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Editorial

Treading Lightly in People's Lives

Anita Speed

All societies develop unwritten rules that guide the conduct of their members and construct a set of norms or standards to capture the various perceived rights and wrongs for that society. Some of the norms in our current society include: the notion that individuals should be able to make their own decisions on how their life should look; that people should be treated equally; and that an individual is at the centre of his or her own life. Most people move through life without being conscious of these norms; they are simply taken for granted. Yet, for some people and groups of people in our society, these norms have not historically applied. Other sets of rules have been developed especially for certain individuals or groups which have resulted in people or groups being marginalised as 'other', and seen as not belonging to the valued core of society.

Through legislation and changing values, society has begun to acknowledge that an ordinary life is everyone's birthright despite the historical thinking that dictated otherwise. Society is also beginning to acknowledge that this birthright extends to those who may need assistance in determining and living that ordinary life.

To illustrate how this is playing out, it is useful to think about how life is typically divided into two spheres: the public and private. The private sphere consists of our home, family and friends. The public or 'professional' sphere includes business, government, organisations, other

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public institutions and the workplace. Both spheres are underpinned by some of the fundamental societal norms – the common 'rules'.

Each sphere uses its own language and worldview to make sense of information and events. The public sphere speaks in terminology where events, production and even human services are described in systemic, rational, scientific, and outcomes-based technologies (depending on the ideology in

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.

fashion). This worldview is reflected in the roles that people have, for example, manager, worker and employer. The private sphere generally uses more social, personal, or emotional language and terminology, and people develop roles such as parent, homemaker and emotional supporter.

People move between these spheres often, usually from work – the professional and public arena – to home – the individual and private arena. They have often adopted ways to help the transition between the spheres so that they can more easily change roles when moving between these uncharted boundaries. It could be by changing clothes when coming home from work to signify the changing role from 'worker' to that of 'parent', or closing a door to the home office when finishing work in order to make the transition into the private sphere.

For people with disabilities who rely on professional support to lead ordinary lives, the boundaries of the public and private spheres and the roles within them are distinctly blurred. Many people with disabilities might require the support of professionals (although it can be argued to what extent) in order to lead their daily lives. In this way, the professional sphere intrudes on the private sphere in the lives of people with disabilities as a common daily occurrence. The result is often confusion and ambiguity of roles. Support workers grapple with issues of friendship and people with disabilities become consumers in their own home. With such differences in perspective, language, worldview and expectation, how can the private and public spheres work together in order for people with disabilities to achieve an ordinary life?

The development of a professional climate of quality systems, standards and other mechanisms within the public sphere is starting to articulate how to further the journey of having everyone acknowledged as valued and full participants in society. The rules of the public sphere are, however, difficult to apply in that area of overlap where the boundaries of the public and the private meet. Yet there is a need to negotiate this territory. By exploring the issues surrounding this complex and ambiguous situation of providing a professional service to a person within their private domain, we can begin to move towards an explicit naming of the ethic which must underpin an understanding of where the public and private overlap. At the point of intersection, the common ground must be based on relationships, which includes the notions of

mutual respect and open communication. It is in this zone of equal power in which a shared vision and common humanity might be nurtured.

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From the President

Mike Duggan

Finding an answer to the question what is quality is the first, vital step to take before establishing any quality system, which is specifically designed to measure quality.

Michael Kendrick has noted that quality is sometimes viewed as being on a continuum from poor to excellent. In this sense, he says, it is assumed that all stages of the continuum are part of 'quality' in that they all express some level of attainment of quality, even if in the lower ranges. This sense is not helpful if what one wants to concentrate on is what is the 'best' effort as distinct from all efforts.

Nowadays the term 'quality' is used to refer to something done by people at a very high level of excellence, and mostly in the sense of a work of perfection as distinct from inferior or mediocre performance. It is this shared interpretation of what constitutes excellent quality which must underpin any quality measurement system.

Only when the individual needs of people are at the core of this interpretation of quality, together with the understanding that individual needs are not static, is a human service more likely to find the answer to the question what is quality and is more likely to achieve excellent quality. A

service which recognises the changing pattern of individual needs of people, and remembers that its key purpose is to meet those needs and be of benefit and of service for every person served, is more likely to provide relevant and meaningful support to people.

When people lack clarity about what constitutes quality, or when there are conflicting opinions about quality and how to pursue quality in service provision, then it is less likely that a service of excellent quality will be achieved.

Quality derives from people rather than organisations. Those individuals who hold leadership roles within any human service striving for excellent service quality must therefore be deeply committed to the people who the organisation serves. They must be able to motivate, draw upon and blend the talents

and energies of both the people who are served and those who are serving.

The values base of a service provides the starting point for measuring quality in service provision. The values of a service should be identified and described, and put into practice. The practice of a service rests upon these values and will guide the quality of service delivery, which can best be assessed by asking the question: do the people we serve derive benefit from our efforts?

In the words of Anne Cross from an article in Issue 12 of *CRUCIAL Times*: 'The quest for quality must focus on better lives, and not just on better processes.'

PEACE!
Mike Duggan

'He's more than just a service user, you know'

Marie Knox is an academic in the School of Humanities and Human Services at the Queensland University of Technology. She is also the parent of a young man with significant disabilities. Much of Marie's research and teaching interests are around a rights-focused approach to supporting people with disabilities to live and enjoy a valued lifestyle. In this article, she argues that the critical yet varied roles that families play in fostering the notion of citizenship are a vital element of quality service provision.

The recognition of the need to assure quality services to people with disabilities, currently underway in Queensland, is welcome. The Disability Services Quality System (DSQS) at present being implemented within the disability service sector is aimed at ensuring such service quality for Queenslanders with disabilities using services funded by Disability Services Queensland. A key feature of this system is the use of ten Disability Service Standards against which service quality is assessed and monitored.

Other states across Australia have similar systems in place to maximise service quality. These initiatives are, indeed, to be commended. Nobody would want to return to the days of poor quality services that were the plight of too many people with disabilities in the not-so-distant past.

However, the quality system and service standards must not be considered ends in themselves, but rather as means to an end – that end being a lifestyle led by the person with disabilities that extends beyond the service sector, a lifestyle as a contributing member of the wider society in which they live. Hence it follows, as the words of the parent at the

beginning of this piece clearly articulate, that the role or identity of people with disabilities must extend beyond that of a service user to that of a citizen. People with disabilities who use services are first and foremost citizens.

Much has been written about the notion of citizenship, and it is, indeed, a topic generating much debate. However, the essence of citizenship seems to comprise a person being integral to their community; a person who both is valued and respected, and feels valued and respected within their community; a person whose inherent dignity as a human being is upheld; and a person whose uniqueness is not only recognised but is also considered a valuable contribution to a rich and dynamic societal fabric. It is these qualities that move a person from service user to citizen.

It is in this shifting from the notion of service user to a broader conceptualisation of the person who uses the service as a citizen where families can and do play a vital role. Despite the best intentions and efforts of individual services and individuals within these services, service systems by their very nature can reinforce the notion of 'special-ness' and 'separateness' of people with disabilities and thus detract from the

broader notion of their citizenship. People with disabilities within the service sector are seen essentially as service users.

I would like to share some perhaps whimsical thoughts on the various roles played by families in the broadening of the relatively narrow role of service user to that of citizen. These thoughts have, in the main, been formulated from my own reflections of learnings from, and indeed, struggles with my own family experiences.

Families as Connectors and Sources of Connectedness

The vast majority of families do not see their family member with disabilities as service users but rather as valued and valuable members of the family. They belong in the family, whether or not they live with the family or apart from the family. The sense of belonging is central.

In this vein, many families challenge the simplistic notion of their family member with disabilities as a burden. Rather, their family member with disabilities is an integral member of the family and plays a pivotal role within the family. This of course, is not to deny the challenges and stresses that are often present. However, these are balanced against the strong affection or deep love that typifies this relationship. Within the family, the person with disabilities is a person who is very much loved and valued, and who belongs and contributes to the family. Indeed, many families acknowledge one of the greatest contributions that their family member with disabilities has made is the transformation in their own lives. The development of a greater understanding of diversity, marginalisation and the like that has added substantially to their lives.

Families as Advocates

Families are great allies in confronting the barriers that inhibit the person with disabilities being an integral community member, barriers that in effect inhibit his or her opportunities to exercise their citizen rights. They advocate strongly with their family member with disabilities for these rights to be respected and upheld. Families, in general, are one of the most effective advocates for their family members, and often play a pivotal role in fostering and maintaining family and community connections for their family member. It is these connections, beyond the service sector, that play an important part in extending beyond the role of service user

to a person who belongs, is valued and respected within a range of networks beyond that of the service sector.

Moreover, within an increasing risk management culture within service provision, opportunities for community participation and to undertake roles beyond that of a service user may be, and increasingly are, compromised. Families are in an excellent position to be able to pose the questions 'What is the risk for the person of **not** participating?' 'What is the risk for the person of **not** having opportunities to be an integral, valued and participating citizen?' They may well argue that their family member with disabilities is entitled, as a citizen, to the natural or ordinary supports that all people in the community need and utilise - along with the inherent 'risks' that might be involved. In effect, they challenge the role of services to move beyond an all encompassing role to one of complementing or 'topping up' the natural or ordinary community supports that all citizens enjoy.

Families as Activists

Thirdly, families of people with disabilities also play a significant role in addressing the oppression and marginalisation of the broader population of people with disabilities. The history of disability services points clearly to the strength and effectiveness of family collective action in ensuring the well-being of people with disabilities. Families have been and continue to be a powerful political voice in ensuring the rights of people with disabilities extend beyond those of a service user to those of citizenship.

Finally, it is important for families to be proud of and to marshal the deep affection that drives them to ensure that the rights of their family member with disabilities are upheld. They must be proud of the affection that they have for their family member and recognise it as a significant contributor to their passion in challenging the marginalisation not only of their individual family member, but also that of the wider population of people with disabilities. They should be proud of being 'too emotional'.

It is this passion that drives their advocacy for ensuring that people with disabilities are seen not simply as people who use services in some areas of life, but more importantly as people who have a right to enjoy and celebrate their citizenship.

Holding on to What Makes Community Organisations Different

Ann-Marie O'Brien describes herself as someone who works in a community organisation rather than a non-government organisation. She views the acronym NGO as defining community organisations by what they are not (non-government) rather than what they are: independent co-operative entities with identities defined by the communities in which they belong. Ann-Marie discusses how community organisations, by reflecting on a set of alternative quality standards, can re-affirm their own identity and reinforce that which makes them different – their values and beliefs about the contribution community organisations can bring to creating a just and inclusive community.

The recent introduction of a Disability Services Quality System for Disability Services Queensland (DSQ) challenges community organisations which support people with a disability to consider whether the quality standards designed for the government and business sectors can and should be applied to community sector organisations. This is not to suggest that the Disability Services Standards being introduced are a bad thing. Community organisations must of course strive to ensure that they meet a set of funding, licensing and legislative standards in the way they operate, while acknowledging that community organisations hold unique and different notions of quality.

The following list of ten standards for community organisations could be a starting-point for a discussion about how to define 'quality' for community organisations. Of course it is highly likely that some of these standards would appear too nebulous for an accreditation process and too difficult to measure (and therefore not considered of value). This, however, does not make them any less real or important. They are at the core of who we are and what we do, and represent the core elements of person-centred, community-connected, authentic, community organisations.

Standard 1

The community organisation has a strong identity and clear direction that is independent from legislative and funding directions.

The organisation understands clearly their reason for existing and alters its direction in line with the goals and dreams of the people it supports, not government policy. The community organisation accounts firstly to the people it supports and then to other stakeholders, including government.

Standard 2

The community organisation has a set of values that guides its development.

These values are known and shared by everyone in the organisation and are referred to

in all decision-making. These values have been tested by time and collective community wisdom and do not alter. While the organisation may accept government funding to assist in the delivery of its services, it is prepared to reject government funding, if required, to stay true to its vision and values.

Standard 3

The community organisation delivers a quality service through its commitment to people rather than policy or procedure.

The organisation actively seeks out quality staff and members who share the vision and values of the organisation and who wish to make a difference in this world, and then nurtures them in a climate of support and creativity. It rejects the notion that policy and procedure can guide the wrong people to do the right thing.

Standard 4

The community organisation has a servant-leadership model where leadership is based on a conscious choice to serve others.

Leaders in the organisation are first and foremost there to provide service to people who use the service and those who work for the organisation. Leaders accept and recognise others for their unique gifts and seek to draw out, inspire and develop the best within others. The organisation values leadership qualities over management skill.

Standard 5

The community organisation balances leadership with good management practices.

The organisation never loses sight of its core service nor allows 'red tape' to distract from the core service. It seeks to develop organisational capacity to be flexible and responsive to the changing goals and circumstances of the people it serves, while staying financially viable.

Standard 6

The community organisation is committed to right relationships with all people

The community organisation is first and foremost a community of people who share their lives with

each other and as such, seek to treat each other kindly, fairly and justly.

Standard 7

The community organisation encourages voluntary action from within the organisation and from the wider community.

Unlike business and government, community organisations foster an atmosphere of freely-given time and energy to reach beyond and achieve more than funding will pay for. The agenda of a community organisation extends far beyond a particular service or program. It extends out to creating a better community and a better world.

Standard 8

The community organisation works for the common good of the society where citizens participate and are connected.

The community organisation seeks to build social capital – trust, reciprocity and networks between individuals or groups in the community.

Standard 9

The community organisation values personal integrity among its members.

Living within the community that is serviced by the community organisation, members and staff 'walk the talk' of community connectedness and right relationships in their own lives. Living according to these values becomes more than a

nine-to-five job, as those who are served by the organisation share a common community life with those who serve.

Standard 10

The community organisation works collaboratively with other organisations in the community sector, as well as with others in the business and government sectors.

Unlike a business, a community organisation rejects concepts of 'healthy competition' or 'marketplace-driven agenda' and works collaboratively with other community organisations towards a higher agenda of inclusive and responsive communities. The community organisation is committed to supporting and sharing resources with other members of the community who are working to address need.

The journey of clarifying who we are, why we exist, and why we need to hold on to what makes us different is as important as any destination we might reach. If the vast majority of DSQ-funded services gain accreditation under the Quality System, will individuals with a disability and family members find all support services to be the same? Or will some stand out as being different? And if they do stand out, will it be because they are struggling to deliver an alternative version of quality?

What is Involved in Delivering a Quality Service for People with a Disability from an Advocacy Perspective

Josey McMahon works with great passion and commitment in her dual role as manager and advocate at a small community-based independent advocacy agency that provides individual social advocacy on behalf of vulnerable people with a disability. In this article, Josey discusses the role of advocacy in safeguarding the lives of vulnerable people with a disability and the importance of providing both relevant and potent service provision to those who are disadvantaged and viewed differently by society.

Many service providers and governments place great faith in the belief that a quality system will assure that human service organisations will provide those they serve with a 'quality' service. Similarly, many people with a disability and families place great faith in the belief that resources and funding will provide them with a 'quality' service. As an advocate I sometimes hear that families believe that a funding package will make all the difference to their family member and themselves and that life will be improved. Yet, receiving a funding package

does not guarantee that a person's needs will be met.

There are many factors which determine if a service supports people well. One of these factors is having people involved with the service, both in positions of leadership and in providing support to people who use the service, who are passionate about what they do, who have a genuine desire to do good on behalf of people rather than do harm and are people with values that are, at the very least, based on social justice principles. Another factor is having

people involved who are external to the service and who are encouraged and welcomed by service providers to participate in assuring that the service meets the needs of the people served. This can occur in many ways. One important way this can occur is when people act as independent advocates on behalf of people who use the service. Advocacy can be an important safeguard for ensuring that service provision is relevant to each person's individual needs.

As an advocate I hear many stories about how services might not provide support to a person which meets their needs. Recently, I heard a story from a parent whose family member was receiving support from a service that was 'quality assured'. The parent advised that they had gone to the home of their family member to find that their adult child, who was totally dependent on the service for all aspects of their personal care, had not received the appropriate care. In fact, the parent reported, had they not gone to the home at the time when they did, they felt their family member most probably would have died. The service provider had ticked all the boxes on the paperwork, indicating that the necessary procedures had been appropriately carried out; however, the reality of what had occurred was quite the opposite. The parent was fearful about confronting the service and raising a complaint, as the service provider might either withdraw support, or reprimand them or their family member in some way. The parent was well aware that the service concerned had previously tried 'exiting' their family member on the basis that the person's needs were too complex and they should be placed in a nursing home.

Strong independent advocacy was needed in this situation. Independent advocacy is based upon taking positive, ethical action on behalf of the sincerely-perceived needs of the vulnerable person with a disability and being on their side and their side only. It is about being autonomous and independent of the service system and acting with minimal conflict of interest and continually focusing on the fundamental needs, welfare, interests, and human rights of the person with a disability. It is done with vigour and with a sense of urgency and remains loyal and accountable to the person over the long term. At times, advocacy can be costly to the person advocating or to the advocacy agency. This is because it challenges the dominant paradigm: the often poor practice in which people with a disability are viewed

negatively and therefore treated with contempt and as second class citizens.

When people have no family relationships, few or no friends and are totally reliant on support from a service, independent advocacy is particularly important. In these kinds of situations, people are very vulnerable and harmful things are more likely to happen to them. Vulnerable people with no voice, choice or influence over how they live their lives need independent advocacy as a protective safeguard.

When a vulnerable person with a disability has an advocate in his or her life, the person is more likely to be treated with dignity and respect. A prime example of this is when a person with a disability is admitted to hospital. As a patient, the person is reliant on the staff for all aspects of their personal care needs, often however, the hospital staff is more likely to treat a person with a disability with little dignity and respect, particularly when the person is unable to communicate their needs. However, I have noticed that if an advocate visits, bringing flowers or personal items for the person, then hospital staff will improve the way they treat the person.

Often it may only be an advocate who has a positive vision and holds expectations on behalf of the vulnerable person with a disability.

If there is no positive vision for the person then it will be very difficult for the person with a disability to plan and achieve a positive future. To begin to build a vision of a good life for the person, it is vital to get to know the person well and to engage in real conversation with them, and with any family and friends still in their lives. For an advocate to provide potent advocacy they need to build a strong relationship with the person and know the person well. This is an important element in the advocacy practice.

If the person's support needs are such that they are unable to be involved in designing their support, then their significant others should be encouraged to do so. This is a legitimate advocacy role for the family and, if the person has no family, a legitimate role for an advocate. Natural unpaid relationships with family and friends provide a sense of belonging, acceptance and security and can never be replaced by paid support services.

Distinguishing Quality

Lionel Evans is a parent of three children and is involved with a number of parent-based community groups both locally and state-wide. In this piece, Lionel considers how having a quality system does not mean that quality can be guaranteed.

Across Queensland, disability service providers are hectically attempting to comply with the state government's agenda of establishing a uniform quality measurement system throughout the sector. Designated people sit in offices scanning glossy documents and preparing strategies, which they hope will meet all the new requirements. Checklists and procedures are being keyed into computers and reams of paper are being projected out of printers in order to provide documents for proof of compliance. So while this flurry of activity rolls across the state, we can ask the question: What does 'quality' actually mean?

The term 'quality' has been defined variously as:

- 1) a distinguishing characteristic, property or attribute
- 2) the basic character or nature of something
- 3) a trait or feature of personality
- 4) a degree or standard of excellence, especially a high standard

So then, how is the characteristic, attribute, nature or trait of excellence that denotes something as having 'quality' decided? Quality is usually measured against a set of key criteria, which are often compiled into a checklist to be ticked or crossed. A tick in the box means that the component meets the key criteria and is deemed worthy of having its status of being a 'quality' item awarded. While a cross in the box shows that the item does not meet the required standard of 'quality'.

Does such a checklist establish quality? A checklist for a car for example could consist of:

- Making sure it had four wheels on the road and a spare in the boot;
- That it has an engine attached firmly to some form of transmission device that transfers power from the engine to said wheels;
- A steering wheel connected to an approved steering mechanism;
- A place to sit while driving;
- An arrangement of gauges to determine the car's speed and one to inform you about the amount of fuel in the tank is handy.

But how effective is this list in distinguishing between the quality of any two cars? Does this checklist tell me whether one car is of a better quality than the other? All the boxes for both cars would be ticked because they both have wheels, an engine, transmission, steering wheel, seats and gauges. Yet, this monitoring checklist has failed to establish the difference in the actual level of quality between the two cars.

Quality must therefore have a slippery nature, or possess an attribute that makes it hard to define. What has entered into our example of a car checklist is a thing called a 'variable'.

Variables are established by people working from perspectives which have specific meaning to them. Variables also occur in things like being able to perform tasks within predetermined times. For example, one person might consider it very important to arrive on time for an appointment, but for another person, punctuality may be less important. The variable in this case is the importance of punctuality to the two parties.

Without knowing the particular variables in the circumstances of a person with disabilities and their family, it might be that false assumptions are made about what is needed for that person and the family. In such instances a service provider may not recognise what would assist the person and may establish a service for the person which would not be a quality service for the person. Here is a scenario to examine - a service worker arrives late morning at the home of a person with disabilities to discover that the family are still in their pyjamas. Without asking why this is so, the service worker would not discover important information which could have an impact upon the kind of service the worker would provide for the person on that day and perhaps in the future.

If the service worker had asked, they would have found out that the person with a disability had had a medical emergency in the middle of the night and as a result, the family had spent most of the night at the emergency room of the local hospital, only returning home in the early hours of the morning. Exhausted, they had all gone back to bed and so, were late getting up

that morning. Without this knowledge, the service worker could have even made a negative judgement about the competence of the family to provide adequate care. What is important to remember about this example is that a quality assurance system may not capture the factors of quality which are truly relevant in a person's life. While quality assurance may be able to measure compliance

with a checklist, there are factors involved with providing care that it cannot measure. How does a quality system distinguish the amount of love and care that exists within a family home? But then again how can a 'quality' such as love and a 'quality' such as care get measured against a sterile checklist contained within a quality assurance system?

Can Person-Centred Planning Help People into Valued Roles and Real Belonging?

John O'Brien discusses some limitations in the contribution that person-centred planning has made so far to the desired quality of people's lives. John considers ways to counter these limitations and invest in positive efforts which could assist to achieve a good life for the people served. This article is a short, edited extract from a recent, unpublished article Moving Past the Limits in Person-Centred Planning. John O'Brien has extensive experience in developing person-centred plans which provide innovative, flexible and appropriate responses to enable the person to live a full, rich and varied ordinary life.

A recent evaluation of person-centred planning efforts in England showed that person-centred plans, while strongly associated with positive changes in people's experience of choice, their contact with family and friends, and their participation in community activities, did not significantly improve the likelihood of a person getting a job or developing friendships and relationships. As social inclusion and access to work are however promoted as key outcomes for person-centred planning, the failure to achieve these outcomes represents significant limitations in the contribution that person-centred planning has made so far to the desired quality of people's lives.

These limitations share two common features: they call on people with disabilities to cross the social boundaries that separate people with disabilities from typical settings and ordinary relationships and take up the socially valued roles of worker, member, and friend; and they call on those responsible for designing and delivering assistance to move from working within the familiar terrain marked by the borders of human services to the less familiar and less 'control-able' territory of typical work and ordinary social life.

There are many reasons why person-centred planning may not commonly inspire the journey into valued social roles and indicate the path that people with disabilities and their assistants can take to inhabit them. Moving past these limits requires two kinds of effort: systematic

effort to remove service-imposed constraints on people forming new relationships and taking up new roles; and learning ways that the person-centred planning process can mobilise more courageous and creative action.

Constraints on inclusive roles and relationships may result because government policies are often incoherent. Many human services are not designed to provide tailored support to people in valued roles in ordinary settings. Instead, they are frequently designed as machine-bureaucracies whose products are the physical care, supervision, or instruction of people in groups and whose processes churn on regardless. Existing supported employment services are often unable and unwilling to assist people with substantial impairments to find jobs that match their interests, for example. Human services with this mindset often perceive ordinary people and workplaces as unwelcoming to people with disabilities if not downright dangerous to them; any risk-taking seems unthinkable. When settings and people outside of a service are unknown before the person engages with them, it's easy to inflate the dangers of moving beyond a familiar routine and thus confirm the so-called benefits of remaining within familiar settings and roles. Uncertainty about the possibility of success in building a more inclusive social network or taking a job can lead people to leave these good things off their list of chosen goals or even to explicitly choose not to pursue them.

The number of people who have good jobs and more inclusive social networks will increase when the human service system operates in ways which reduce the constraints that people experience, such as incoherent policies, services that congregate people, inflexible patterns of assistance, and demoralising habits of social exclusion. Similarly, the significant limitations in the contribution that person-centred planning has made so far to the desired quality of people's lives strengthen the case for changes and should motivate those who facilitate person-centred planning to add their energies to those of other advocates for a straighter, simpler way to positive roles, relationships and community inclusion.

Concerns for safety, health and privacy, and procedures for risk management have slipped their mooring to commonsense and float aimlessly in many people's lives, blocking the channels to full community life. Responsible person-centred planning identifies people's vulnerabilities and designs intelligent responses to them, but the larger context of action needs to shift from attempts to bureaucratically protect every detail of people's lives to a search for ways to offer people the dignity of risk.

Individual budgets allow people to exercise effective control over their support and accord people the dignity of responsibility for deciding how to make the best use of their funds and increase the flexibility with which people can focus their paid assistance on helping them occupy roles that matter to them.

The desire to experience a good life in a society and system that aspires to inclusion but too often operates to produce segregation sharpens the life-question that person-centred planning wants to help people explore. Reducing the constraints on finding a way to valued roles and relationships reduces the drag on a person's life, but it leaves a central question pending: What particular conditions allow this unique person to show up in ordinary life as a contributing citizen and a valued friend?

The way to an answer to this question is not as ponderous as it seems. In fact, approached competently, there can be both enjoyment and power in pursuing it. Enjoyment flows from the camaraderie that grows as people work hard to honestly explore important matters together, even when those matters have painful, frightening or angry aspects. Power comes from the alignment of energy that results when a

group of people generate clarity about possibilities that embody their highest purposes.

There are several reasonable approaches to person-centred planning, and each is as capable of liberating the power that comes from faithful exploration of the central question as it is of slipping off into debate about less vital and less powerful questions. The differences among approaches lie chiefly in the sort of information people will attend to as they seek the clarity that demands positive action. In one approach, a group may look attentively at the person's preferred ways of making their way through life's routines, or in another, they may seek aesthetic expression of a person's identity and highest possible future. They may carefully work their way through a person's history or, they may draw an arrow to the heart of a hopeful goal. In yet another approach, they may listen to a person's dreams for the seeds that can grow into a contributing life.

Whether a plan leads to positive action or not depends on the ways that four kinds of knowledge come together: knowledge of the person's gifts, capacities, and dreams; knowledge of what values the person wants to steer her or his life by; knowledge of the possibilities for supporting the person's participation and contribution through such strategies as arranging adjustments to the physical or social environment, using adaptive equipment, offering systematic instruction, and providing tailored personal assistance; and knowledge of community opportunities.

How these different sorts of knowledge emerge, shape and blend with each other to generate positive action depends on how well the planners can create positive answers to at least six questions.

- Does the person at the centre accept the invitation to plan?
- Do the people who gather to plan come with an open attitude to a different future for themselves?
- Does the group have sufficient leadership to face the hard work necessary to achieve the clarity that demands action?
- Does the group include people with some awareness of the possibilities for individually tailored supports?
- Does the group include people who want the person at the centre to experience the good things that come from valued social roles and an expanding social network?

- Does the group include people with some awareness of community opportunities?

These six questions remain alive from the moment the idea of planning comes up until action toward new possibilities produces new experiences. One way to improve the chances that person-centred planning will lead to positive action is to complement efforts to refine the various approaches with a search for fruitful ways to understanding the process of generating new possibilities. This search for an understanding of social creativity raises an important question. Will we find what we desire

by proceeding in a straight line from where we are, taking our direction from our past and doing more of what we are already doing? Or do we invest time and energy in moving beneath the surface of our current understanding of the person and the possibilities for action in order to produce what we desire? – a substantially greater number of people succeeding in work roles and enjoying a widening social network.

The full text of this article and references are available upon request. Please contact CRU for further details.

THE ONGOING SEARCH FOR A GOOD LIFE

David Bowling is a consultant quality auditor with funded services in Queensland. David is also involved with a citizen advocacy program and is involved as a volunteer with grass-roots primary health-care projects in rural India. In this story, David relates a personal journey to re-connect with a family member after many years. This story tells us much about the importance of relationships and connections with community in the lives of people with disabilities and in particular for people who have lost the connection to family.

In 1960 as a young boy I said goodbye to my eighteen-year-old cousin Peter as he set off by sea with his parents in search of a better life. He and his parents undertook this journey in desperation after Peter had been offered only one option for living the rest of his life: permanent admission to a notorious institution thirty-five kilometres from his home. In the early 60s this was the only option offered to many families. My aunt and uncle decided to follow up a referral to an overseas doctor who 'works with children like your son' and set off on their journey with Peter.

Peter was soon offered the opportunity to join a small farming community in its early pioneering phase. He moved into the farmhouse of the 180-acre farm with the farm manager and his wife and fifteen other early community members. My aunt stayed in the community for the first six months with Peter.

Peter lived on the farm for nearly fifteen years but, then, contact with his family in Australia was lost and Peter's life took a dramatic turn. The community was unable to continue to support Peter and he spent the next twenty-two years in a local psychiatric hospital. During this period of institutional living, Peter lost most of the skills he had developed on the farm.

Over three years ago, Peter's next of kin advised me that he felt family contact with Peter would probably be detrimental to his well-being.

I could not reconcile this with the personal stories I had heard of people placed in institutional care as children who, after many years, were able to be reunited with their families. I felt intuitively that I should try to find Peter and so I wrote to the community where Peter had first lived to find out if they could tell me how to contact him. Three days later, I received a faxed reply, telling me how to contact him. Ten years ago, Peter had moved into a group home where he currently lives with four other men of similar age. Two weeks later, I received a long hand-written letter giving me a detailed account of the time that Peter had lived within this community. Over the next three years I developed regular written contact with Peter and finally visited in early 2006.

I had not expected to receive a prompt hand-written reply giving a detailed first hand account of my cousin's life from the service so many years after he had lived there. This letter and subsequent conversations with some of the people who had lived with Peter revealed to me that this had been a real community, in which people developed relationships and friendships which were long-lasting and meaningful. Some of the people I later met when I visited the community shared stories of the time when Peter had lived with them; they spoke about Peter's strengths and gifts. One couple spoke about how the community had been based on the belief that all members of the community were working together to develop the farm and

that everyone brought their different gifts to the task of building community. It was deeply moving and demonstrates what can happen when people make life-long commitments to help create a good life for people with disabilities.

Peter is now supported by a small support service and lives in a house near the centre of his town that is outwardly the same as the other homes in the street. His bedroom is decorated in his choice of colours and furnishings and he shares the house with four other men in their 50s and 60s. Until recently, he walked three days a week to a nearby day centre, but as he has serious health challenges he now prefers to go there in a minibus. He assists with the day-to-day tasks of running the household and has learnt some new skills, like ironing his own clothes. Once a year Peter chooses where he wants to go on holiday (with two support workers) and as he has had a lifelong interest in cars, his support workers hire the vehicle of his choice for his holiday. In the last two years he has spent his holidays at a five-star hotel and on a remote island. A weekly visit at home by a masseur helps with some of the aches and pains of arthritis. While his basic needs are met and he appears to co-exist with the other men in the group home, it is evident that his deeper needs and aspirations are neglected and he still yearns to return to the farming community of which he has many positive memories.

While Peter's present life is an improvement on the twenty years spent in an institution, little effort has been made to establish and develop Peter's skills and capacities and his support workers have no knowledge of his childhood, his adolescence, how he came to be in that country or his history prior to the institution.

In 2006 I visited the farm community in which Peter had lived upon arrival in the country. As I was leaving the community I was given a gift, a beautiful sterling silver ring set with a polished moss agate. Peter had spent a year working with a jeweller who came to work in the community and had shown great aptitude for working with precious metals and stones. The jeweller said Peter learnt more in a year than most apprentices learn in four years. Peter had crafted this ring and given it to a person on the farm community.

Forty years later I had been given this ring to take back to Australia to give to Peter's sister

who had had no contact with her brother since the early 1970s. This object of real beauty, crafted many years before by her brother, reminds us that we all have different gifts. While Peter had lost his connection to family, he had found a community where his gifts had been recognised, nurtured and had found expression. Peter's sister recently visited him and stayed with him for a week, re-establishing a family connection. Her visit also established elements for the first time of who Peter is, as she shared many of the stories that are part of Peter's life story with his support workers.

So what did I learn about quality and the search for a good life? Quality derives essentially from the inner intention of those who seek to serve others, not from any external structures like quality standards, policies, procedures, mission statements or strategic plans. It arises when the isolating thought of 'them and us' disappears. It is won through great effort and persistent struggle over many years and it can easily disappear. It is grounded on relationships of genuine respect and it can flourish when people are working to build community, rather than run a service.

The challenge of regaining some of the essential elements of a good life for Peter continues. His support workers now have a much better understanding of the capabilities he demonstrated as a young man and I hope to see that Peter is supported to participate in some of his previous interests and hobbies. As a result of the contact with family, Peter now has an independent, local, paid advocate who has been advocating for Peter on a range of issues and to ensure he is not moved into a more restrictive setting as he approaches sixty-five years of age in poor health. He has also advocated strongly for Peter to continue to access an age-appropriate day program. It is perhaps too early to tell if the contact with family members has resulted in other obvious improvements to his quality of life.

Not only has my own life been enriched through my ongoing contact with Peter, but also other family members have acknowledged their own deep familial connection with Peter, and are committed to re-building a relationship with him. As we seek to deepen our relationship with Peter we are challenged to reflect on what is a good life for him and how we might contribute to this life from the other side of the world.