
REFLECTIONS ON BEING A PAID SUPPORT WORKER - TEN THINGS I'D LIKE TO SHARE!

by Deb Rouget

Deb Rouget is the Manager of Belonging Matters which is an independent education, capacity building and advisory service in Melbourne that assists individuals with disabilities and their families to imagine and enjoy lifestyles that are enriched with the same opportunities as other citizens. Her major interest has been in fostering and supporting advances that leave people who have a disability and their families with greater control over their lives so that they can lead fulfilling community lifestyles that most people take for granted. Deb has lived in Melbourne all of her life and has two children. She has spent over 30 years supporting adults who have a disability and families in various capacities. She has a Bachelor of Applied Science in Intellectual Disability, presents at various seminars and conferences and consults nationally on efforts that search for genuine personcentredness.

This paper is based on my many years spent as a support worker, the countless interactions I have had with people with a disability and families in my role at Belonging Matters and a recent survey sent to people with a disability and their families about what they thought makes a good support worker. I hope it's useful!

1. The ability to exchange oneself with others.

The ability to exchange oneself with others is summarised in the following quote by Matthieu Ricard "If we think about the vast majority of human problems, both on a personal and on a worldwide scale, it seems they stem from an inability to feel sincerely involved with others, and to put ourselves in their place".

One of my guide posts over the years as a support worker has been to ask myself the following questions. How would I feel if this was done to me? How would I feel if I never had the opportunity to go to get an education, get a paid job that I enjoy, change job, earn an income, meet a variety of people, move out of my parent's home and live in my own home, develop a range of friendships and relationships? How would it feel if I was spoken to "like that",

degraded, humiliated, ridiculed, treated like a child as an adult, pitied, spoken about by others, not included in the decisions about my life? How would I feel to depend on others to meet my needs, have strangers support me with my most personal needs, be done to, not be loved, live in a facility, become isolated, never have any privacy, live with people I had never met before or rely on welfare?

The unassuming but important ethic of putting myself in another's shoes or exchanging myself with another's situation has helped me develop a sense of moral discipline which in turn helps me to reduce or see my contribution to injustice. I have tried to resist imposing actions on another human being that I would not expect for myself or my own children. Exchanging myself with another has also helped me to understand why a person may do the things they do. For example would I be aggressive and angry if someone locked me in a room all day, week after week, year after year? I think so!

If we exchange ourselves with others we're much more likely to approach people with kindness, love and compassion. People no longer become the other, those people, they or them. While my mum was receiving

in home support recently she suddenly became one of “the other”, “they” or “those people”. Many workers would say, in front of my mum, things like “they like to get up early...they get restless at this time of day.” I was left wondering who the “they” were in relation to my mum: a mother, a grandmother, a loved member of a family, a retired person, a person who loves ballroom dancing, a wise person, an older person, person with dementia, failing heart, cancer or emphysema? If we look closely the “they” does not exist - we are us, me and my children, my mother - all unique human beings.

However, as mentioned by people with a disability and families who responded to our survey, exchanging ourselves with others does not mean imposing our views, religion or culture on others – just as we would not want others to do this to us!

2. To recognise and nurture personhood (and feel sincerely involved with others)

In most of the surveys sent to people with a disability and families they spoke about the ability of support workers to view their role as more than a job. They spoke about getting to know the person well and tuning into the person’s interests, idiosyncrasies, passions, communication, personality, etc. This leads us believe that people don’t want to be seen as a commodity, a pay cheque or a career but a unique human being with distinctive longings, feelings, passions, interests, abilities, habits, attributes, suffering, needs etc.

I was reminded of how easy it is to overlook another person’s personhood recently while mum was staying with

us. She needs help with almost all of her needs. Out of sheer ignorance, ego and lack of mindfulness I would find myself annoyed when she wouldn’t fit my routines, ways of doing things and opinions! After

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all, isn’t my opinion always right? Mum wanted her clothes folded a certain way, her medication not only at a precise time but in a certain way, she didn’t want to go out if it was raining, only liked doing certain things, wanted items placed in exact positions, didn’t like the TV shows we liked and she had to go to bed at precisely 8.40 pm! It took me a long time to accept her personhood and her idiosyncrasies that made perfect sense to her! I realised that upholding my mum’s personhood and dignity while encouraging her, ensuring others viewed her in a positive light and letting go of my ego was a continual balancing act. The more I let go of my ego, felt her suffering, treated her with the respect she deserved and did my best to make her day better the happier we both became!

3. Respect is more than a word

Most of us, if asked would say we respect people with a disability. However nearly all respondents to the questionnaire raised the ethic of respect – which makes me wonder if it’s not present! The Oxford Dictionary defines respect as a feeling of deep admiration for someone; due regard for the feelings, wishes, or rights of others and avoiding harming. If we look at our

actions and relationships with people with a disability can we genuinely say I admire this person, I have due regard for their feelings and wishes and I cause no harm? As a support person I have found it helpful to think if this was one of the people I respect most in the world how would I treat them, approach an issue or make suggestion? Respect is more than a word – it needs to be lived. But it is much harder to offer genuine respect than what we think!

4. Relationship

Most of what we do in our lives depends on our relationships with others. Our relationships often stem from small encounters and they grow over time depending on our connection with the person. If you think about the good relationships you have in your life, the potency may depend on trust, dependability, reliability, how much you enjoy the persons' company, kindness, compassion, support offered during difficult times and other desirable qualities etc.

I think relationship is the heart of the work that we do. It's hard to have a relationship with a system when they often counteract the basics of what relationships need to flourish. In a conference presentation recently Marg Ward, a parent from Queensland, said "relationship doesn't automatically happen and it certainly doesn't come in packages or in an email"! A good reminder for us professionals!

In our survey respondents spoke about the importance of trust, honesty, reliability, good relationship, talking to the person – not past them, getting to know the person well, being happy to be there, feeling comfortable in each other's presence, being open minded, warm, friendly, genuine and fun.

As a support worker I have found over the years that when I focus on building a good relationship with people over time we were able to make much progress towards creating a better life. People and their families become more open, trusting and honest. They accept ideas and feedback more readily, try new things and we make progress together. In order to create relationship I also need to give something of myself. Sometimes it takes a cup of tea!

5. Getting the match right

Over the years I have learnt how important it is to get the "match" right between the person and their support workers. The match is not only important in regard to values but also the task that needs to be done. In the survey many spoke to the question of values e.g. respect, empowerment, seeing the person as a unique individual not their label, egalitarian, people orientated, trustworthy, honesty, recognising potential and creativity.

These are all valuable traits however even if you hold many of these traits you may not have the skills to carry out the task. The reverse might also be case - you may have the skills but not the right personality or values. For example, if you want someone to help you become a member of the local footy club you wouldn't ask me – I loathe football even though I would hold many of the values stated above! I would dread this task, feel very uncomfortable and my instinct would be to find another person who loved the idea of sports men and women chasing a ball in the rain and pulling each other to the ground! However there would be many Melbournians, unlike me, who love footy, understand the written and unwritten rules, get the culture of a football club, can seek out valued roles and build relationships over a beer!

Or on the other hand if you want a paid job you need someone who can find you an actual job that you like! Someone who knows how to seek employment based on your interest and abilities, negotiate opportunities, analyse what is needed and secure the job! If you're looking for a job you don't want someone who's afraid to ask, will melt on the first knock back and revert to volunteer options or programs for people of your own kind because they don't believe you should or could work!

If you want to pursue abstract art then you want support from a person who knows about abstract art. If you want to build relationships you want someone who is social, outgoing and a good connector - not an introvert! If you want to pursue Accapella singing then you want support from those who know about Acapella singing! If you want to study astrology you want support from those who know how to study and better still know about astrology. The specific interest area can be just as important as values. More often than not the specifics about the person's support needs can be taught.

Recently one of our creative staff was looking for options around craft for a young woman. Not knowing anything about craft she researched the internet and found people who are involved in craft. From this research she found a group of young people in the community who meet weekly to do craft together. She also found a good young person interested in craft who was willing to support the person to attend! The perfect match!

Another important "match" is age. As a young person I knew what young people did, where they were inclined to hang out etc. I had no idea for example about what older women or men did! These days this wouldn't be the case! Also younger people

don't always want to hang out with people their parents age! They will also have links into all kinds of networks and opportunities and have a shared language, dress sense and so on. Respondents to the survey said that qualifications and being a "disability" support worker were far less important than values, match and the ability to get the job done!



6. Recognise and harness people's potential to contribute to the community

As a support worker I found it useful to start with an assumption that a person could understand and do anything with the right support. This was a useful antidote to casting people with a disability into the life restricting realm of low expectation. Too often I'd hear people say things like "This person could never learn to do a certain task, cross the road, move out of home, live in their own place etc." or "This person doesn't have the capacity for a paid job" or "This person needs a transition program to get ready for work". I think if any of us were assessed before we moved out of home or got our first job, most of us would

have failed! I know I certainly would have! Nor did we have a transition program – we learnt on location often with much support from others!

Overwhelmingly respondents to our survey talked about the need for supporters to see the potential for growth in people and raise expectations and responsibilities in line with what is typical for most people of a similar age. For example how can you learn to be a Baker if you never work in a bakery and are not taught by a Baker to learn the skills to be a baker! How will you learn to be part of a team of typical Bakers if you were kept away from them? How will you ever get paid award wages if you worked in a sheltered environment and it's never an expectation? How would you learn to pick up on many unspoken work ethics in a particular workplace?

Still today I witness a great deal of imitation. Rather than get someone a job in a bakery many would try to imitate real bakery. For example the tendency might

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be to locate or develop a “special” bakery for “special” people to provide shelter, protection and the illusion of real work. Another is to create enclaves, or even send a group of people with “special needs” to work in a workplace when others have gone home! I have learnt that special places, enclaves etc. never connect people with a disability to the community.

It's also misguided to assume that such congregate care arrangements are safer. For example many of the reports written by the Office of the Public Advocate identify

many abuses in congregate care.

If we continue to foster imitation the consequence is that the community will never see the potential of people with a disability. It will continue to assume people are different and should be kept away from typical places and opportunities. As support workers and as a field that seeks inclusive lives we need to vigilantly steer clear of imitations. They're tomorrow's sheltered workshops, create pity and inequality.

Over the years, as a support worker, my commitment to social inclusion grew as I saw its benefits. Now my automatic response to developing a person's potential is to take the common path that is open to all other citizens. The support is then added, one person at a time to make it a success. Imitation is not required – opportunities are abundant in community.

Many of the respondents to the survey spoke about support workers having the ability to encourage potential through creativity, imagination, vision and open

mindedness. For example one man, we have known for some time, was locked in a room all day because those around him

didn't think he had the capacity or potential to learn. Now he runs his own dog walking business! The reason is that his family and support workers believe in his potential. He's now making plans to move out of a group home into his own home!

7. Recognise and harness the potential of community

From the moment we're born it's an expectation that we will be part of community. Most of us are immersed in an intricate web of social relationships that

arise through numerous and varied social contexts, situations and opportunities. However, for many people with a disability, opportunities are limited to sharing time with those who share the same label or with people who are paid to be there. This sends people on a parallel journey away from each other. A world that is separate -where people feel like an outsider, wanting to be included. Often we hear people say that the community discriminates but in all of my years of working alongside people with a disability, if I paid attention to each person and thoughtfully connected them to other citizens with similar interests and offered the right support, rejection was rare.

Our shortcoming is that we prevent connection because we believe that labels or perceived shortcoming are the only way to support people. Or we believe community is unsafe and people require protection from each other. Over the past 30 years I have been very fortunate to witness the potential of community. Time and time again I hear community members say "of course you're welcome," "I'm a better person for knowing this person," "our workplace is a better place," "I have always wanted to assist but I didn't know how" or "nobody asked". Community is not a panacea, everyone needs safeguards and sometimes we need to work hard to connect those who have a history of disconnection.

It's time for us to reach out to community, invite others in, support and encourage people's efforts embrace its potential and view everything as an opportunity for someone we know – a possible job, friendship, connection, role, association, home and so on.

8. Enhance positive and valued ways

As a young support worker I was exposed to Social Role Valorisation (SRV) theory

which was formulated by Dr Wolfensberger in 1983. Although the theory has many aspects, I recall as a support worker that it assisted me to understand marginalisation and what/who society tends to value and devalue. For example wealth, work, education, home ownership, valued status and materialism are highly valued by our society. Whereas other things are perceived negatively and consequently devalued e.g. the unemployed, certain types of job, the homeless, the uneducated, those on welfare, difference. One only needs to meet someone new and they will ask "What do you do for a living"! SRV still informs my efforts today.

This is not to say how society acts towards those who do not have valued status is "right" or "correct" or that there shouldn't be another way that liberates us from our attachment to materialism and wealth etc. but it provided me with a useful framework to understand today's society. It also helped me to reflect on and how we often deny people with a disability access to positive and valued opportunities and roles such as work and education because of negative attitudes and assumptions. For example, one of the families who wrote for our periodical recently, described how her son had been denied a mainstream education because of his complex communication, physical and medical needs. Just by having such needs an assumption was formed that he couldn't learn. This then led to a denial of any academic education, typical expectations, peers and routines etc. Fortunately, through the determination of his parents he is now a student at his local primary school – learning at last, making friends and is viewed as a valued member of the school community who teaches the other children about diversity!

SRV also taught me that if we want others to engage positively with a person

with a disability we need to be good role models. This means interacting with each person respectfully i.e. not embarrassing or ridiculing the person, treating an adult like an adult not a child etc. Sometimes it meant providing an explanation to a person in a very respectful way and assisting people to put their best foot forward. For example, advising people on suitable dress codes, not casting people into roles or situations that are not typical for their age etc.

9. Recognise our own limits, fallibilities and shortcomings

It took me a while but I have come to realise we're all human beings with shortcomings, limits and fallibilities - it's the nature of being human!

When I look at myself with humility, although often confronting, I witness the shortcomings of my efforts. For example when I speak too much and do very little. When I'm more concerned about my

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reputation or the service looking good than practicing or doing the work that really makes a difference in people's lives. When I avoid scrutinising my own efforts but happily criticise others. When I avoid the practicing because it's too hard or I'm too scared to act because I might make a mistake. When I make excuses rather than try or pay attention to non-programmatic things because it's easier and quicker to get done than standing with someone in the mess of life! Rather than say "how", I find a thousand reasons to say "why not" or I'm defending my inadequacies. And so

on! One parent recently said she feels like a broken record – people say they will do things but no matter how much she pays the job never gets done! Questions such as - did I do what was asked, what have I actually done to really help a person get a good life, did I make a real difference etc. provide an inner examination and leads us to do better!

After many years of working in human services I know what it's like to work within the limits of the system. When you're passionate about social inclusion and you hit program blocks, rules, regulations, limits of time and funding etc. it's frustrating. However even given the limitations of systems, with a commitment to social inclusion, I have always found space to create a moment of genuine inclusion in which a person can pursue an interest, passion, relationship or role in the community. A moment can always be found – even within the confines of the most rigid situations. Once you have found

one moment you can build another moment which leads to a day, which leads to a week, month, year and life! It

can take just one moment to rally people and liberate people beyond our own limitations. Such moments can begin to change systems and societies and can be witnessed throughout history in stories such as Ghandi, Nelson Mandela, Rosa Parks and so on.

10. Seek out others who believe in social inclusion

As a support worker I have witnessed many acts that have caused people great suffering. I have also come to realise that time and time again, when people with

a disability have access to positive and valued opportunities in the community, that not only does the person flourish but so do the lives of others. I think this is the type of society that we seek for all of our children – one which has a positive regard for difference.

However at times it feels like you're swimming against a current of segregation and congregation. Sometimes you need a life raft or a community of others who believe in the same thing. To support me in my efforts I have had to seek out advice and wisdom from others who not only believe in a social inclusion but practice it. Leaders who keep at it, are humble, welcoming, challenging and inspire your potential. We are what we do not only because of our own actions but of the kindness and inspiration of others.

References available on request.