

Personcentred Approaches

Deb Rouget (2005)

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“Deb Rouget is empowering people who have a disability to determine their own future by marrying love, understanding and compassion with disability service provision. She's the project facilitator of the Personalised Lifestyle Assistance (PLA), a small government funded resource and assistance project that works with people who have disabilities and their families to design solutions, arrangements or projects that enable them to have greater control over their lives [and enjoy lifestyles that are “typical” and inclusive]”. (Quinn Stacpoole)

Infoxchange's Quinn Stacpoole recently caught up with her and asked a few questions to find out more:

Q 1. (QS) What is the person centered approach to disability service provision?

(DR) There is much discussion currently about person-centered approaches to services and supports in regard to people who have a disability. Personcentredness is often confused with technologies and fads e.g. person centred planning approaches. However personcentredness goes well beyond any technology or plan, as it is an ethic that speaks to how we treat those we serve and what we **do** in people's lives.

Genuine personcentredness means treating people as unique human beings with distinctive and/or even idiosyncratic longings, aspirations, visions and needs. It's a belief that no two people can be treated the same and thus they will simply not want exactly the same things in life. Therefore genuine personcentredness means starting all efforts with the person first or starting with each person separately in a unique manner one by one. This means we can no longer assume just because people share the same label or disability they will want the same things and thus we need to avoid predetermining our models of support or giving people a list of limited options and confusing this with genuine choice, self determination and personcentredness.

Genuine personcentredness searches for the identity of each person and forces us to ask the person specific questions that search for their uniqueness and how they want to live their life. For example, where they want to live, work, study and recreate and who with. If genuine personcentredness is our guiding ethic then inevitably we will need craft a unique response around each person. Such responses may not even presently exist. This takes imagination, creativity and thinking beyond what might be presently available today. In this sense we would create as many service or support responses as there are people.

Q 2. (QS) What's an example of the current system not taking the individual's needs into consideration?

(DR) It would be quite easy for us to simply believe that relabelling what we currently providing today as being person centered as this is what most of us hope to achieve when we support people with a disability. However if genuine personcentredness is about starting all efforts with the person rather than a predetermined model or way of doing things then many of our current support structures may be inadequate as they are designed well before the person arrives. Thus the person needs to “fit” what is offered on a limited menu or even experience responses that seem peculiar to most other people in society. Often what is on offer is standardised and thus there tends to be a one shoe fits all approach. This would be suitable if it is actually what the person needs but if we believe the notion that all human beings are complexly unique, predetermined models become an inflexible way of serving people and may only go part of the way to meeting a person’s needs or even miss the person’s needs completely. Some people may say they have “chosen” a standardised option but if it’s the only option available then it is not really a choice. Examples of this would be services that congregate people based on their label and offer predetermined models of support that are designed before the person arrives.

Q 3. (QS) What's your future vision for the disability sector and how far have we come?

(DR) It is difficult for any of us to predict the future and in many ways although there have been some very good efforts we still have such a long way to go in getting supports right for people. In our efforts over the few past decades we have searched for many solutions. Some solutions have led us to creating large highly structured bureaucracies that are based on managerialism and technological responses. But there exists a sense that such advances have moved further away from people rather than closer to them and what they actually need and desire.

There are examples however throughout Australia & overseas that have tried to build capacity back in communities and with the people themselves. This has led to the creation of many small grass roots efforts in which people with disabilities, their families & allies have imagined better and have searched for innovative solutions that promote personalised responses that are culturally relevant, socially inclusive and crafted around each person i.e. one person at a time. Such efforts have led to the creation of small, self governed services that aim to support people to have highly tailored, flexible support options so that they can remain or move into their own homes, share life with those they love and choose and become active contributors to their local communities. Such efforts have challenged the notion that the only solution for people with significant needs are costly and often standardised 24 hour congregate care models that tend to serve people in a group response. Rather than seeing people as needing to fit a pre-designed, medical model or standardised service system people have created ways in which each person can be supported in a personalised manner that encourages their uniqueness, influence & desires and maintains people’s integrity, dignity and contribution to the social and economic fabric of the community.

These types of responses take much thoughtfulness, a different way of thinking, imagination and willingness to implement ideas and “step out on a limb”. What also underpins most of these projects are deep ethics and principles and a sense that keeping influence close to people is better achieved when people are well known and services are small, responsive and intimate.

There may be a belief that small services are not viable but when the people themselves direct their own resources they are often used wisely and directed where they are most needed. Many of these small grass roots efforts have been sustained viably with no more funding than is available to those who use more traditional responses for well over a decade.

It would be misleading to believe that we can change such a large service system overnight and there are many good efforts by many people. However, what would assist people would be space and encouragement from government departments and agencies to support and encourage the creation of small, family/self governed semi-autonomous projects that build capacity in people and communities. One way of achieving this would be to expose people to others who have imagined better and have a proven track record in creating genuine personalised support arrangements. This would not necessarily use more resources but rather seek to use current resources differently.

Q 4. (QS) What do you see as the greatest success story of the person centred approach?

There are possibly too many to mention. But I would like to share a recent story of a young man in country Victoria. The story highlights that given the right assistance people can imagine and create better lifestyles that are personally relevant and that people with disabilities do not have to live in congregate care models in order to obtain the support that is needed.

Cameron shares life with a friend (who does not have a disability) of his choosing in his own place. His housemate receives free rent in return for support but it is more than an inexpensive model of support. It's driven from Cameron's wants and need for friendship and companionship rather than an over reliance on paid service or staffing model. Cameron's story also highlights the notion that people will come forward to share life with people who have a disability if asked. Recently his housemate said that Cameron was the best person she had ever shared with!

Cameron's story is an example of a continual search to get it “right” for him. To listen deeply and for those around him to admit that they did not have it right rather than think something was “wrong” with Cameron. It's an example of where people came together to assist Cameron to create a typical lifestyle that embraces his own desires. It is a genuine attempt towards personcentredness as all efforts begun with Cameron and will change with Cameron as he so desires.

Maggie Skinner: Cameron's story

“As the parents of a young man with a dual disability who attended mainstream education facilities, completing Year 12 (modified) with integration support throughout, we had high expectations of Cameron's life post secondary school.

However, our expectations crashed and burned during the next few years as Cameron found it difficult to gain meaningful employment. Several disability services were accessed by Cameron but, he found these standardised programs un-stimulating, and could not maintain motivation to continue attending.

Also at this time, we were aware that Cameron needed more space and privacy and investigated several options. This resulted in us building a small self-contained unit on our property some 40 meters from the family home. This project had been undertaken without thorough discussion with Cameron about what he wanted for himself. We assumed that Cameron would flourish in his own space, still within close distance from the family home. We were very wrong.

The move to the unit in June 2001 created stresses and strains on Cameron which resulted in a major psychotic episode, requiring him to move back into the family home. In March 2002 Cameron felt confident enough to move back into the unit, but it became obvious that the unit itself was only part of the problem.”

Around this time I received an invitation from DHS Gippsland Region...to attend an information session where Michael Kendrick, George Vassiliou and Deb Rouget were guest speakers. At this time I had not heard of any of these people and was unsure what the purpose of the day was. However, I attended and was amazed and delighted to hear what they had to say. After this meeting I kept in touch with Deb Rouget. When we as a family were ready, Deb came to our home and spent time talking with Cameron and ourselves to find out what it was that Cameron really wanted and needed.

This was a very important meeting in Cameron's life and occurred in November 2003.

Once Cameron was able to express his desires, we helped him expand on these and it became evident what we needed to do was to help Cameron start the process of working towards his aims and vision.

With assistance from the Personalised Lifestyle Assistance project we developed a submission which was lodged with Gippsland Region DHS in March 2004. Within a few weeks we had a positive answer from the Department who advised us that Cameron had been allocated a Support and Choice package.

This was when the hard work really started. We were now committed to put Cameron's wishes into reality. Ironically the next stage, which we had assumed would be the hardest, was in fact much easier than we imagined.

A potentially suitable housemate was located. After several discussions with a young woman (non-disabled) she agreed to move in with Cameron. A private rental property was found which met Cameron's criteria. The managing agent was aware of the situation and the landlord, having reservations initially, is now a staunch supporter of Cameron and his housemate.

The second component of the funding submission was that a co-coordinator be appointed to work with Cameron to find meaningful employment. To date Cameron has commenced a

traineeship as a builder's assistant for a 13 week period. We are confident that ongoing work will be found for Cameron in the very near future.

...[with assistance we were able] to coax, tease and encourage Cameron...to look outside the square..... We did not realize that we were limiting our options because of the existing systems and our experiences of them. **Without the limitations we saw that Cameron could 'fly' and we could help him do this.**

Since commencing this process we have shared our experiences informally with a number of local families who express great interest in developing similar options for their son or daughter

Earlier this year we as a family submitted a proposal to DHSto create a small family governed project called Yoorrooga. This will enable up to 10 families to work towards similar personalised, inclusive living and lifestyle arrangements similar to what has been achieved for Cameron for their sons/daughters...." (Maggie Skinner, 2004)

Post Script (January, 2005)

For the first time in our lives we are so satisfied with Cameron's supports and living arrangement that Greg and I have planned a trip around Australia this year. We feel that there are adequate safeguards around Cameron and his enjoyment of life now enables us as his parents to also have a life and pursue a dream we never thought possible.

Q 5. (QS) What are some common questions or issues raised by people who come from a more traditional service approach but want to know more about the person centred approach and what would be your response?

(DR) 5.1. Confusion about what genuine personcentredness is or involves

Often traditional services adopt the terminology or language of a particular way of doing things. Thus we see congregate care facilities adopt the terminology of "personcentredness" but when one examines what is being provided people are still served as groups of people and come together based on a label rather than a genuine desire to share life. Some of the practices of congregate care facilities may aim to be "personcentred" to a degree e.g. people may be able to choose the clothing they wear, the food they eat and perhaps some of the outings but some of the more fundamental and possibly more important questions of, for example, where a person lives and who with are often over looked. Similarly in day programs people may have choice over a limited menu of predescribed program but crafting their own life in the community based on their unique aspirations and dreams is not possible, as they need to remain as part of "the group" or part of "the program". Thus it is important to remember that genuine personcentredness has no prescription or set menu and we need to show humility in regard to what we are actually achieving in people's lives and label or describe our efforts for what they actually are. Otherwise our vision in regard to what might be possible in people's lives becomes clouded in self-justification and the misuse and misinterpretation of language. Asking a person what their dreams are is quite different to having the courage to take action on them.

5.2. Difficulty in imagining better

People have trouble imagining better as they often rely on what has gone before or have become conditioned over time to think only certain models of support are possible.

In the absence of any precedents or examples people are often unsure about what might be possible and rather than imagining personalised or personcentred arrangements they will believe the only option available is congregate care because this is all they have seen or know. Thus people need to be exposed to examples of genuine personcentredness that have a long track record as they can provide important learnings, guidance and ideas around what might be possible.

We have also found once exposed to such notions that people become quite enthusiastic but are unsure of where to start. Thus the type of assistance people receive to nurture, develop and implement their vision is essential. For example in Victoria there are currently few services that provide such options for people with significant disabilities who want to move out of their family's home other than congregate care facilities. Thus if people want to live in their own home they have needed assistance to write and submit proposals to funding bodies and implement their ideas from scratch. This was one of the reasons the Personalised Lifestyle Assistance (PLA) project in Melbourne. The PLA project is designed to assist people to imagine better, craft support arrangements and enjoy lifestyle arrangements that are typically available to other members of the community.

5.3 An assumption that individualised funding or brokerage systems is all that is required to create personcentred approaches

Individualised funding mechanisms and brokerage systems can be quite useful to people. However we should not assume that such systems are all that is required in the lives of people who are vulnerable. Quite often when people have individualised funding or the opportunity to “broker” services they will purchase standardised “off the shelf” services rather than create uniquely tailored support responses that are life giving because they do not have the assistance required. In other words money alone is not enough to create better lives for people who are vulnerable.

We need to place faith in the reality that there are simply some things that money cannot purchase or produce. For example money does not purchase love, compassion, trust, understanding, humility or respect. It does not end loneliness, seek out relationships, or make a house a home. It can't on its own assist a person who has been isolated from their community to become intertwined in their local neighbourhood and develop friendships. It can't be “with” people in times of crisis, need or desperation. These things come from the hearts of people and their personal investment to find the humanness in each other.

To assist people to live the lives they chose and become enriched in relationship then it takes people who are willing to stand with people over time and assist them to imagine and create better with the resources available.

5.4 An assumption that genuine personcentredness is more expensive

People often think that genuine personalised i.e. one person at a time supports are more expensive. However many people have created such arrangements with the same amount of money that was previously available in congregate care facilities. Thus people have “done differently” with the resources available.

In addition if we were only to rely on paid “one to one” support such arrangements would not be financially feasible. Many people have had to be creative around supporting people with a range of informal and formal supports. Often it is the case that in doing so people’s lives have become enriched by a range of relationships that are unpaid. Some very good examples of this would be Onondaga Community Living in Syracuse, New York (www.oclinc.org) and Jay Nolan Services in California (www.jaynolan.org). Both of these agencies have transformed their congregate care service i.e. group homes and day services into personalised one person at a time supports using no more money than was previously available so that people can live in their own place and pursue their interests and dreams in the community. Homeswest in Queensland, Australia would be another good example together with One by One in Melbourne. These are examples of small family governed initiatives that assist people to have personalised (one person at a time) lifestyle arrangements and supports to assist each individual to pursue their aspirations and live life in the community.

5.5 An assumption that living in one’s own place is limited to either living alone or sharing with another person with a disability

It is often assumed that living in one’s own place (or what also might be considered as “living independently”) means living alone. But living in one’s own place does not mean having to live alone if ones’ vision is to have company. It’s the choice of company that is important and who makes that choice. Nor does it mean that if one wants company then it could only be with another person with a disability. There may be many alternatives that a person could actually consider.

Originally Cameron’s family had thought that it would be less expensive and more feasible for Cameron to share with another person with a disability. However when they really listened to Cameron he was not saying that he specifically wanted to live with a person with a disability. He was saying he wanted to live with a friend that he got on well with. This led Cameron and his family to exploring other avenues and people who might share life with Cameron. Sharing with his housemate (who doesn’t have a disability) has also meant far less reliance on a staff driven model, which may have occurred if he shared with another person with a disability. He now shares a more “typical” relationship that one would experience when sharing a home rather one dominated by program rules and restrictions. Cameron and his housemate, like all people, have had to negotiate many of the intricacies of sharing a home but problem solving has not been determined by a systematic response but by mutual agreement via conversation and understanding of each other’s specific needs.

5.6 An assumption that those who come forward to share life with people in an unpaid capacity will move on more readily than paid supports

It is often a fear that if a person with a disability shares their home with a person who is unpaid that eventually that person will move on. This could be the case but what we often forget is that paid staff leave too! Sometimes quite frequently! So the important thing to remember is that continuity of people is at risk in both types of support arrangements but neither more than the other. There are examples from Onondaga Community Living where people have shared life in an unpaid capacity with people for over 17 years. Such longevity might also be witnessed in some staffed arrangements. What is important to consider is that people will come and go but why people come forward, what they give and how they might be replaced is vital. Often in staffing models services replace staff when they move on rather than the person themselves. Many of the more personcentred services simply assist people to choose a new housemate if need be thus not leaving the person without the necessary support. Thus the role of the project or agency is still to provide the assistance needed but with a view to finding people that the person wants to share life with rather than advertising only for professional roles.

5.7 An assumption that unpaid people who might come forward to share life with people can't be trusted

It is also often assumed that unpaid people could not be trusted or would only come forward for some sinister reason. This is based on an unfortunate assumption that no one would want to spend time with a person with a disability unless they were paid. But when people come forward for reasons other than pay it is usually due to a calling or a commitment to people as witnessed in Cameron's story. In reality staff are simply people! They may have actually begun as unpaid people who eventually took the opportunity to make a career out of their desire to support people who have a disability. Of course they have gained experience along the way but the pay is a subsidiary issue to who people are as people.

It would also be important to look for qualities in any person that came forward to assist, whether paid or through voluntariness. It would also be important to set safeguards in place perhaps through personal selection criteria, checking people's backgrounds and other things that might be important to the person.

It may also be assumed that unpaid people do not have the expertise required. However all people need to learn about how to relate to each other and thus we need to guide people in their efforts and teach them what we know about people and how they like to be treated. Our guidance should be the same for paid supporters and those who come forward to support people in friendship. People who come forward in voluntariness can also learn as well!

It may also be possible to consider other ways people are reimbursed for their support other than salary. For example many people feel a great deal of personal satisfaction around coming forward to assist in the lives of those who are vulnerable. In the case of Cameron's story the person he lives with receives free rent in return for support.

Thus we should never say “never” but rather anything is possible if we open our minds and see people as the human being they are rather than pre judging people or making assumptions just because people are paid or unpaid.

Q 6 (QS) Are personalised arrangements more work?

(DR) No matter how we are involved with people who have significant disabilities if we want them to enjoy a life that most people take for granted it is going to require effort in mind, body and spirit. It is a fact that people with disabilities have needs that must be met and that will require effort but how, when and where such needs are met, are the most fundamental questions and should be determined and addressed by the person and their loved ones not a group of strangers.

In much of my experience I have seen people/families worn out and exhausted because their needs are not adequately met. This is often because the person has been required to fit a predesigned service structure that has only met some of their needs. Often people are not understood, listened to or taken seriously. This becomes tiring, frustrating and annoying. However when people put the same amount of effort into imagining, designing and implementing supports that are uniquely tailored, the effort seems worthwhile. Efforts often become rewarding rather than exhausting because the person is closer to living their life in a way that makes sense to them and supports are relevant to what’s needed the most.

Some of the existing consumer/family governed services that aim to create personalised supports craft responses that take some of the workload away while still delegating the necessary authority back to people. This might be via the employment of a Coordinator that is chosen and directed by the people, in the creation of small support circles around each person or employing a “hosting” agency to take care of the administrative/legal requirements e.g. Cameron’s example, Person by Person and One by One.

Conclusion

(D.R) Genuine personcentredness is an ethic that considers each person as a unique human being. Its about starting all efforts with each person and crafting a unique lifestyle around each person that is imagined, designed, created and guided by each person and their allies. At this point in our history, genuine personcentredness may seem extraordinary as there are few genuine examples that exist but it should not be that difficult as so many of us enjoy the “ordinariness of life” its relationships and a sense of belonging to community. Imagining how we might make “ordinary” life experiences more readily available to people who have a disability is our next challenge.

Further information Contact:

Deb Rouget
Personalised Lifestyle Assistance
Email: deb.rouget@plavic.net.au
Phone: 0412 001388

Dr Michael Kendrick has also many interesting and useful readings on such advances.
Email: kendrickconsult@attglobal.net
Web site: www.kendrickconsulting.org