests; 'choice' is idolised as a yardstick for freedom and control over one's life. Therefore it is not surprising that we frequently hear of people with cognitive impairments making a 'choice', sanctioned by others, to do something that is not in their best interests and may even be life-threatening. Clearly, people grow as people when they have autonomy; one learns, becomes more competent, can enjoy more of the world, is given more positive regard, and is better able to relate to and with others. But autonomy without thought of others, choice beyond a level of safety, these do not present opportunities for human growth, for self-actualisation. The autonomy to choose is situated within the context, the setting and the relationships that define our being. The parameters of what may be chosen are determined by the context in which the person finds him or herself, and thus are largely defined by that context.

Regardless of the terms empowerment, autonomy, and self-determination having many values, beliefs and nuances inherent in them, they do share one important foundation. They all reveal a sense of individual people striving to have, at the very least, as much say over their own lives as does anyone else in society; they are about individual people wanting and needing to be part of their social world.

Autonomy, independence and the transition from school

Selina Maffey

Selina is a parent from Far North Queensland where she and her daughter live on a farm. In this article Selina reflects on her role in supporting her daughter's growing independence, and the tensions and rewards that this brings her.

My daughter was diagnosed at birth with an intellectual impairment. She also had severe heart defects that caused her life to swing in the balance. Once over these initial hurdles there was a search to give her as much positive encouragement in life as possible. That journey sent me seeking global research, travelling extensively, consulting widely, and challenging specialists and professionals. Later, I worked with the education system to try to influence the direction of education for children with disabilities. I held a strong belief that an inclusive approach was going to give a valuable long-term outcome for my daughter. I attended numerous workshops and listened to many parents speak about the way they planned for the future of their sons and daughters.

When my daughter was about fifteen years old, I remember going to a meeting that was part of a review of Disability Services Queensland. The Regional Director asked parents what stage of our family member's life would be the most significant in the long-term. We had already been through some very significant stages that required enormous soul-searching and an ability to adapt. So when fellow travellers concluded that the post-school years were the most significant, some sense of awe and trepidation embedded itself into my otherwise positive outlook.

My daughter had no one evident passion for a career path and we needed to explore. I felt the best way forward would be for my daughter to experience work and in doing so, greater life experiences. I felt that in this way, she would learn about real options. My daughter had ten different placements where she did real work experience while she was still at school. I realised that this particular timing was critical because of the support the school could offer and insurance cover issues. Such a range of options is generally not possible once a student finishes school. I assisted in finding the placements, and when requested, in finding the support. My daughter's placements were in shops, aged care, a preschool, a laundry, an employment agency, at TAFE, as an office worker at a major resort, and as a crew member on a large tourist boat. In the school holidays I found a mainstream arts program in a large city.

This wide variety of experiences provided a great opportunity for my daughter to gain a sense of independence. Over a period of three weeks she stayed in a hotel managed by young people. Even though when at home my daughter would sometimes come into my room at night due to her insecurities, she was also very keen to experience this kind of independence. She loved those weeks, particularly having a mobile phone and her own hotel room. There was a lot of planning and work around this event, but I believe this experience, along with the work placements, gave my daughter a real taste of her own autonomy. Her confidence blossomed.

However at home, after school and in the holidays I noticed patterns developing that worried me deeply. Perhaps this was a part of growing up, I thought, but I really worried that my hopes for my daughter were deeply at risk. My daughter expressed deep dissatisfaction that her peers had someone close in their lives and she found it very painful to always be the outsider.

During this time we were invited to a party. At this event my daughter discovered a soul-mate and the seeds of young love were sewn. Her soul-mate lived in Brisbane and this was yet another challenge for me. How could I assist my daughter to have a relationship and enjoy it, yet at the same time guarantee her safety and autonomy? Once again, others helped pave the way. The young man’s mother had so much wisdom: she helped us to manage some planning with these two young people. Her timing was impeccable and the way she asked about ‘the plan’ and assisted in the review of the daily plan bought about a great sense of respect, enjoyment and cooperation from the young couple. I learnt to remain calm: I had a mentor to assist me in treating my daughter as an adult. For parents, I wonder if this is one of the biggest needs.

Shortly afterwards our family took a holiday. We travelled down to Brisbane, the Northern Rivers and then on to Sydney. We reconnected, after five years, with many of the families and friends I have known since the birth of my daughter and who had shared some of my daughter’s life journey. On this trip, my daughter found herself in their photo albums. She was thrilled. She learnt to catch trains in Sydney, to visit an old friend, to walk alone to our rented apartment and she learnt to text messages to her friends.

She was very interested in what other young people did – both those with similar disabilities and young friends who were at university. My daughter felt great respect and love from all who reconnected with her. Meanwhile I had some very interesting conversations with other parents. I felt their sons and daughters were also very lovely unique young people, doing great things. As ever, I was inspired by them and felt enriched. At the end of the holiday, I cancelled my daughter’s flight home and organised for her to travel by car with her father for a further ten days. This also enabled her to spend three days with her boyfriend.

When my daughter returned home, I saw her with new eyes. She was so excited, telling me of her experiences. She seemed so grown up. I was simply full of pride and love.

My daughter is now developing a full weekly schedule of activities and tasks in our small town. The community has been very willing and pleased to support us in finding real learning opportunities in mainstream life. She will be returning to do two weeks training in the regional city and then flying to Brisbane to spend a weekend with her boyfriend to celebrate his birthday. Travelling alone will be her next big challenge. I hope I will be ready for it.

> “All of us as human beings need help, yet we yearn for a society where we do not just ‘help’ people with disabilities – we enable them as fellow human beings to help us. In this way, we move beyond whether particular groups of people deserve particular or even special treatment to asking what we as a society need to do to bring about justice and fulfilment for all.”
>
> Gerard Goggin & Christopher Newell, 2004

When Services are Beyond 'Caring'

Kellie Nelson

Kellie Nelson is the coordinator of a recreation and leisure service for people who have significant impairments. In this article Kellie reflects on the role services have in supporting people to have more autonomy in their lives, and what it takes to move 'beyond caring'.

When thinking about the meaning and interpretation of the word 'autonomy' I asked colleagues in the service where I work what they think it means. They responded:

> 'Imagine having someone else making your decisions for you.'
>
> 'I'd die without it!'

Staff members were obviously clear as to its importance. The tea-room went silent as each of us thought about the people we support in our work and wondered how our service users continue to carry on each day without being allowed such basic choices as what clothes to wear or whether to have a cup of tea, let alone make their own decision about where they live, where they go each day, and what they do each day.

I then asked, 'So what is it that we do that makes a difference to the lives of the people we support; and how are we creating autonomy for the people we work with?' The responses were quick and fast. The team talked of working for a small service where there is no bureaucracy, having a belief that people with disabilities belong in their local communities without exception and believing that our service users have the same rights as everyone else in the general community.

While this was reassuring, and indeed what I had hoped to hear, the most potent thing that was said was: 'We listen to people, take their ideas seriously and work to know people well'. However I wonder whether this is enough.

Often a well-meaning support worker ensures that people are 'well cared for'. Unfortunately, it is possible to care for someone yet fail to meet some important needs. Autonomy is the ability to determine one's own direction, make decisions (small and large) and generally be enabled to lead the direction of one's life. This is central to one's sense of self. A friend of mine with a disability is a very capable young woman, yet she is losing some of her skills, such as travelling by public transport and the preparing of her own meals because she has workers who are willing to 'help' to do all of these tasks. In addition her service providers mentioned to me recently that they were doing a Grooming program where my friend was learning to brush her hair!

I think of another man I know, who has lived in institutional care for the last fifteen years and is one of the liveliest people I know. When our service started working with him I was told he was noisy, annoying, and had no speech. The inference was that, given his physical and intellectual disability, it was difficult to see what our service honestly hoped to achieve. Three years on, this man does volunteer work, knows all his work colleagues by name and communicates through an assistive device. His accommodation provider has at last stopped questioning why he must wear shoes when he is unable to walk. However there is still a lack of belief that anyone with significant intellectual disabilities could do anything productive or be anything more than a burden. Does this man have autonomy? Well yes you could say that he does. It is heartbreaking however to know that this sense of autonomy is only existent in a tiny proportion of his life. Imagine the potential and the opportunity for this man if all of his staff believed that he could be a valued member of his community.

Clearly, the direct care workers that are employed by organisations have such a pivotal role to play. It is these workers that can really make or break a person's life. When I think about what makes a good support worker it is not a certificate, diploma or degree; nor is it the years of experience as a worker with people with a disability. It is the passion, attitude and creativity that matters. It is the ability to create inclusion, to advocate and to have a strong sense of inclusive communities. It is moving beyond the notion of simply being a 'carer'.

It is my opinion that as service providers we need to have a high degree of consciousness about our place in a person's life and how our support will enhance an individual's competencies and sense of autonomy. It is easy to espouse good theories and ideals, but much harder to translate them into models of support that make a true difference in the life of each person.

The Gift of Choice

Patrick Heraghty

Patrick Heraghty is a resident of Far North Queensland. He has Multiple Sclerosis and works part time. He has a wife, Jenny, and four children, one of whom has an intellectual disability. His main aim in life at the moment is to fix their family bus and travel again. Patrick makes the link between autonomy and self-determination and the notion of 'choice'.

I believe that choice is one of the core aspects of the human condition. However choice is far from a simple concept. The writer Carolyn Myss suggests that 'of all the gifts of the human experience none is as powerful or profound as the power of choice and none is as misunderstood'.

I have found that having a physical disability sometimes gives me plenty of scope for not taking responsibility. I have a gallery of reasons or excuses. However most reasons come back to my not taking responsibility for the consequences of my actions or choices. Every choice has a consequence. We need to recognise the power of our choices on every aspect of our lives.

I am well-educated, articulate and of a mature age. My disability does not affect my ability to make or to understand the consequences of choice in my life. This is clearly not true for all people who have a disability, especially those who have a cognitive impairment. We only have to look at the fact that the number of people with a disability displaying so called 'challenging behaviour' is reaching epidemic proportion. So much so that the Disability Services Queensland paper 'Have Your Say' proposes a separate program to address this issue. We cannot understand how other people experience the world. Consequently, we make assumptions about what people are 'choosing' to do or how they are 'choosing' to behave. We also assume that some individuals do not have the capacity to make a choice. Individuals who are denied choice are denied the opportunity to access the full power of being human.

Having a physical disability does not mean that I am immune from negative influences. I live in a world whose orbit includes the 'Human Services'. Simply having workers in one's life has an impact on an individual's power of choice. My experience is that workers can have a profound effect, both positive and negative, on the ability of a person with a disability to truly exercise the power of choice and hence have more autonomy in their lives. Relationships develop between individuals and their workers. Communication, understanding and an accommodation of individual differences and preferences are critical if the relationship is to be an opportunity for growth and conscious choice for both people.

For example, I have realised that in my interactions with workers, I tend to change myself for a whole range of reasons: to please, to be accepted, to impress, to avoid offending and sometimes simply as a means of getting my own way. Carolyn Myss refers to this as 'shape-shifting'. At times I can be such a shape-shifter that I cannot remember my real shape or self. Although I have been fortunate to know some truly excellent workers, they still have had an influence, both positive and negative, in the choices I have made. The impacts of workers on choice for people with a more severe impairment may increase exponentially.

Stephen Covey says that if we keep doing what we have always done, we will keep getting what we have always got. For real change to happen, in our roles as service providers, workers, parents and community members, we need to fully understand the power of our choices. These choices are not the superficial decisions about what to wear or where to go. Instead they are the choices that spring from our attitudes and beliefs. We must be conscious of how our attitudes and beliefs influence our perceptions and our judgements, and be guided by wisdom in our actions.

> "Power then, which is the ability to effect change, works not from the top down, but from the bottom up. It is not power-over, but power-with…We experience it when we engage in interactions that produce value. We can experience that with loved ones and fellow citizens, with God, with music, art and literature, with seeds we plant, materials we shape. Such synergistic exchanges generate something that was not there before and that enhances the capacities and well-being of all who are involved."
>
> Joanna Macy 1983

Mutuality as a Framework for Autonomy

Belinda Drew

Belinda Drew is the Company Secretary Mutual Aid Manager with Forester ANA Mutual Society. Belinda trained as a social worker and has been involved with services offering a range of support to people with a disability including respite services, recreation and individualised support services and service for people with an intellectual disability who are homeless. In this article Belinda explores the way in which the principles of mutuality can inform human service delivery and support people to have more control of their own life.

Mutuality offers an alternative framework with which to support the development of autonomy in a person's life. I believe the principles of 'mutuality' have the potential to inform and extend current approaches to human service practice. Yet, these principles are easily lost in the challenges of providing services efficiently and effectively.

The principles of mutuality rest on three important concepts: self help, reciprocity and solidarity. The concept of self help is about people being the authors, to the extent that any of us can be, of their own destiny. The concept of reciprocity is about people engaging in relationship with one another in order that they may give to one another. The concept of solidarity is about joining in the common aim of helping those with fewer resources; one of the ways that this is achieved is by pooling resources.

The principles of mutuality are illustrated in the most pure form when they are practiced together. The glue that binds this practice and process is to be found in reciprocity, actively relating to one another, appreciating one another's skills and deficits, and a willingness to do these things over a long period of time as these relationships grow and develop. The energy that drives the process can be found in people's innate desire to problem-solve their way out of difficult circumstances, and in addition, to experience the value derived from having achieved that success oneself – with the support of others. Finally, and perhaps most importantly, a commitment to pool resources is necessary in order to fully realise processes of mutuality. Solidarity is really a commitment to offer to those whose resources are fewer, opportunities that they would otherwise not have. The principles of mutuality acknowledge the capacity and desire of all human beings to be part of relationships that are characterised by genuine giving and receiving. At the same time, through the pooling of resources, opportunities are able to be offered that would not ordinarily be on offer.

In turning again to the context in which people with a disability are offered support, I am not disputing the importance of service in the lives of individuals with a disability. But it has also been my experience that the delivery of these services can become routine and mundane. I have certainly experienced the limitations of service from the perspective of only being able to offer specific types of service within set hours of work for limited periods of time. I have often pondered the limitations of service responses in the face of the often vast challenges of community living for people with disabilities. People's needs invariably and naturally extend beyond the scope of services.

What value then, can principles of mutuality add to the practice of human services? Firstly, I believe that these principles can help those of us working in human services to take stock of the nature of our relationships with people who have a disability. Mutuality asks us to consider how we can achieve greater reciprocity in the relationships that we have. Its principles encourage us to think about how we can extend ourselves to connect some of the people we know with one another, and to include more fully in our own lives, people with a disability that we have relationships with.

Once we grow these connections and achieve greater reciprocity, the next question is to consider what we could do together as a group. What are the common concerns of the group, such as saving, socialising and meeting others, trading skills, teaching and so on? Finally, we need to think through how we continually extend this help to others.

A practical example of mutuality is the application of micro finance methodologies by a group of people with learning difficulties. The 4US Savings Group formed with support from Foresters ANA Mutual Society. The aim of the group is to assist members to save by pooling small amounts of money. The 4US Savings group is sponsored by Community Living Program, which means that an amount of money is contributed to each group member by the organisation, as a bonus for their savings efforts. This bonus acts as an incentive to continue to save and also helps people reach their goals faster.

The benefits of this group are more than simply saving money. Because the group is grounded in principles of mutuality, members benefit through the development of relationships with one another. The group's membership is open to the broader community, however the criteria for broader membership is limited by certain criteria to ensure the safety of group members both personally and financially. Group members develop broader social connections through other micro finance initiatives and groups. The group also assists members to develop practical skills such as planning, budgeting and saving.

Mutual Aid and the application of its associated methodologies is not unique to Foresters ANA Mutual Society. However what this example demonstrates is our capacity to work alongside individuals, groups and communities to identify how we might resource them to apply the concepts of Mutual Aid for their own benefit and the benefit of others. Through the benefits of collective endeavours, the principles of mutual aid offers an alternative framework for autonomy, and some exciting points of exploration for people with a disability and their supporters and friends

Why Independence Does Not Equal Individualism

Fiona Kumari Campbell

Fiona Kumari Campbell is a lecturer and convenor of the Disability Studies Program, in the School of Human Services at Griffith University. She is also a person with a disability. Fiona has a strong interest in systemic advocacy and human rights. Fiona provides an analysis of some of the philosophies that inform discussions of autonomy and speaks to the importance of challenging these dominant mindsets.

The political theorist C.B. MacPherson describes the optimal citizen as one who is endowed with the virtues of *possessive individualism*. By that he means that the contributing adult is one who is:

> 'free in as much as he [sic] is proprietor of his person and capacities. The human essence is freedom from dependence on the will of others, and freedom is a function of possession … ' (1964)

This kind of logic – or *illogic* from my perspective – has dominated much of western philosophy and has been absorbed in social planning and human services modelling. Many of the ways we think of and apply the concepts of independence and self-determination of people with disabilities replicate much of MacPherson's thinking. Independence and self-determination have become inextricably linked to ability. In turn, ability has become a possession, a marker of one's identity. Underpinning self-determination with this kind of possessive individualism is dangerous because it can lead to the divisive strategy of ranking bodies, according to those presumed to be able to grow into autonomy and those who can't.

This ranking of people by their apparent ability or inability, and the privileging of certain abilities over other abilities is known as 'ableism'. Ableism means that certain kinds of people are seen as more desirable, or even more perfect than other people. One of the legacies of ableism on the lives of people with disabilities is the view that disability is inherently negative, and that *nothing good* can be said about disability. It is therefore not surprising that disabled people and our allies have strived to unchain ourselves from such crippling bondage by articulating a view that 'we are just like you' – and with a bit of help, and a minimum of fuss, we will fit in. The problem is that in doing so, citizenship becomes characterised by the independent, self-determining and ultimately productive body.

In our pursuit of independence, individualism and self-determination we need to resist the notion of equality as sameness. Indeed equality of outcomes does not always occur because of equality of treatment; in fact the opposite may happen. The pursuit of the self-contained autonomous individual may create greater divisions in society where the pursuit of perfection means that normalcy becomes a forever unreachable concept. Increasingly many readers who today are regarded as 'normals' will become in the future the new, and growing hoards of abnormals.

Thomas Hehir provides us with an insight into the way ableism reveals itself:

> … the devaluation of disability results in societal attitudes that uncritically assert that it is better for a [person] to walk than roll, speak than sign, read print than Braille, spell independently than use a spell check, and hang out with nondisabled [people] as opposed to other disabled [people] … In short, it is preferable for disabled [people] to do things in the same manner as nondisabled [people] (2002, p. 3).

Ableism is therefore a product of power relations in our society. The lack of power by people with disabilities is not just due to limited resources, education or the peculiarities of a particular impairment. Disabled people are often powerless because we as disabled are not valued. In the world of ableism, disabled people have a different relationship to the world; just as people of colour, in a world where whiteness is privileged, live under the reign of racism. An illustration of these relations of power can be seen in the way greater resources are provided to programs although seemingly disability friendly, still privilege ideologies of ableism. One common example of this is the inclusion of people with disabilities on panels and reference groups in tokenistic ways. Another example can be seen where people with disabilities are not employed in disability programs or disability services because of a supposed 'conflict of interest'.

Our task is then to reject an uncritical stance towards notions of individualism, independence and self-determination. One critical question to ask is: Who is excluded by dominant formations of self-determination? Is it those bodies seen as deviant and perverted such as people who are indigenous, disabled, gay, young, aged and eccentric folk – what Owen Wrigley calls 'outlaw bodies'?

Another important question is to ask: What does the focus on rampant individualism and self-determination distract us from? The terms of a discussion or policy agenda can veil or obscure other important issues. For example, a focus on self-determination could be seen as a way of expunging guilt about polices of incarceration, almost as if we believe that the 'new independence' of disabled people will ensure that institutionalist programs will never happen again. It is salient to remember that institutional policies were not about a lack of capacity or resilience on the part of disabled people, they were about power, and in particular, who had the power to define, classify and divide.

In the rush to run away from memory in the form of functionalist responses, such as new houses, new service types, new imagery, have we rushed way from thinking about history? The lessons of Holocaust studies are useful here. Whilst is it important to tell the stories of violation and harm it is also fundamental that these stories don't create an impression of Jews, as passive, docile victims. Instead Holocaust stories have also sought to recall and retell stories of resistance. This lesson is also valuable to the disability rights movement. Not withstanding the appalling history and current realities of treatment towards people with disabilities – instead of a place of despair, the margin can be a place of opportunity to rethink concepts of relationship, interdependence and collective identity. We know what violations were carried out in the name of 'care' – but we are less certain about the histories of disabled people and their allies fighting back – individually and as a group.

The pendulum has swung the full measure from forced congregative living to organisational policies that actively disperse disabled people. Both approaches constitute an act of power. The separation of disabled people from each other mitigates against starting a movement. What disabled people need more than ever is to engage in consciousness-raising – just as people in other social movements have done throughout history: the suffragettes and feminist movements; the civil rights movement; the gay pride movement; and the First Nations movements. It is necessary for people with disabilities to come together to share experiences of disability with each other.

Such a move is not about creating alternative segregationist agendas (allowing for the possibility that some people with disabilities may choose this). It is not about denying the essential role of non-disabled people as both leaders and allies in social change, nor to ignore our greater shared humanity beyond disability. The call for collectivity is about people with disabilities coming together to see commonalities in differences, to gain role models and mentors and to encourage leadership. We need to speak differently about independence and self-determination and look at what the experiences of disability can contribute to the common good of society.