CRUCIAL TIMES

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

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

Editorial

Person-Centred Approaches: Pursuing the Means to an End

Jane Sherwin

The large injection of funds that was announced in the recent state budget could be good news for many in the disability sector in Queensland. However it will also challenge the system's capacity to offer personalised responses to the many individuals who receive funding. More money may actually cement routinised menu-driven ways of serving people. This edition of CRUcial Times explores a counter to these inflexible service orientations through the explication of personalised approaches to support.

Personalised approaches are not new, nor are they unique to the disability sector. For example, in the 1940's, the field of clinical psychology and counselling embraced personalised approaches through the work of Carl Rogers. These approaches, which have relevance to responses to people with disabilities today, are underpinned by the assumption that individuals can grow and develop in terms of managing their own lives. They assume an inherent desire in all individuals to reach their full potential.

Within the disability sector the development of the theories of Normalisation and Social Role Valorisation provided people with systematic ways of understanding the impact of services, especially those that relied on congregation and segregation, on the lives of people with disabilities. As consciousness of the limits of many models of service grew, so too did the desire to respond in different ways that would lead to people with disabilities having access to the ordinary and valued things in life and that would change society's perception of people.

An additional compelling force in the adoption of personalised approaches has originated in the people most affected by human services: the individual with a disability and their family. It has been fuelled by people's desire to retain control of their own lives and to solve their own problems. Many of the articles in this edition of CRUcial Times explore the deeper nature of the relationship between the parties in a helping relationship. They speak to the ethic of person-centred*ness* which brings a stance to the relationship that is both humbling and focusing. As these writers acknowledge, person-centredness is not merely the application of certain knowledge and skills, nor the use of clever techniques and tools; it is a journey of the heart and spirit.

This journey calls forth certain personal qualities. Person-centredness rests on unconditional positive regard and empathic understanding. It is therefore incumbent on the paid worker to bring genuineness to the relationship, rather than a distant professional façade. A parallel belief is that the self-regard and autonomy experienced by the individual and the family should be protected in helping relationships. Another important quality is the paid worker's commitment to humility and an abdication of the pursuit of control or authority over other people, in favour of sharing power and control.

Person-centredness is facilitated in a number of ways. For example, the structure of the human service can encourage a more personalised response by limiting the number of layers between those who are served and the organisational decision makers. The use of conditional delegated authority makes it possible for a service to meet its accountability requirements to a funder, while still transferring significant levels of power to individuals and families, within pre-negotiated parameters.

The nature of the employment arrangement between the individual and the worker can also facilitate a person-centred focus. For example, when the person or family is in an employing role, then it is more likely that the person with a disability and their family remains the focal point of all support arrangements. Who makes decisions will also influence the degree of person-centred focus.

CRU's MISSION STATEMENT

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

Editorial Cont

The family or person being served may have responsibility for a range of decisions, from guiding and influencing the direct support arrangements to deciding the direction of the entire service. These types of arrangements can be contrasted with the experiences of many individuals with disabilities and families who are actually excluded by service processes, despite rhetoric of 'respect and dignity'. Major decisions about how the service is delivered and the direction of the service can bar the participation of individuals and families in their own particular service arrangements. High levels of bureaucracy, a reliance on paperwork and the use of exclusionary language – especially acronyms and words peculiar to service-land – also result in the rejection of the people the service is intended to serve. The experience of the excluded individual or family is one of helplessness and disempowerment. Even if it is *their* life that is being discussed and coordinated, it becomes owned by the service and ultimately the service system. Individuals and families become disqualified from shaping their support arrangements and influencing the direction of their own lives.

> *Person-centred approaches require that services truly appreciate the real identity of each individual, that resources are utilised in flexible ways, that forms of assistance are personalised in community settings and that they are committed to evolving the relationship with the individual and the family as circumstances change.*

The lack of person-centred approaches can be reflected in the failure to recognise limitations of the system in meeting people's needs. This can lead not only to a misinterpretation of the service recipient's needs, but also the needs of the staff. For example, one service that identifies 'staff communication skills' as its key training need allows staff a mere twenty minutes to assess and deal with the needs of people with intellectual disabilities. Similarly another service claiming a person-centred approach rotates different staff through people's homes once every two weeks 'to ensure clients do not become dependent upon staff'. These are system responses that prevent personalised approaches.

Working in a person-centred or family-centred way is a way of working from the ground up, not from the top down. This challenges the service to not rely on recipes. This can feel like working in ambiguity in an absence of certainty and black-and-white answers. It negates the possibility of *one* service model, or easy steps, or a check-list for service responses. It means letting go of the certainty of being right, or the comfort of well-trodden paths. Therefore workers should not try to find, for example, a list of workplaces that employ people with disability or clubs that include people with disabilities. For example, one worker revealed to us that she had never met any of the people she had been assigned to, and had no idea what their interests were 'but if I can get a list of workplaces, then I can slot people in'. Person-centredness requires starting with the person, not the service. It means starting with what is desirable for the person and their family, not with what is currently available or possible for the service.

Responding in a person- or family-centred way is more challenging for a service than offering a fixed menu of responses. For example, from a service point of view, running an institution is much easier than responding to a range of people in multitudinous ways. There is a fixed environment, and a fixed number of staff with fixed shift arrangements and with fixed things to do. Likewise, minimising the participation of service recipients in the running of a service creates the illusion of harmony and predictability. In the current service environment other agendas, such as economic efficiency, ease and industrial matters take priority and trump the interests of the individual.

Personalised approaches are a counter to such technocracy. They are a counter to professionalism and the expert model, although the skills of the paid professional are still important. Person-centred approaches require that services truly appreciate the real identity of each individual, that resources are utilised in flexible ways, that forms of assistance are personalised in community settings and that they are committed to evolving the relationship with the individual and the family as circumstances change. Central to all of these is negotiation of the relationship between server and served, and of the ways that a good life will be pursued. Personalised approaches also require that each individual has access to social resources: unpaid relationships, membership of community through valued roles, influence over their own lives, and the presence of a range of people committed to understanding the person's well-being. Person-centred approaches are a means, not an end: a rich and meaningful life in the community is the desirable outcome.

** Article references are available upon request – please contact the editor for details.*

From the President

Mike Duggan

It is relatively easy to claim a person-centred approach to the people that are served. Many people believe that being person- or family-centred is about the nature of their everyday interactions with people. For example, there is a great deal of attention paid to language used to address people, and to according people respect. Whilst these are important elements, true person-centredness goes beneath the surface of these interactions to the heart of the relationship. It is about who is placed at the centre of each interaction and who is placed at the margins. In other words it is about asking 'in whose interest' that something is really being done. There is a substantial paradigm shift in the concepts of power and control. People are no longer being 'done to' by the expert approach, but instead become the centre – the heart – of the service they receive.

It is entirely possible that at a surface level people might treat each other with genuine respect, but at the heart level of the relationship one person exerts power over the other. This is fundamentally where person-centred practice risks being misinterpreted. Professionals may interact in a manner that might be seen to be respectful or pleasant or even friendly, yet their work may actually be driven by much deeper concern over agency issues, program issues or even self-interest, such as the need to feel good or to be viewed positively by those around them, rather than being solely driven by the welfare of those whom they are supposed to be serving.

As the articles in this edition of CRUcial Times demonstrate, person-centredness is based on trust that emulates from a deep understanding of each person or family in the relationship. This deep understanding of the person does not occur overnight. Usually our deepest or most meaningful relationships develop over many months or years of getting to know each other. This is not only in an intimate sense but even our friendships and meaningful acquaintances may develop this way. It may even develop with one's motor mechanic!

It is this deep understanding which enables us to see what a person values in life and what is unimportant, to imagine what someone might need in life to make it rewarding and satisfying, and to appreciate what is missing in the other person's life and how it might be fulfilled. Person-centredness requires us to imagine a different version of 'service' that is not simply about being nice or being friendly or according respect. It is about locating people in the centre of our relationships and listening to them differently and deeply. Subsequently, the *service* ultimately becomes more accountable to those it serves.

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Being at the Centre of My Life

Lisa Lehmann

Lisa Lehmann is a young woman who lives and works on the Sunshine Coast, with many connections in her local and wider community. Lisa seeks to be a change agent in people's lives. Lisa also has a physical disability.

I thought I was in control of my life once and I was for a while. I utilised a service known for its high standard of person-centredness for about five years. However a change of management and the subsequent erosion of organisational values led to deterioration of the delivery of service.

The illusion of person-centredness persisted in that all written material continued to state that I was the employer and I was still encouraged to think I was in control. However I discovered that the managers and staff of the service I was using were having meetings about me without me. The tasks that I instructed the workers to do were ignored. Workers did what they 'thought' I needed to have done. As a result my health suffered because things were left not tended to despite numerous requests. Workers went away from my home with preconceived ideas and unfounded perceptions about my life and my friends that were not only none of their business; they were harmful to me and to my friends' reputations.

I exited myself from that service and it was during that process that all my fears were confirmed. The service providers did everything in their power to punish me for my decision and undermine my abilities and to diminish my reputation and confidence. So much for being in control!

I am always keen to learn from the things that do not work or that go wrong. I began thinking: how was I going to use what I was learning? What could I do to bring to my life the kind of supports I actually wanted in a way that allowed me to be me, totally? These questions have led me on an exciting and powerful journey and have made a number of things very clear.

I am the only person at the centre of my world. Anyone who believes they put me at the centre of their thinking has misconceptions about their role in my life. There are too many competing factors. It is impossible to put someone else completely at the centre of one's life, without one's own needs impacting on the other person. The needs of the service also compete with the needs of the individual. The amount of support provided is based on budget formulae, the culture of an organisation and its ability to attract and nurture good people. It is unrealistic to think that I or other people who use such services could be at the centre of things. Too often the needs of the service and staff come to be valued more than the person themselves.

It became clearer to me that the reason I encountered such empty words and inadequate support was because I was being perceived as my disability. My needs were merely related to the needs of my disability. However I am not my disability – I am Lisa first. In reality I simply need some assistance with a few parts of my life. It is not complicated, nor would I want it to be. A significant step in living my life the way I want has been thinking about what I need and want separately from the perception of needs my disability creates, and then breaking these into easily identifiable roles. For example, I need help with my housework so now I employ a cleaner. I found her in the Yellow Pages and she is a professional. She is not employed by any disability service; in fact I am probably the only person with a disability who she cleans for.

Likewise I need help with my personal hygiene; this need also is now met through the employment of professional nursing staff. Both the nurse and the cleaner are very clear about their roles and do not try to take over other aspects of my life. They do not have a need or the opportunity to meet or discuss me – I am not at centre of their existence nor would they ever pretend that I am.

When I contrast this with what I was receiving from my previous 'disability support workers' the picture is dramatically different. They saw their role as overarching my entire life. They did not really want to clean my home, they did not see that as being their role, yet clearly that was what I employed them for, and what I needed and expected from them.

I am grateful for the lessons which have contributed to the way I live my life now. Without these insights I would still be treated, done to, and done for in my own home. I now know the difference between good service and bad has nothing to do with you being at the centre, it is totally based on how much you are valued and respected. I know I have an equally respectful relationship with all the people who play a supporting role in my life. Without this, person-centredness is an empty phrase. I am now back in control of my life, and my destiny is mine once again. This is true person-centredness to me.

PLANNING FOR THE PERSONAL OR PERSONALISING PLANNING?

PETER MILLIER

Peter Millier is currently Senior Trainer with Training and Evaluation for Change Inc in South Australia. He has worked in a variety of human services for over 30 years, including as the Director of Client Services for the Intellectual Disability Services Council in South Australia. In this article Peter identifies and critiques some of the current perversions of person-centredness.

I often wonder what I am going to say when someone knocks on my door, introduces him- or herself as my supports coordinator and offers to assist me to prepare a plan for my future. Will I politely decline the kind offer or be very rude? Will I have a choice of whether to decline or not? Will I say something pithy such as Oscar Wilde might have said, like 'All plans are hazardous, especially those concerning the future' – so, thanks but no thanks? Will I be so much in need of company that I will welcome the person in? Will I be seduced by the language in which the offer is couched? If the person tells me that this is a person-centred plan, will that comfort me?

These and many other thoughts rush through my head when I hear the words such as 'personal', as in Personal Futures Planning, or 'person', as in Person-Centred Planning, or Person-Centred Service. One part of me feels annoyance at the assumption that a person who does not know me well or at all would presume he or she has the authority or the ability to help me plan – or perhaps plan for me – my future. Yet, that is the reality for many people who have a need for support or service. Another part of me acknowledges the benefits of planning and the need to be practical in considering the future and how best to meet ones needs as one grows older and frailer. Yet another part of me – the part that has been involved in the human service arena for many years – recalls the history of service assessment, planning and delivery systems which purport to be personal or person-centred but which are simply the same things dressed in new clothing.

I recall well the era of assessment. When I was doing my clinical psychology training the joke was 'if you cannot do anything else, do an assessment.' Then there was the era of task analysis. Every human action or behaviour was broken down into many steps, analysed backwards and forwards, and implemented in a stepwise chain. The era of planning followed. From the early 1980's onwards there was a plethora of planning and plans. There were GSPs (general service plans), ISPs/IPPs (individual service or program plans), IEPs (individual education plans), IWPs (individual work plans), and IRPs (individual recreation plans). In reality, the plans were not truly individual, as they followed the same protocol and formula as did everyone else's plan; only the names were different. They seemed to be based on assumptions that people with disabilities required a lot of preparation for the life they were never going to get. In other words, people were still imprisoned in the assumptions of service-hood and most would not truly get a life in the same way as the rest of us.

In a recent paper, Michael Kendrick reminds us of the questionable assumptions underpinning so-called personal planning processes. Whilst acknowledging that there may be some merit in 'person-centred service' he urges caution in overstating its claims. He also encourages an examination of underlying assumptions, such as: planning on the basis of what building or amount of money is available; existing service models dressed in new garb; or people actually needing or wanting a formal planning process – 'person-centred' or otherwise. The human needs we all have for love, acceptance, dignity and respect do not change very much. Yet in human services, we often dress up the way we assess, plan and address human needs as though we have discovered some wonderful new thing. We fail to acknowledge that we have been there before in some other guise or disguise. As service providers this re-invention can make us feel better, but the reality does not change much for people with disabilities or their families.

Two assumptions which I consider to be particularly problematic are those concerning relationships and having control of one's life. The evidence, gathered from many sources over many years, is that human services – though necessary and important – do not do very well by the people they serve in either of these areas. Paid relationships are not a real substitute for unpaid ones and indeed, tend to drive out unpaid relationships. Human services tend to manage the lives of the people whom they are paid to serve. Thus, dressing up acts of service in the garb of 'personal' tends to disguise the reality for both the server and the served: that this is still a paid relationship; that the person or service probably does not know the person served very well; and that the worker and service are still in control of the process and the outcomes.

We need to check our assumptions very carefully when we use the word 'personal' in planning and delivering supports to people who are vulnerable. For instance, do we really know the person, their needs and wants well? Do we really have their best interests at heart? Do we make space for hopes, dreams, desires and dreads? Can we imagine more than one future or are our hearts, minds and souls, our very imaginations, seized by the rhetoric and reality of human service land? Do we assume good hearts, good intentions, and good language necessarily lead to better lives?

We also need to be careful not to elevate personal planning and support above other things which are purportedly potent for personal progress. Other 'ingredients' might include such things as high expectations for people, committed advocates, a vision of a good life and a real future, supportive people, and a commitment to the long term.

It is not easy to provide typical homes, education, jobs and recreation for people with a disability. Even though the services and supports may look like the real thing they are not the homes we would want to live in, the schools, jobs or leisure activities we would want to pursue. Just because we call it by the same name does not make it so. Similar cautions should apply to the word 'personal'. When I want to plan for the rest of my life I want to do it with people who love me and know me well, and want to be in my life in the future. I do not want someone to dance briefly into my life, plan for a future they cannot see or do not want to share, and have the temerity to call it personal.

This is not an argument against planning, or the involvement of services. Rather, we should be honest with ourselves, and not pretend that what we offer is more than it actually is. Planning the future is very, very **personal.**

Recapturing a Sense of the Whole

Veronica Brady

Person- or family-centred approaches require us to think about who we are, and how we are as people in the world. Veronica Brady offers the following perspective.

Popular wisdom tells us: 'it's not what you do but how you do it which matters'. Most of us have to work within the present order of things, as social workers or teachers or organisers or as business people. But we can relate to people with sympathy, respect and pleasure, create a climate of trust, understanding and mutual respect.

But how does this affect government, business and financial institutions, social agencies and so on and beyond them the larger movements of the economy and indeed of history? If I am right, in the long run their centre of gravity lies in human consciousness. Their power depends on the assent, willing or enforced, we give to their goals and values. As I have been arguing, by and large these goals and values are out of synch with reality, and this has affected our lives and the life of the planet. Most of us live piece-meal with no over-arching vision of the whole so that the imperatives of one part of life, the economy, 'success', efficiency, technical expertise and so on tend to impose themselves on everything else. But these are only means to limited ends. We need to recapture a sense of the whole, put the details in their place.

So too with our notions of history. If it is the story of the winners then we cannot really affect it, or help its victims. But if the history which matters is the story of the losers, then we can change it. The suffering of one child demands redress. Those who are poor, disabled, oppressed, humiliated or ignored remind us of our real task if life on this planet is to grow and achieve its proper shape in which each human being lives with hope and with dignity and the natural world on which we depend is to flourish. If we enhance the life of one person we have changed the world.

These extracts are taken from 'Out After Dark: Keeping the Fire Going' by Veronica Brady, from the CRU Publication ***Gathering the Wisdom.***

Knowing Us as a Family

Shirley & Ian Prouse

Shirley and Ian Prouse live in Hervey Bay with their three children: Jacob, Kerryn and Leah (aged 13, 8 & 7 years respectively). In their spare time Shirley enjoys ceramics, sewing and gardening, and Ian pursues computing and electronics. In this article, Shirley and Ian describe the characteristics of a family-centred service by reflecting on their experience of Local Area Coordination.

A few years ago we travelled to Brisbane for our daughter Kerryn, who has Down syndrome, to have heart surgery. The five-hour operation went well, however post-operative complications developed. We nearly lost our beautiful daughter a couple of times, but for once her stubbornness worked in our favour.

In the midst of this emotional turmoil, the car broke down. We had the radiator flushed, but soon realised that we needed a new radiator to make the trip home. With all the costs associated with the trip, we could not afford to have the car fixed. Fortunately for us, Kerryn is registered with Local Area Coordination, a program offered by Disability Services Queensland in some regional, rural and remote areas. Ian sent a text message to our Local Area Coordinator in Hervey Bay and within three days our car was fixed and we were able to transport our little girl home safely.

Whilst the access to discretionary funding is very much appreciated, it is certainly not the thing we value most about this program. Our Local Area Coordinator is a great resource for the whole family; she puts us in touch with the people we need to know to ensure Kerryn's needs are met and that we all enjoy a reasonable quality of life.

Some professionals we have come across are very distant or aloof; their professional persona totally masks their humanity. Our Local Area Coordinator is very much a professional and she knows her job well, but she is also very human in her approach to her work. She takes a personal interest in our family and it is obvious to us that she is not simply someone doing a job. Other people come into our home and primarily do things 'to' and 'with' Kerryn. The Local Area Coordinator comes into our home and spends time with all of us. She knows us as a family. Over the last four years we have shared stories, meals, photos, jokes, sorrows, triumphs, and lots of cups of tea.

Initially, we were suspicious about the longevity of Local Area Coordination. We found it hard to believe that a government department could organise assistance to families when they most needed it, and do so relatively quickly without bureaucratic red tape. We were wary of the on-going support that this program promised, however that fear was also unfounded.

High staff turnover in many disability and general health services has often resulted in Kerryn's individual needs not being understood and hence, not met. Kerryn does not trust people easily; it takes a long time for her to get to know someone, and for them to get to know her. Our Local Area Coordinator has known Kerryn and our family for four years. Over that time, we have developed a real relationship: one based on honesty, trust and mutual respect. Together we have identified the needs of both Kerryn and our family and have set goals to ensure those needs are met now and in the future. Like most families we have had a few obstacles thrown in our way, but our Local Area Coordinator has always been there for us, and we have worked through these problems together.

The quality of our relationship with the Local Area Coordinator is reflected in our practice of walking her out to the car when she leaves our home. The children help her carry her things and when she beeps the horn we all wave goodbye. We realised just recently that we do not wave goodbye to any other person who is paid to come to our home. It is an honour bestowed only on relatives and friends.

To us, family-centredness means understanding that in the midst of medical emergencies, long periods away from home, emotional turmoil and financial anxiety, it can be the small things that make all the difference. Car radiators, cups of tea and the beep of a car horn may not relate directly to issues of health and disability. However they do strengthen our family's resilience and our ability to support our children and each other.

Listening with Intent and Acting with Purpose

Kathryn Treston &
Bronwyn Moloney

Kathryn Treston and Bronwyn Moloney have each been involved in the lives of families and individuals who have disabilities in formal and informal ways for over 20 years. Bronwyn is a Key Worker for families supported by Mamre Community and a strong advocate for change in the disability sector. Kathryn is Director of Mamre Community. She is leading the Mamre community at a time when the organisation is striving to deepen family-centred approaches in order to ensure effective support for families. In this article Kathryn and Bronwyn explore some of the key questions relating to person-centredness and family-centredness by thinking about some of the practical work they are engaged in.

Our work on person- and family-centredness draws on two powerful aphorisms. The first is Henri Nouwen's exhortation *'to live the questions'*. The second is Ruth Gorman's call to *'listen with intent and act with purpose'*. We are privileged to be involved with a family who has long been part of the Mamre Community. This family is currently engaged in planning for the future with Rod: their son, brother, nephew, and friend. Our involvement with Rod and his family deepens our understanding of what 'listening with intent and acting with purpose' means in practice. Below we explore the questions we are 'living' as we endeavour to work with Rod and his family in person- and family-centred ways.

Can we reasonably dream of a world where people, whatever their race, religion, culture, abilities and disabilities, can find a place and reveal their gifts?

Person-centred and family-centred approaches are helpful for planning and building supportive networks and lifestyles. They support people to find their place in the world, to reveal their gifts to us and to contribute. Unfortunately there is a strong tendency for good concepts such as these to become over-formalised and bureaucratised. The consequence is that people with disabilities continue to be regarded as 'special' and their lives become highly planned, coordinated and reviewed to achieve goals. Yet planning will never result in a happy, tidy, well-constructed future. The process will always be an evolving one as we form ongoing relationships – relationships being far more important than rules – engage in good planning, find good people, participate in ongoing conversations, share insights and explorations, make constant adjustments and recognise that this is how it is in all our lives.

For example, in Rod's life, family, friends and support people have all been challenged by Rod in many ways. Sometimes, we do not understand what his behaviours are indicating. However we also believe that he is a 'great bloke'. He is known and respected by all of us. Coming together to assist Rod to find ways to move into the next stage of his adult life so that it is truly *his* life has been a heart-warming experience. The struggle to get to know him, to understand him, and to communicate with him is balanced by a strong belief in possibilities for him through recognising his capabilities. There is agreement in his network that having listened with intent, it is now timely to step out and 'act with purpose'. The people in Rod's support circle have agreed to support one another in this resolve.

Whose life is it?

The second question we live, 'Whose life is it?' sits at the heart of person-centredness. This question contrasts person- and family-centredness with service-centredness. History shows that people's lives have often been orchestrated by what services were able to do for them, by the availability of funded resources, and by a predominantly custodial model. Life was equated with a place in a facility, efficiency with the filling of beds, and service with support formulae. People were not in control of their own lives but had to fit in to a designated service. This strategy emanated out of a focus on the disability rather than the person.

Movement away from this service-centred approach is only possible when the focus shifts from the group to an individual and to the individual's hopes and dreams. This change also assumes the building of formal and informal networks around the person, and the organising of supports to assist the person where assistance is needed. This is an extremely personal – not merely individual – approach. It is dependent on the formation of trusting, intentional and resilient relationships with people who will ensure that the person stays at the centre and that planning progresses into some positive outcomes in real life.

One of the positive outcomes of our planning sessions with Rod is that he is now incrementally moving away from his parent's home to his own place. His network of support, both paid and unpaid, continues to back him. Life is messy at times and arrangements often need to change. This necessitates flexibility by everyone involved. No doubt there is some discomfort for Rod as he moves out of his comfort zone, and certainly it is difficult for his parents to let go and to live with a degree of risk. However, there is a belief that Rod wants to move forward in his life and it is up to those with him to find ways for this new direction to happen, by continuing to listen with intent and act with purpose.

What is 'family business' and what is 'service business'?

As service providers it is easy to fool ourselves into thinking that we are working in truly person-centred or family-centred ways. We can find ourselves engaged in practices that belie our stated belief in the need for individuals to own their own lives. For example, sometimes as workers, we facilitate planning sessions with a person and his/her network and then immediately pick up the planning notes from the meeting and assume ownership of them. It's imperative that we ask, 'Whose plan is this?' 'Who owns the notes?' 'Who owns the communication book?' We need to find more respectful ways of determining with the person how the transfer of information is achieved, how privacy is guarded and how the person can stay more in control of his/her own information.

Partnership is a term that we use more and more without a lot of attention to its meaning in a particular context. If the partnership is between a person or family and a service then it is important for there to be an acknowledgement of what is 'family business', what is 'service business' and of the interface between the two. In this context, partnership is about how family members and professionals work together to achieve the outcome that the person seeks. It requires identifying the things that are in partnership and the things that are outside either partner's control, such as some aspects of funding. The concept of partnership assumes transparency, clear communication, information and each partner respecting the role and boundaries of the other.

For Rod, change requires the involvement of many people with different roles and responsibilities, different relationships and unique histories with him. Partnership in this situation is viewed very positively and has been characterised by a deep respect for the different way in which each person contributes to the overall change for Rod. The lynch-pin is effective and clear communication with all those involved.
There is also a need for clarity about decision making processes, to be clear about what decisions rest with the individual or family and which decisions are in the domain of the service provider. Clearly some matters need to be acknowledged as family business only and others remain the responsibility of the service. This means that agreements made are not altered without input from the other parties involved. Rod's plan has been developed with his families, friends, workers, and allies. However Rod owns the plan. He and his family have final say about what is in the plan and how this is implemented. No changes will be made without his consent and that of his family. As his service provider, Mamre recognises its accountability to Rod and his family and also to the funding body.

What do you really believe?

The fourth question we are living is rooted in values and requires some honest reflection if we are to engage in this process with an individual. It suggests that in thinking about how people with disabilities can find their place in the world and reveal their gifts, the starting point is actually a strong belief that this is truly possible. Further, that it is much more ordinary and simple than we imagine, or at least as much as anyone's life is simple and ordinary. Over the years, it has sometimes been a struggle for those who know Rod to believe that he would live in his own home, have a network around him, have a healthy and involved lifestyle, be out and about doing things he loves, making his own mistakes and living with the consequences.

Living the question of what we really believe requires us to challenge ourselves about the degree to which we are open to possibilities for the person who has a disability. It is about being totally committed to the idea that people with disabilities can lead ordinary lives, and being strong in this belief so as to empower others to think differently, and to be able to ask the alternative question, 'Why not?'

Whose needs?

The fifth question we live challenges us to think about meeting the needs of the individual and also the needs of the family. Living this question means acknowledging that the family is vital to the ongoing wellbeing of the individual. It is also a recognition that both have important needs to be addressed. Rod and his parents have different needs right now. Rod needs a number of things that have been identified and there have been steps taken to address each of these needs. These will change as things progress. There is a commitment to meeting each question or challenge as it arises. For his parents there is the need to know that there is sufficient support for Rod, that plans have been made to keep him safe, and that they will be included in discussions, planning and decision-making.

Are there people?

It has often been our experience that parents find it challenging to recognise that there are people who share their vision and who want to be involved in the lives of their sons and daughters. Experience also shows that more often than not there are such people. However it takes some careful consideration to identify and engage them. What we do know with certainty is that it is vital to build networks around people: some will be developed intentionally, and others will be born from spontaneous interest and friendships.

Rod's friends, mostly discerned by his parents at this time, met to do some planning. These were people who know and love Rod, who share a vision for him having his own home and an active and engaged life. The group gathered to do some talking, dreaming, sharing of ideas, and to look at what resources were available to build on, to see how all these things might fit together and how Rod might achieve his dream. The group named the people who may take on different roles to ensure the future. Rod has a great group of paid support workers who put a lot of energy into assisting him in his life. It is also necessary to build other supports and friendships. The little circle that gathered to think through possibilities is a first step – sufficient for today. Planning for tomorrow is the next step.

Developing person- and family-centred approaches is a broad topic. It is an important alternative to service-centred orientations. However, like all approaches it has limitations. It is important therefore to take a discerning approach in all parts of the journey and to build safeguards by building relationships around each individual.

Reflections on Student-Centred Learning: Three Principles for Conscious Practice

Paul Toon

Paul Toon has worked in the field of community development and education for nearly thirty years in a range of settings, including Primary, Secondary and Special education, as well as within the Tertiary sector. His approach to education and community building is based on mutual learning within the context of community life. In this article Paul explores person-centredness as it applies to the learning environment through student-centred approaches.

Both person-centredness and student-centred approaches to learning are part of a broader body of understanding that relates to people-centred development. My initial assumption was that as someone dedicated to person-centred development that of course I would be a student-centred educationalist. Yet in reflecting on my own practice as an educator and community builder, I have been forced to challenge my own thinking, by asking 'Do I have a conscious understanding of what is meant by student-centred learning and how this applies to my practice?' Below are some of the elements from my reflective journey. I share them not as an expert in this field, but rather as a fellow traveller on that endless path of people-centred development.

As someone who identifies as a 'teacher' my first response is to identify 'students' as learners whom I teach. I can then think about applying those techniques necessary to perform that task. It is possible to think of myself as being student-centred in the sense that I am focused upon maximising the learning of the student.

However, this outlook on learning and development separates the student as an individual who has to do the learning, from me as an individual required to do the teaching. Two separate individuals involved in two separate processes. One individual, the teacher, thinks about the learning process, the other, the student, responds to the processes as prescribed. The effect of my 'intervention' is to treat the student as a separate individual and as a consequence contribute to his or her isolation in the learning process. It can have the same isolating effect on me as the teacher.

As a teacher I am not centring 'on the student' but centring myself with the student and making their issues, challenges and problems the centre of our learning.

An alternative is to consider that as a 'teacher' my role is to facilitate a process of mutual learning, where the student and the teacher are each both the teacher and the student. The focus of the learning process is the real issues, challenges and problems that the student and teacher share and would seek to transform together. This approach assumes an ongoing dialogue between the teacher and the student (involving others as the process evolves). So the notion of student-centred learning becomes an exciting one because as a teacher I am not centring 'on the student' but centring myself with the student and making their issues, challenges and problems the centre of our learning. We could call this an expression of the **principle of mutuality,** in so much as we seek to arrive at a position of mutual learning. This is not simply learning for its own sake, but learning as part of working together to be more active in our world. This first principle in student-centred learning, the principle of mutuality, assists us to transform ourselves and the worlds around us by centring on a common humanity.

For me, the process of arriving at a point of mutual learning is not a quick and easy road. Many obstacles lie within me and within the society in which we operate. I have to move beyond the power I derive from my role as teacher, educationalist, expert, professional, worker or whatever title I may feel attached to or has been attached to me as part of the structures or organisations to which I am connected. Within those structures I may have to deal with work loads, case loads and program outcome targets that make mutual learning seem an unrealistic intention. However, I have come to appreciate that it is necessary to move out of role and into relationship if I am to have any hope of breaking the cycle that in which the professional assumes the knowledge, skills and authority to change realities for others. It requires the development of relationships with students not merely as individuals but as members of learning communities in which, as teacher, I am also a member. Thus centring on the person learning involves locating his or her identity within a learning community. The culture of a community of learning involves different people making different contributions but all being valued. Thus it becomes important to see our organisations in terms of their cultures rather than their structures.

As a teacher, I can do my best to be present to each and every student, to engage in sustained and faithful dialogue. However, I have come to appreciate I must do so with the intention of building community and interdependence. So the second principle would seem to be that of **building communities around human relationships rather than roles.**

The journey within myself as a teacher who seeks to be a mutual learner with others, with students and with all learners is a long and challenging journey. I take some comfort and experience great support when I locate myself as a member of an expanding community of such learners. In this way the journey of mutual learning in a culture of community acquires a vocational outlook. This brings us to the third principle of practice, the **principle of consistency and persistence**. Consistency holds us in mutual relationships with others so that we are all able to be learners and to be active within our world. Persistence requires me to be honest about my limitations, knowing that I will not always be consistent and that it will take a lifetime of mistakes and successes to really learn enough to contribute to the development of learning communities. I don't feel I can really make much of a difference in any one job or role, or even in my lifetime. I need to feel I am working within the context of a vocational commitment to change within myself, within and between others and our world. I can then have faith that person-centredness, as I experience it through student-centred approaches to learning, is not about my role with any single individual. Rather it is about humanity coming closer together as community to seek justice in our world.

I have to move beyond the power I derive from my role as teacher, educationalist, expert, professional, worker or whatever title I may feel attached to or has been attached to me

Listening Differently

Patricia Fratangelo

***Patricia Fratangelo** is the Executive Director of Onondaga Community Living (O.C.L.), a relatively small organisation in Onondaga County in central New York. Pat has worked with people with disabilities for over twenty years, the last thirteen at O.C.L. Last year Pat visited Brisbane to share her experiences of working in person-centred ways. In this article Pat builds on this work, by exploring how we can learn to listen more deeply to people.*

When we are talking about developing services for those with high support needs, we often fail to think about normal lives. Typical homes with people who are loved and cherished are often not the first options discussed when people are perceived to have a disability. Service systems and professionals have developed a different way of supporting and maintaining those who do not fit the typical mould. Traditionally, people who are perceived as unlike the typical populations are pulled from the roots of family, neighbours and friends and are served in a system of supports that is very foreign to them. Strong parents and advocates, who are not afraid to fight, have worked long and hard to break out of the traditional mould that meets few people's true needs.

A typical and valued life, along with the attributes that each person brings, should be paramount in all decisions that are made. But unfortunately normal lifestyles and personal gifts are often clouded or unrecognised because they are disguised by people's perceptions of a disability and their assumptions about appropriate models of support. Many of the individuals I have known are challenging to most, difficult to many and extremely misunderstood. They have been institutionalised, incarcerated, managed, medicated, controlled, clientised and victimised. A normal life is seen to be far-fetched, or even unobtainable, by those who see the disability. The person is then not recognised for the gift of who they are, but instead they are seen as the perceived difficulty that they bring. This is illustrated by the experiences of Susan, a young woman I have known for many years.

Susan was institutionalised for most of her life. In her mid-twenties, she was finally accepted into a group home. At this residence, she became highly agitated every time someone left the house without her. She repeatedly damaged property and injured others. Susan was purposely communicating what she needed, but not in a way that was easily understood by others. Susan knew what she wanted but staff did not understand her.

Susan has many gifts, one of which is the gift of personal determination. No matter how much she was controlled, punished, or medicated, she kept trying to communicate to the staff what she felt and needed. Realising that Susan was trying to tell us something was the first step in changing her life. Susan did not change; it was the staff that learned to change their ways and to begin to understand what Susan was trying to tell them. It was finally recognised that Susan just wanted to be on the go and did not want to compete with others from the group home.

After much planning, Susan moved to her own home with the support of typical community people. Because of her own determination Susan now lives a more peaceful life. She does not have to live with or compete with others. Susan now lives peacefully with Ingrid, a person who loves and respects her. She lives in a beautiful home with stylish furnishings and a person who enjoys her company. She no longer damages property or injures others. She has deeper relationships and more involvement with her family than she has ever had before. These relationships were paramount to her but highly disregarded in the past.

Developing a more realistic and normal life based upon the attributes that Susan has is not far-fetched when one lets go of the perceived disability and sees the strengths and gifts that Susan brings to her life and the life of others. Susan gives to us the gift of deepening our ability to listen. She helps us to be more thoughtful as we consider what services she really needs. She helps us to think about the safeguards that are really necessary in her life. She has taught those around her how to listen differently to perceived problems, to be creative and flexible, to believe her and to work towards her personal dreams. Her voice has finally been heard.

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