

The importance of starting with the person rather than the money

Deb Rouget is the coordinator of Person by Person, a small family governed service in Melbourne that aims to assist adults who have a disability to pursue their aspirations and abilities in the community and develop meaningful relationships with other community members. Person by Person is an alternative to standardised, segregated, institutionalised responses to people's needs. Deb focuses on the creation and provision of innovative services by starting with the person.

With good intentions we have searched and invested a great deal of time, effort and money in systematic solutions that aim to assist people who have disabilities to live in the community. However we remain troubled and somewhat puzzled by the continuance of segregation, notwithstanding the many advantages now more commonly enjoyed by people who have a disability in community life.

It would be comforting to know that by simply investing additional money in our current service systems, that all things "good" would subsequently happen for people who have a disability. However even with a great deal of resources most of our current practices constantly fail to live up to the life-giving rhetoric used to describe them.

We have invested vast amounts of money in technology, paperwork, buildings, bureaucracy, planning tools, management systems, procedures, regulations and so on. Whilst there was great faith in the potential outcomes of such investments, the practical experience of what has happened in people's lives makes many of us wonder whether these investments should have been our priority. We have come to believe that people who have a disability need to fit a particular systematic response rather than ensuring that all efforts need to start with the person first. We are now grappling with what should be the real priorities for our investments and what would bring value to the way in which we serve people who have a disability.

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 or, as Michael Kendrick suggests; from being in "right relationship" with each other as human beings. To have the ability to listen, be "with", and search with a creative passion for how a person can be included rather than excluded is a gift one finds in people and community rather than in service systems. As Jack Kornfield states "Love and compassion are not the possession of any group or religious system. They are woven into our human spirit and our very cells. The only nourishment they require is our intimate and heartfelt attention".

Recently I was reminded of the gift that can occur when one pays intimate and heartfelt attention to another's life and when one searches with deep commitment, passion, creativity and endurance. Felicity lives in a small Melbourne community with her family. Following several years of segregation, Felicity and her family have been on a search to find places where she can belong, contribute and become more actively involved her local community. Felicity was successful in obtaining a job in a local supermarket: work which Felicity loves and which has become a place where she is well respected and known. However Felicity, her family and support worker knew there had to be more. So in the first instance they started with Felicity rather than a predetermined system or way of doing things or what it would cost. They took time to

“imagine” what might be possible. They came up with an idea of Felicity setting up her own stall at a weekly community market. Although there was much thinking, work and some hesitation involved, all were willing to give it a go. It was a great success with Felicity doing what she loves best – meeting and talking with people. Quite amazingly other stallholders offered to help Felicity out when she needed it. But perhaps what is more significant was the “investment” in Felicity, her family and their choice of supports. They employed a support person who was well connected to the community, who could be in “right relationship” with Felicity and her family, who could creatively help with imagining better, look to the local community for opportunities and support, use her own networks and believe that anything is possible.

So perhaps now the priority for our investments is to search and foster support for those who can be in “relationship” with each other and assist people who have a disability to become actively intertwined in their local communities. Rather than continuing to invest money in technology and systems that tend to group and segregate people we need to add value to our approaches and begin to invest more in people who can “think” and “imagine” better lifestyles. We need to invest in people who have the ability to discover each person’s uniqueness with compassion, sound ethics and humanity and discover what quality actually means for each person.

Throughout Australia there are many examples of unique small grass roots efforts that are often governed by the people who use them, that have attempted to create supports that are highly relevant to people’s needs. Such efforts have demonstrated instances where people have found some measure of progress and meaning in their lives within their local communities while keeping bureaucratic processes at a minimum. One example of such an effort is *Person by Person* in Melbourne, which is a small family governed service that strives to assist people to pursue their aspirations, abilities (and things yet to be discovered) in the community. Each person has influence over their funding and support to imagine and create a very personalised lifestyle and support arrangement from their own home. No two people do anything together, as quite naturally enough they do not share the same interests and desires. *Person by Person* has a fundamental belief in starting with the person first. It believes in the ability of people themselves to be innovative and recognise what is most important in their own lives. This is not something that money or systems alone can produce. Although *Person by Person* has had its challenges, people are moving closer to what they actually want and desire in life that to most people is quite ordinary.

Small grass roots efforts such as these have often gained encouragement from government departments to try innovative responses that occur simultaneously with a whole range of other traditional responses. Thus there has been no need to “wait” for the whole system to change to create small pockets of innovation. However what has been most important for those seeking innovation is to be clear on a range of guiding ethics and principles for living one’s own life as part of the community.

In some instances such grass roots efforts have been given new resources to create personalised lifestyle responses but it would also be possible to extricate current resources invested in segregated responses and get them close to people so that they can design their own personalised solutions and responses. In this sense new resources may not be required, but existing resources could be used differently to create solutions that assist people with disabilities to live typical lifestyles within and as part of their own communities.

In our search to do this we need to invest in people who have disabilities together with their allies, as often when their sense of what is needed and possible is recognised and harnessed as an active and decisive force, they can be very positive and innovative. This is not always forthcoming. It is often difficult to “imagine” something that is different as our imagination is often limited by past approaches and traditional ways of doing things. This means we need to set aside, even for a moment, what we currently know to give space to

thinking about what life might look like if it were how we imagined. As Toni Packer suggests “The emergence and blossoming of understanding, love and intelligence has nothing to do with any tradition – no matter how ancient or impressive – it has nothing to do with time. It happens completely on its own when a human being questions, wonders, listens, and looks without getting stuck in fear”.

Once we begin to question, wonder, look and listen to people who have a disability, their allies and community and to seek genuine alternatives with space and encouragement that is free from fear, then we can start to “imagine” what might be possible. Rather than saying “it’s not possible” we need to open our hearts and minds to the liberating idea that anything may be possible if we put our minds to it and if we imagine better in a sense of “withness”.

From what we know about human history and the wisdom of others we need to begin to recognise that investment also needs to be made in people. It is people who will “think” with compassion and innovation not money. It is people who need our heartfelt attention and this is not often easily measured or priced. Even though resources are much needed it is not so much the money that is most important but what we do with it, and how we reach out to our fellow human beings.