

CRUCIAL TIMES

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EDITORIAL

While much progress has been made in advancing the status and opportunities of people with disabilities, there is still much to do. This edition of *CRUCIAL TIMES* examines how we can become stuck at different points when supporting people to have roles of substance in their lives. This can happen in two ways: people with disabilities can become stuck in roles that are either demeaning or lacking in real opportunity; and secondly, those involved in the lives of people with disabilities can get stuck in their thinking about what is possible. These circumstances could be because of: low expectations; low creativity; loss of hope; or because there is an acceptance of the idea that lives that are either wasted, or have only short episodes of positive roles, are all that are possible for people with disabilities. The challenge is to find ways of opening the doors to richer roles and more fulfilling lives for people.

Two contributions to this edition (one by Bob Lee, and the other an excerpt from a recent South Australian publication) illustrate how people can be captured in demeaning roles and clienthood. While these contributions describe the experiences of older citizens, there are strong parallels between these experiences and the experiences of many people with disabilities. In an article about the valued role of 'employee', Tara Woollett points out that working life would be barren without social interactions and relationships, yet this absence is precisely the experience of many people with disabilities in employment. Tara's article offers helpful principles for supporting a person to be embedded in the role of valued employee. A helpful body of knowledge that continues to underpin good human service practice is Social Role Valorisation and an illustrative article

provides readers with an example of how SRV principles can guide our actions when we want to support another person. In another article, Ann Greer reminds us of the valuable yet delicate nature of good friendship, and describes some of her own learning as a parent.

Some of the achievements in the lives of people with disabilities have been possible because of their families, paid workers, and interested citizens. Their vision of a good life has been clear, even if the path to that good life has been less clear, and they have been vigilant about seeking opportunities for the person they are concerned about. They have also shown an understanding that human service practices are subordinate to the values and ethics of those involved, and a piece of writing by Michael Kendrick points out that "personcentred-ness" is a characteristic of people, not systems.

Speaking of roles, I am privileged to have been appointed to the Director's role at CRU, and delighted to congratulate Anne Cross on her new role as Director, Strategic Development at CRU. CRU has been extremely fortunate to have had Anne as Director for the past twelve years, in which time she has nurtured and strengthened a movement for authentic change. Her commitment, generosity, and capacity to connect with people who have disabilities, their families and supporters have underpinned her clear vision, sharp mind, deep insights, and her ability to advance compelling arguments. She has been integral to the progress made within the disability sector, having encouraged and nurtured many people. CRU is pleased that Anne will continue in a key leadership role within the Queensland community and also continue a close association with CRU. ■ *Jane Sherwin*

CRU's MISSION STATEMENT

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

FROM THE PRESIDENT

Mike Duggan

Often people who have disabilities are unable to achieve recognition or to feel valued. This could be because our roles in life have either been bestowed on us or because we have not been able to gain substantial roles through lack of opportunity.

I believe that some of the obstacles causing people with disabilities to become stuck in roles that are neither valued nor meaningful arise out of the fact that people in general are so preoccupied with getting a valued life for themselves that there is no time for them to think of others. In other words, a personal agenda can get in the way of actions that might bring about positive change for another person. Even the pursuit of a professional career in Human Services could actually prevent a person from acting in the best interest of those needing assistance to gain more potent roles in society. With particular regard to the valued role that might be acquired by a person with disabilities when gaining employment, overall there seems to be a prevailing lack of imagination in cultivating such important opportunities.

The crucial thing for those who want to be of assistance is to be aware of personal values and beliefs. If we are not aware, we are in danger of invoking harm on those we say we want to assist. What is even worse is that we might be oblivious to the fact that we could do harm or

that we might simply be appeasing our own egocentric nature. We must learn to transcend our egocentricity and our pathological preoccupation with self, so that we can truly reach out and assist others in meaningful ways.

One of our most fundamental human needs is the need for recognition. All of us need to feel valued. One way of feeling valued is established through having meaningful, well-regarded and respected roles in the community. To quote my dear friend, Joe Osburn, our major goal is to: *"create or support socially valued roles for people in society, because if a person holds valued social roles, that person is highly likely to receive from society those good things in life that are available to that society, and that can be conveyed by it, or at least the opportunities for obtaining these. In other words, all sorts of good things that other people are able to convey are almost automatically apt to be accorded to a person who holds societally valued roles, at least within the resources and norms of his/her society"*.

In order to assist people to gain and maintain the roles that are likely to lead to their attaining the good things in life, we must constantly examine our belief systems and motives. I believe that one cannot assist another person to attain substantial and valued roles unless an honest and genuine relationship has first been formed; such a relationship is a prerequisite to being able to assist. ■

As the President of CRU I am honoured to announce that at the end of June, Ms Anne Cross resigned from the position of Director to take up the new position of Director (Strategic Planning) and that Ms Jane Sherwin has been appointed Director of CRU. We extend to Anne and Jane our best wishes and continued support.

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Anne Cross • John Armstrong • Peter Millier • Michael Kendrick

DIMINISHING THE DIGNITY OF OTHERS

Bob Lee writes of an experience that led him to deeply reflect on the impact that is made on people when there is a mis-match between what people need and what they get. In recounting the experience, Bob gives readers great insight into the kind of demeaning roles that are often imposed on older citizens.

This was one of those life-changing experiences that we hear people talk about. I was part of a group of eager students visiting a Day Respite Centre for older people. We were in a nice part of town, in a nice new special-purpose building with nice new furniture. The aim of our visit was to talk to the people who came to the Day Centre and to understand what their lives were like.

I found myself talking to two men - they were probably in their late seventies. They courteously invited me to sit with them and hear about their lives. Our discussion started over morning-tea but was shortly interrupted by the distribution of items that were necessary for playing a game called "Pingo" which, according to the day's program, was the scheduled activity. For those who don't know, Pingo is a little like Bingo without the numbers, and more importantly, without the cash prizes. In Pingo, numbered cards are replaced by pictures. In this case the pictures featured toys such as dolls and teddy-bears, items of clothing and household implements. As I looked up from a picture of a teddy-bear I met the eyes of the retired engineer across the table. He gave a slow, deliberate wink and said, "It's a good game - if we win, we get lollies!"

I saw the humour in his eyes. It was the dry humour of a man who is tolerant of the bizarre thinking of professionals who learn, as part of their training, that matching small pictures of teddy-bears is somehow a therapy for older people. We played the game with great skill, earned more than our share of lollies, and laughed often, but the organisers just didn't get the joke at all. During the game I heard more about the lives of these men. As young men they had both served in the army during World War Two. The engineer had a long and distinguished career building bridges and multi-storey office blocks. His friend was a man who, starting with nothing, built a successful sawmilling business. Both men attended the Day Centre because their families believed that it would be good for them to have something to do during the day.

Lunch at the Centre was followed by a scheduled activity that seemed to be a disguised form of exercise. It involved everyone sitting on chairs in a circle while doing movements to music. The Diversional Therapist who led this activity looked like a cast-member from *Love Boat*. He wore white running-shoes (although no one was running anywhere), white designer-shorts and polo shirt, and a chrome whistle hung from a cord around his neck.

I think it was when they launched into the chicken-dance, so beloved of children and drunks everywhere, that I looked for the retired engineer. This time there was no wry humour. There was no slow, deliberate wink. There was only profound embarrassment. At first I thought that this might be because our student group was present. But then I realised that this proud, successful man was sitting on a chair moving his arms to a chicken-dance in front of fifty women who, not so long ago, would have partnered him on a war-time dance floor. What did they think now?

After the chicken-dance it was time for us to leave. I thanked both of my new acquaintances for the time and understanding they had given me. The man with the chrome whistle reappeared and organised the older people into a circle to hold hands and, to my disbelief, sing *Auld Lang Syne*. I thought that this just added to the ridicule and humiliation of dignified, elderly citizens that I had witnessed all day, but as they all smiled and sang with gusto, I realised that I had it wrong. They were doing this because, despite our best intentions, they knew this was the last time they would see us.

They were right of course. I haven't returned to the Centre and I don't know how the engineer and the sawmiller are getting on. But I will never forget that slow wink over the game of Pingo, or the dignity and tolerance shown by people who were subjected to humiliation under the guise of a service. ■

"A UNIQUE LIFE TO LIVE": AN EXCERPT ABOUT CLIENTHOOD

CRU recently received a publication that has been a true inspiration. "*A Unique Life to Live*" reports on a project undertaken by a South Australian organisation called Community Options: Aged Care and Housing Group. Unlike many reports that focus on such things as theories of management, strategic planning and statistics, this report is destined not to sit on a shelf or be forgotten. The publication is a celebration of what is possible when thoughtful people deeply engage with the experiences of the people who receive support from their service, and learn from them. The following excerpt from the publication is offered to readers as a way of illustrating how easily 'clienthood' can displace meaningful roles in the life of a person.

Mrs Black provides an example of an aged person who slid easily into clienthood and now doesn't see a way out. As a not-very-old senior citizen who became a client of a Day Centre, she assumed automatic transition into the neighbouring hostel and nursing home. Now ineligible for hostel approval (as the rules of eligibility tighten) she almost reluctantly remains in her own attractive unit within reach of the sea, peering longingly at the care workers who visit a neighbour daily, compared with her twice-a-week visits. Mrs Black sees herself as being equally as sick and frail as her neighbour.

Mrs Black is eighty-one, she walks easily with a frame, gets into a car or chair without assistance, needs no assistance with personal care and has a loving family she sees regularly. She has mild arthritis but can still crochet, cook and iron and attends clubs three times each week. Her focus has become: "how can I receive more hours of help?"

Community Options South initially entered Mrs Black's life when a friend, who had regularly joined her to shop and lunch, went overseas. A worker from Community Options South then accompanied Mrs Black. When Mrs Black's friend returned from overseas she saw that Mrs Black was 'OK' and that there was no need for her to take up her previous role of shared shopping and lunch. Mrs Black did not want to lose her worker or the 'perfect' situation that she had orchestrated although it had none of the give-and-take inherent in the natural relationship she had previously shared with her friend. Mrs Black began to express feelings of loneliness and depression, often saying things like, "no one comes to see me any more". We asked ourselves how we had contributed to Mrs Black's dependency

upon the 'perfect' human service paid-role and how we had lacked the insight to safeguard the long-term relationship with her valued friend.

While Mrs Black may have thought it was too late for her to rejoin society as a contributing and valued citizen, whether this was true or not, we believed it was extremely important that other people did not slide into a similar dependency of clienthood and miss the opportunity for a new approach. Reflecting back, we discovered that human services could either enhance the underpinning concepts of citizenship or impact negatively on them. The barriers to citizenship within human services were beginning to emerge.

Mrs Black's life centered on services filling up much of her days. She was not isolated in this experience as we met many people 'waiting' for one service or another to be delivered or provided. This set up a circularity of expectations for Mrs Black, believing that within the client role, all of her needs should and would be met by services.

As time went on, the service was finding it increasingly difficult to maintain a worker to accompany Mrs Black to go shopping. Workers were finding it difficult to be with her due to what they described as 'demanding behaviour'. Mrs Black's behaviour led to her being labelled as demanding, whereas it has now become obvious that her behaviour may well have been a manifestation of the clienthood role.

This realisation is just one of the learnings about practice issues that came out of the project. The report explores many issues relating to services for older people including: the impact on older people of becoming 'clients'; the negative impact of human services on older people; the challenge of understanding what is truly helpful to older people; the importance of working with families, neighbours and networks; and looking for ordinary and unpaid responses to the needs of a person, as well as paid responses.

This important publication represents the thoughtful work of people who decided to make better things happen for the people that their service supported. Their stories and insights are certain to inspire others. ■

[Copies of the report *A Unique Life to Live* are available from CRU for \$13.20]

Employee: a potent role

In this article Tara Woollett offers some helpful principles for facilitating the development of workplace relationships that are likely to support the valued role of being an employee.

While most people would agree with the concept of 'community inclusion' for people with disabilities, there are differing views on how this is achieved. For many, the fact that a person is living in the community would be considered to be community inclusion. Fortunately, there are others who do not consider physical presence to be the only aspect of inclusion. People need to feel that they have valued roles in relationships with others who care about them, as distinct from paid relationships.

Employment is one valued role that assists community inclusion for people with disabilities. The myth is that a job automatically equals inclusion, however, physical presence in the workplace is not sufficient. Many of us know from our own experiences that we can feel very isolated in a work environment, especially when starting a new job.

For people with a disability such an experience can be even more isolating because there is a risk that they will be present in the workplace without ever truly being a part of the workplace culture. There are a number of reasons for this increased risk. Firstly, many co-workers may not have had any previous interactions with a person who has a disability and may be afraid of saying or doing the wrong thing and unsure of how to react. They can take the easy way out by avoiding the person with whom they feel uncomfortable. Secondly, the person with a disability may have low self-esteem and avoid contact with co-workers because of shyness or feelings that others won't want them there. Thirdly, support workers sometimes take ownership of the person they are supporting and co-workers can then feel edged out.

There are no easy answers to overcoming these barriers because the solutions are as individual as the people seeking the solutions. However, there are some basic ideas that can be factored into most situations if a support worker is involved. Where possible, the support worker should discuss with the person who is starting work what information the person would like their co-workers to know that might enable them to

interact more easily. The support worker could then informally talk to co-workers and let them know what to expect and how to include their new work-mate. It is important not to dismiss co-workers as potential allies because of some prejudices, but rather to encourage and support them to accept and welcome the person with a disability.

The majority of support and encouragement should, of course, be directed to the new worker. Starting a new job can be stressful and the new person may need guidance on how to relate to others in the workplace as well as how to perform particular duties. The support worker should become a role-model for both the person with a disability and that person's co-workers.

Rather than taking ownership of the situation, support workers should keep an eye out for co-workers who look as if they want to be involved with the new worker and help them to engage with that person. Initially, this may mean that the support worker is heavily involved in discussions and initiatives, but the support worker should then withdraw and take a back-seat allowing co-workers, wherever possible, to take over the training of the person who has a disability. Co-workers are more likely to include a new worker if they have some input into the training of the new person and feel that they have something in common with that person.

Whether a person with a disability will be truly included in the workplace will also depend on whether the work itself is suitable, or whether co-workers are open to becoming a part of someone's life. And a willing, positive new worker together with a support worker who is open to opportunities will also be essential elements in setting up successful workplace relationships.

Employment is not the only way to achieve community inclusion, nor should it be the only facet of a person's life. Employment is, however, an important component of community living as it is deemed to provide individuals with one of the most valued roles in our society. ■

THE NEED FOR ROLES & RELATIONSHIPS

At the heart of the teachings of Social Role Valorisation is the acknowledgement that people with disabilities experience social devaluation, and that this has multiple ways of impacting on a person. Jane Sherwin provides an example of what an SRV frame-of-reference offers when thinking about the most helpful forms of support that could be offered to someone she knows, called Anthony.

Anthony grew up with his mother and older brother and attended Special School in his town. When I met Anthony, he was in his early twenties, living with his mother but spending more and more time in a respite house. Anthony had been working in a sheltered-workshop for six years, but had run away from that environment three times. He had no interests apart from listening to the radio. His mother had declining health and his brother was planning to move to another town. The future was looking limited for Anthony.

The principles of SRV encourage us to understand the needs of the individual, both human and specific, that flow from having an appreciation of the true identity of a person. In Anthony's case, this meant that there needed to be an appreciation of the experiences that had contributed to shaping his identity so far. The years spent at special school and the increasing amount of time that Anthony spent away from his mother needed to be deeply appreciated, and their impact on Anthony deeply understood if he was to be well supported to have an enhanced future.

Having an appreciation of a person's particular strengths is one of the ways in which a person can be positively perceived. One of the impressive things about Anthony is his strength, courage and dignity. He has battled with epilepsy all of his life. At times Anthony's charming swagger can deteriorate into a stumbling gait, and his cheeky grin can give way to slurred speech and confusion. Yet Anthony continues to assert his resistance to being treated in ways that do not take him seriously or respect his individuality, or that underestimate his abilities.

The insights of SRV show how important it is to understand Anthony's particular vulnerabilities. Anthony's segregated life-path has barely equipped him to feel a real part of his neighbourhood. Because of his segregated schooling, Anthony has not had the usual

opportunities to learn about the formation of friendships; he has not had these opportunities in the school-yard, in sport activities or at school camps. As an adult, getting a job has been made harder for Anthony because graduating from Special School holds no sway with prospective employers.

These experiences show that Anthony, like many other people with disabilities, has endured being labelled, rejected and marginalised by society. While Anthony strongly tries to assert his personal dignity and identity, he is frequently perceived in negative ways that define him as forever-child, burden to his family, and even as a menace. Given all of these negative experiences and perceptions, unless Anthony and the people around him could craft a life that was different from that which he was experiencing, there was a high risk that Anthony would always be living on the margins of society.

One of the most potent strategies of Social Role Valorisation teaching is that it offers a vision of a "good life" for people with disabilities. It asserts that enabling people to gain and maintain valued roles holds one of the keys to a good life. It asserts that if people with disabilities have roles that are appropriate to their age, gender and culture then they are more likely to be perceived in positive ways and to have greater access to what most people take for granted in terms of life's experiences, comforts and relationships. This is a far more potent vision than that of people merely living in 'home-like' environments, or of having a life that is simply full of service programs.

There are two-fold gains when people with disabilities acquire positive roles. Firstly, the person with a disability is more likely to have access to the good things in life, and secondly the observer has their mind-set about a person with a disability challenged or changed.

For those who were seeking a different kind of life experience for Anthony, one of the important questions that needed to be asked was: how do other men of a similar age live their lives? This question needed to be asked while at the same time acknowledging Anthony's particular vulnerabilities – his health, his changing family circumstances, his limited life experiences, and a lack of relationships outside his immediate family. The vision that was crafted with and for Anthony, was one that was characterised by positive roles at home, in employment, and in his spare time.

Using an SRV framework and its multitude of strategies helps us to think deliberately about how to make a difference in a person's life.

SRV is a probabilistic theory.

It proposes that if we do 'x', then it is highly likely that 'y' will happen. For example, if Anthony moved to a group home, and spent all of his time in places

where he was not mixing with ordinary citizens doing typical things, then it is probable that the following would happen:

- Others around him would continue to have negative beliefs reinforced; beliefs such as: 'they like to be with their own kind'; 'they need a life separate from others';
- Anthony would continue to have low exposure to positive role models, and so miss out on rich learnings from people who he might like or admire, and aspire to be like;
- Anthony, as well as others, would continue to have low expectations about his capacities and abilities.

In contrast, if Anthony had strong, positive roles such as those of tenant, home-maker, house-mate, neighbour, son, brother, music-fan, cinema patron and model-train enthusiast then it was probable that the following would happen:

- Anthony would be perceived to be more like any other young adults;
- Relationships would grow out of these roles;

- Anthony would develop competencies and be perceived by himself and others in more positive ways;
- The expectations held of Anthony would rise, leading to other opportunities.

These were, over time, things that did happen for Anthony. As Anthony began to be more involved in typical life experiences and to take on more positive roles, people around him began to notice that he had a greater sense of himself and more confidence. The people around Anthony used extra-ordinary strategies to help Anthony to achieve these things. As one person said, 'It looked easy on the surface, but much work was being done in the background.'

An SRV framework uses strategies that are not only consistent with what is typical and valued in our society, but it also encourages us to go-the-extra-mile in our willingness to

support someone to gain valued roles and to maintain those roles. The teachings of SRV also confront us with a consciousness about how people with disabilities have a heightened vulnerability to wounding experiences at the hands of society, and even at the hands of human services or good-hearted people.

The theory of Social Role Valorisation help us to understand the challenges that arise when we want to counter the impact made by social devaluation on a person. Applying the principles of SRV requires great discernment and an ability to deeply understand and appreciate the life experiences of another person.

Anthony will always struggle with the impact of conditions that make him vulnerable to ill health and marginalisation. It is hoped that the valued roles that Anthony now holds, and the people that are now in his life (in paid and unpaid capacities), will go some way to meeting Anthony's everyday needs of having a sense of belonging, having a home, and a variety of relationships. ■

'Using an SRV framework and its multitude of strategies can help us to think deliberately about how to make a difference in a person's life.'

GOOD FRIENDSHIP – A fragile and precious thing

Ann Greer lives in Townsville and has three adult children. This contribution is about an important long-lasting friendship in the life of her daughter, Jane.

My daughter Jane is now twenty-five years of age and recently acquired a traineeship with Queensland Police Services in an administrative role. All of her life Jane has instinctively understood the importance of taking an active part in her life and in being taken seriously. She is a very independent woman despite significant disabilities including Down Syndrome and significant hearing disability. When she was little she was at great pains to remind her sister that she was the oldest child; and as a young adult, she was at great pains to remind people that she was grown-up and not a child – even when she was only being defined as a ‘child of our family’. For many years I thought that Jane denied her disability but I have come to understand that she refuses to be *defined* by her disability.

Over the past six years, Jane has twice lived with young women of her own age, she has also lived alone in a unit, and has lived with her family. In all of these situations she has been required to take on many roles – housemate, account payer, confidant, and antagonist – to name a few.

One of Jane’s most important roles has been that of friend to Shelly. Shelly and Jane played together as toddlers and over the years they have remained firm friends. It has always been a very equal relationship, with Jane often actively in the role of giver as well as in the role of receiver. In past years, Jane was able to give Shelly a place to stay when she returned home from Melbourne and they shared a unit for about a year before Shelly found ‘true love’ and moved out to start life with her partner Stuart and to give birth to Shonell.

Shelly and Jane have lived together again recently and this time Jane was able to learn a lot about the art of giving through helping Shelly with Shonell (now aged two), taking an active role in the household. When I see them together and see how much respect and equality exists between them, I know that they are truly blessed to have such a wonderful long-term friendship. This has not prevented them from having difficulties. Their living arrangement fell apart

recently and the strength of their friendship carried them through a difficult time. The reasons for the break-up were complex but some of the difficulty lay in Jane’s inability or unwillingness to take up some roles that Shelly expected her to undertake. After endless discussions about the issues it became apparent that it was not working and Jane moved out. It was a very sad time for Jane (and for me) but they are still the best of friends and both agree that they may live together at some time in the future.

Over the years, I have been actively engaged in walking-the-tightrope of supporting the friendship while trying to do no harm. This is a potential landmine for me, because my instinct as Jane’s parent is to protect her and stand up for her even when she is in the wrong. I have also had a need for Jane to do things properly and my instinct to walk in and take over a task or issue is enormous. I have been humbled to discover how often Jane is able to do a job as well as I can, or better! Added to this, she and Shelly are able to work out many things and if they can’t, I have come to realise that it really is none of my business. I now use a set of guiding principles for supporting Jane in her friendships, and they may be of help to others.

- For relationships to grow, there is a need to nurture, not suffocate. Jane and Shelly’s friendship must be able to take its own course and not be driven only by Jane’s needs; Shelly’s needs and wants are equally important.
- There must be equality in the relationship: each must be prepared to give-and-get. This does not mean that one may not be needier than the other from time to time.
- As an outsider, I cannot make Shelly or Jane act well all the time. Relationships are made up of the human beings in them. By definition, ‘to err is human’ and this requires forgiveness and understanding from me because I am always in danger of placing unreal expectations on both Jane and Shelly.

- Where paid supports are involved, there is a need to acknowledge how difficult it has been for all of us to truly respect the friendship. There are so many conflicts of interest (eg. turning Shelly into Jane's paid worker, or treating her like a paid worker).
- As a parent I have always wanted my children to live in attractive environments. I have had to come to terms with the fact that Jane and Shelly may not always have similar expectations or may not be in a position to deliver such ideals. Much to my chagrin, Jane's living arrangements have never looked like an illustration from *House and Garden*.

- Finally I have learned to back off. I have had to relinquish control over Jane's life in order for her to have a life of her own. My initial learning-stages were ugly but Jane has reaped the rewards: she has learned through her own experiences; she has not been shielded from the reality of relationships; she has had to negotiate her own terms; and she does have Shelly – someone she can truly call 'friend'.

Lastly I'd like to offer these words on friendship from Randolph Bourne in *Youth and Life* – 'good friendships are fragile things and require as much care as any other fragile and precious things'. ■

Person-centeredness : a characteristic of people, not systems

In this excerpt from his keynote address to a conference early this year Michael Kendrick shows that when modern technocratic methodologies are applied to human services, people with disabilities are once again cast into the role of object, thus denying the uniqueness of their personhood.

To the dominant technocratic mindset in our human service culture at this time, there is a profound temptation to try to translate all desirable human capacities into bureaucratic methodologies. Such a mentality locates ostensible "solutions" as being solely a property of organizations and systems but, in reality, one cannot get from organizations what is essentially lacking in the people who inhabit them. Well before an organization can make progress on matters of human sensitivity it must have nurtured these same sensitivities in the people associated with it. In this way, people and what they are authentically like are greater predictors of what an organization can achieve than are the formal mission statements, policies and slogans that supposedly guide the individuals in the organization.

The "real" policies are written in the hearts of people and will express themselves in practice notwithstanding what is contained in official policy. In this way, person centered planning ought to be seen on at least two levels. The first is that of its increasing use as a formal tool of agencies and bureaucracies. The second is as a tool often used by widely varying but often sincere people seeking better solutions. In the first case, person centered planning

methodologies are simply techniques and thus ought not to be equated with the kinds of qualities in people that would best underpin their use. Like all technologies, the final product depends very much on the qualities of the people using them. Thus, person centered planning in the hands of those who lack sufficient regard for the person, could actually be used harmfully.

It is much too easy for any of us as well as the formal human service systems to adopt person centered approaches as a kind of technology and not see that an authentic adoption of their use would require profound personal and systemic transformations. Instead we may simply take up a supposedly new language and planning methodology while failing to see that we need to go much further. People with disabilities can guide us as to how we must change, but we must first be willing to be led. The ethics underpinning our use of person centered approaches will eventually reveal whether this approach ultimately leads to the liberation of such people or their continued oppression.

At the same time, it should be recognized that it is quite possible for a person to be treated quite well without the use of any person centered planning

methodology whatsoever. Whole civilizations have come and gone without person centered planning so it is useful to recall that this, after all, is just a tool developed in the last several decades of the twentieth century and ought not to be endowed with much credibility. What should be taken seriously is the more enduring and universal question of the qualities of human beings that tend to result in other people being treated better. To use the language of today, the more profound question is one of "personcenteredness". This quality could be thought of as the optimal or desirable ethical and values base held by the kind of people who tend to bring about improved respect and treatment of others. In this sense, "personcenteredness" is a characteristic of people not systems. It would seem obvious that this is the more central factor to focus on rather than the utilization of a method that cannot, in itself, guarantee that such human qualities will guide its actual use.

It is useful to recognize "personcenteredness" as something that begins within people and radiates outward to others. In all likelihood, it is a set of qualities in each of us that is very dependent on our deeper values and aspirations as to what constitutes being a good person. In this respect, it also reflects some sense of morality about how people ought to be treated. Even if we don't always live up to such ideals it is important to see that they are nonetheless present in us or can be acquired by the sincere seeker. Equally they can be cultivated and refined over our lifetimes and are thus developmental in nature and can lead to yet further insights into our human nature and the ways that people can be of assistance to each other.

What is also clear is that it would be silly to try to reduce such challenging matters to a simple formula. Our relationships to others and to ourselves are far too important to be so readily codified. Nonetheless, it is useful to try to express the kinds of insights and ideals that would be helpful for the sincere seeker in regard to how they ought to be towards other people, including people who live with a disability. What follows ought not to be seen as the final resting point for this discussion but rather as an offering of what might be the kinds of capacities we would see as desirable. In the end we must all find our own way as this is at the core of being a person.

It is not at all easy to understand others or ourselves. Even when one does understand something of whom

another person is or even understand something of our own nature there is clearly much left to know. We can do a disservice to others and ourselves when we presume to know what their or our personhood is. A better approach is to recognize that what we think of as personal identity, while so seemingly fixed in many ways, is actually a "work in progress" and is always in a state of unfolding. "Knowing" is perhaps not as useful a term here as would be "appreciating" the person, since knowing is always a matter of degree whereas appreciating can still occur even when all is not known or revealed since it applies simply to what is currently evident. This insight tends to come more easily for people when their own "unfoldingness" as a person is better appreciated.

Since people are constantly changing towards unknown ends it seems sensible for the supporter of that person to recognize that they are to accompany that person's daily search as to wherever each day brings them. It would seem that one is never past the stage of "discovering" the person since the person themselves is still unfolding. This suggests an ethic associated with the process of seeking to understand another person and an attitude

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wherein we see ourselves as mutually sharing in the process, to some degree, of searching for the personhood of the other. In this way our commitment and obligation is to retain an interest and curiosity in the person and to avoid assuming that all that is to be known about the other has already revealed itself. The difficulty in the past has been that we have presumed to understand people without actually taking the trouble of being open to what they may be. We also did not take the time to properly get to know people. We have too often limited and ignored their real identity and assigned them an identity of our making. All of these shortcomings could be overcome by a sincere desire to understand the person.

It would seem quite pointless to seek to understand people if one is not going to do something with what one begins to understand. Insight alone, without action to support the person in their struggles for a better life for themselves, would be voyeuristic and an indignity. More positively, insight that is coupled with a desire to act in helpful ways sets the stage for the kind of partnership of effort that would be of service. There still remains the question of what would be authentic service to another. This cannot be easily answered, as the proper response to the ever-unique

constellation of wants-and-needs of each individual is something that is rarely self-evident. Nevertheless, the commitment to engage the question of what would be best for a person is essential to eventually settling on strategies of service. The key here is that the supporter resolves to be of service rather than just being present without a commitment to the person and their well-being. Because we tend to reflexively assume that our motives are the proper ones, a measure of searching honesty about ourselves can be valuable.

A common criticism of services that comes from service users, their families and friends is that of the person being served "on" or "at" or "to" rather than "with" the person. Service is done "to" people rather than in ways that enable the person to be an active force in their own life. This is often due to the professionalistic assumption that the service provider ought to or does have "answers" and that these have to be imposed on the person. Such an action can render the service user to be merely a spectator in their own life while the initiative and control shifts into the hands of the alleged "expert". Equally, few services actually arise from or are guided by service users and therefore such an approach is often outside of the usual experiences of many professionals and staff. Consumers and families may themselves be schooled by their own experiences to believe that "professionals know best" and thus contribute unwittingly to their own disempowerment.

These errors can be limited by the supporter taking a different stance. It is both realistic and necessary that they seek out, engage in, and submit to the instruction

contained in the "guidance" offered by the person as to the directions and details of their lives. The word "guidance" used here is not the formal articulation of needs and wants so much as the ideals, hopes and fears the person holds for their life but yet may be unexpressed. This collaborative response requires a highly submissive posture on the part of the supporter to the often-opaque guidance offered by the person being supported. Nevertheless, it is valuable to assume that the person ultimately needs and wants to be a decisive factor in their own life even if they are unclear or not very articulate about what this might mean in practice. Though it may not seem so to many people, even those persons with apparently very limited intellectual and verbal abilities might still have considerable capacity to sense what they most deeply need and want, and benefit as much as others from having this respected. The key here is not what is mutually understood or not at a given point in the process. It is more the posture of the supporter in regard to genuinely seeking to be guided by the person. This desire for service done in the spirit of "with-ness" is very much bound up with honouring the person and seeking a right relationship with them. ■

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Anne Cross says "Thank-you"

After twelve years I have resigned as Director of CRU. During this time I believe we have witnessed greatly improved expectations about what is possible for people with disabilities and seen the development of a community-living movement which progresses these heightened expectations. I think we have also seen many practical changes and improvements, which have benefited some people with disabilities. I am proud that CRU has a key role to play in much of this work, and that I have had an opportunity to be part of that. During this time, however, many new challenges have emerged for people with disabilities, their families, and the field. In my new role, I hope to have the capacity to talk with many people in Queensland and across Australia about these challenges, and to look at what else could be done.

I have taken up a new role within CRU as Director, Strategic Development on a part-time contract basis. In this role I will continue to be involved in assisting CRU to develop its programs and services, and I will undertake some specific pieces of work on CRU's behalf. I am delighted that Jane Sherwin will take over the Director's job, and I look forward to working with her in that position.

The past twelve years have been enormously rewarding and interesting for me. Many people have supported me and challenged me, and I thank each of them. I'm looking forward to the next phase with great enthusiasm. ✎

