

# Families for Change

Promoting and defending the rights and interests of people with a developmental disability.

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## Unfamiliar Roads

family  
ADVOCACY

At a time when the New South Wales Government's 10-year plan, promising over \$1 billion dollars for more services, is being analysed and discussed, the question of how such long-awaited and much needed funding and commitment will be used in the future is timely. The questions of whether it will be largely invested in what is already known – even though what is already known has many flaws – or whether there will be investment in ways which support people to experience the new and even unfamiliar, become that much more important.

What is in place now, designed by powerful others, and reflecting a stereotypical view of where people with developmental disability "belong", means that few services respond to the uniqueness, individuality, history, culture, wishes, desires and interests of individuals with developmental disability and their families.

Luckily there are people who are thinking differently and creating exceptions – sometimes starting with little or no funding. They are people who are prepared to dream and to take a leap into the unknown – essential elements for challenging the status quo.

Venturing into the unknown, however, is a scary business for most of us, let alone individuals and their families who are dependent on a large and distant service system to provide them with something, no matter how small or unresponsive. It's really only possible to take a leap of faith when you're not on your own, when you know that others are doing it, and you have others around you who will help explore the unknown and be with you if things don't go according to plan.

There is no recipe for building the support people with disability and their families need to help them dream of something different and more satisfying, only some essential ingredients.

Many parents, particularly, find asking others

for help a huge barrier to overcome. Finding ways to really meet the needs of the person with disability in their family in the face of a large and complex human service system with its impenetrable "accepted wisdom" is a scary place. When you have been engaged for a long period of time "doing battle" on your own, asking for help from others, or being prepared to be challenged in your thinking by others, is hard; it is, however, a necessary first step to creating something different.

The contributors to this edition of *Families for Change* offer their ideas and experiences to inspire readers to be prepared to take a leap of faith into the unknown, but not into the dark. Their insights are invaluable to people with disability and families who desire an ordinary life, characterised by those essentials which most people see as making for a real and ordinary life – being able to follow one's own interests and desires, decision-making and control, friends, one's own home, security, love and reciprocity, relationships, connections and a sense of contributing to the community and the economy.

Be they parents, workers, or social commentators, they emphasise some crucial ingredients, including:

- Being prepared to find others who will challenge your own thoughts and ideas
- Linking up with others who will support you on your journey into the unknown
- Not being afraid to ask others to join you in the quest
- Challenging yourself to step outside your comfort zone, whether you are a parent or a worker, a manager, a co-ordinator, a person with disability
- Not going along with the well-worn but false view that a real life can only happen for people who do not have high and complex support needs because of their disability
- Being sensibly unrealistic!

As more and more people strive to direct their energy to tread the untravelled roads, it is entirely possible to consider that the funding promises made by governments could really make a difference. Rather than investing in what has been around for a long time which often keeps people trapped in exclusion and powerlessness, there could be a larger investment in nurturing what might be – the yet unconsidered realities of inclusion and empowerment.

*"It's really only possible to take a leap of faith when you're not on your own, when you know that others are doing it, when you have others around you"*

### Inside this issue:

<b>Editorial: Unfamiliar Roads</b>	1
<b>Not Waiting: Creating</b>	2
<b>The Difficult Step of Letting Go</b>	4
<b>False Realism and the Unexplored Potential in People's Lives</b>	6
<b>A Personal Reflection on Making Authentic Change</b>	8
<b>Everyday Happiness in Heart, Home and Community</b>	10

# Not Waiting: Creating

By Margaret Rodgers

*Margaret Rodgers has a long involvement in the lives of people with disability and their families. In this article Margaret draws on her current work with Mamre Association's 'Building Informal Networks' project. The project emerged in response to separate requests for assistance from five men and their families. These young men wanted to get on with their lives, move out of home and make friends. Mamre is committed to working slowly and individually to explore the possibilities.*

In his book, 'A Bunch of Poesy', the Cartoonist, Michael Leunig has a cartoon entitled 'How to get there'. The directions for 'getting there' are as follows:

*Go to the end of the path until you get to the gate*

*Go through the gate and head straight out towards the horizon*

*Keep going towards the horizon*

*Sit down and have a rest every now and again*

*But keep on going. Just keep on with it.*

*Keep on going as far as you can.*

*That's how you get there.*

My work to build informal networks for five young men from the Mamre community in Brisbane emerged from their desire and the wishes of their families, that they be connected with other people. They wanted the opportunity to have friends, close relationships and to get on with life. These are hardly outrageous hopes and yet are often out of the reach of people with disability. Most people would agree that having strong, supportive networks around people can be a great starting point for other things to happen, but many people are left wondering how that can be done.

I think, that in our efforts to assist people with disability that we care about, a Leunig style framework like the one above is much more helpful than pretending there are 'Ten Easy Steps' or that there is a recipe somewhere.

In fact, embracing this quest means letting go of certainty and straight forward answers and muddling along until you find the right answer for that person, at that time. Using Leunig's directions on how to get there, I want to share with you some of what I have learnt.

**Go to the end of the path until you get to the gate.**

The important word is 'go': start now; do not wait; it is never too early and it is never too late to begin dreaming and scheming with this person about how they can live their own life or perhaps a fuller life. If you have been waiting then work out what you have been waiting for.

Many people wait for funding. Paid support will continue to be an important component of life for many people, but funding will never buy friendship, belonging, intimacy or commitment. These are things that money can not buy which means they can be worked on at any time. It is always an interesting exercise to do a stock

take on the resources you already have, both paid and unpaid, and to think about how they might be rearranged.

The gate is a good place to stop for a moment. If this is your job and you do not even know the person, or if this is a relative and their life is so tied up with yours that it is difficult to know where you stop and they start, then do not go through the gate. Wait at the gate until you are confident you can truly appreciate and represent the fullness of the person and the gifts they have to offer, and believe that they have a unique life of their own to live. You have to believe they are entitled to live their own life and not simply fit in to the lives of others. If you cannot do that, retrace your steps and find someone who can, or wait at the gate until the right person comes along.

**Go through the gate and head straight out towards the horizon.**

Once you've gone through the gate and made the commitment to the person, another important task in figuring out 'how to get there', is to spend some time working out where 'there' is or could be. This may involve the finely tuned skill of listening to a number of voices at once without forgetting what

you also know to be true. Listen carefully because some voices are practiced, articulate and seductively logical. Others are hesitant, afraid, unclear and can initially seem unreasonable. It is not a simple or quick process to find a balance between a person making their own decisions and choices, and the vulnerability that comes with disability. When you have heard what people want, it is good to be able to talk about it clearly because it may be your job to ask other people to help make it happen.

Find out who enjoys this person: ask about the people who love them, believe in them and see the best in them. This is not about finding people to fix the person; it is not about gathering people to be clever about another person's life. They are not unpaid workers in the disability field. It is about inviting them to share a part of life's journey with the person and being open to having the person share their life journey with them.

Ordinary people are interested and are sometimes just waiting to be asked. Ordinary people have a lot of information about ordinary life and relationships. There are people who know about budgeting and bank accounts and how clean a teenager's flat is likely to be. They have a good sense of what is not really important and what is downright unfair.

Find a way to give these interested people the information they need about what is happening and what

the person needs and an invitation to be involved. There are lots of ways that others have found to do this, but you will need to work out what will be best for the person you are supporting and their family. In some situations, having people work together as a group is very helpful, but this does not work for everyone.

**Keep going towards the horizon.**  
You can learn from others and listen to what they have tried.

***“Start now.  
Do not wait.  
It is never too early  
and it is never too late  
to begin dreaming”***

There is much literature on helpful approaches, such as person centered planning and circles of friends, but eventually you have to create and invent and muddle through to find something new and unique to this person. There is no computer program to shortcut this process. This is not a case of someone having the answer and refusing to share it with you. Listening to one more overseas speaker or reading one more book will not take away the need to eventually just start working it out.

**Sit down and have a rest every now and again.**

If you try something and it does not work, have a rest and a think and then try something else. Celebrate what has been achieved. One of the networks that I know keeps notes of their gatherings and progress because they expect things to change for their friend. They think this change might be slow and subtle, and they want to be able to look back and see how far he and they have come.

**But keep on going. Just keep on with it.**

Build and work and think and plan for the long term. If there is a group, make sure someone has the job of keeping the group working together over time. Get organised. Have guidelines about how you will work together. For some families, an important reason for building these networks is to have people who know their son or daughter well, *before* a crisis occurs or they are too old to keep on doing everything.

**Keep on going as far as you can. That's how you get there.**

Keep on going as far as you can and go as deep and as broad as you can. Go into the excitement and fun and the pain and frustration of a real and ordinary life. Just keep on going. If you think you have arrived, well perhaps you need to go back to the gate and wait there for a little while, and my wish for you is that you never get there.

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# The Difficult Step of Letting Go

By Roseann Schoch

*Roseann Schoch lives in Queensland. She is the mother of Martha and Dan. Dan is a young adult who has a disability; he wanted to move to his own place and Roseann, with the support of the organisation Mamre, helped him achieve his goal. This is the story of a journey, with its joys and its difficulties; but above all, this is an inspiration for all parents, siblings, aunts and uncles, or cousins who want to help their family member with disability get a life of their own.*

*"That's what he wants!"*

My son Dan approached Mamre and told them: "I want to leave home, fix it with Roseann." I am Roseann, and whilst I supported this idea of my son's leaving home, I felt it was quite a long way into the future, years in fact. It seemed so complicated, with issues to deal with such as Dan's readiness and ability to cope, my readiness and ability to address all that needed addressing, including gathering some financial resources to enable him to get set up, and having the focus and the energy to do it. Dan's friend had left home and Mamre had supported this happening, so obviously Dan knew that approaching Mamre was how you went about it.

We have been receiving support from Mamre for over 20 years and Dan has always loved going into respite there. I have enjoyed parents' weekends and Martha, Dan's sister, was on the sibling program when younger.

Margaret Rodgers, from Mamre, Dan and I started meeting about 10 months prior to his leaving home, but I still imagined then that the event was a long way off into the future. Dan was very ready to leave home in many ways, and had been expressing the need for some time. His name is on a public housing list but the wait is long. Our meetings, and some support being put in place

to help him improve his cooking skills, helped placate his frustration with the situation.

### *Asking for help*

Like most families of people with disability, I have issues with asking people for help and support. The issue of a support circle has been a difficult one for me, as I am quite steeped in doing it all on my own. I felt unable to ask anyone to be on a support circle but one day, during a lunch break at work, I was speaking to a few people about meetings in relation to Dan leaving home, and three of my colleagues said they would like to be involved. One other friend also voiced the will to be part of it, so we had what I call an "Arc" rather than a "Circle"! Somehow to me a circle would be a much larger number of people. Whilst we have asked the Arc to come together a few times to brainstorm, to date the group has not been an ongoing one, as some support circles are.

Margaret, Dan and I continued to meet throughout the year, searching out what Dan wanted in a place of his own, what skills Dan had, what support he would need etc. His requests were for a dishwasher, sliding doors (meaning built-in cupboards) and then... close to mum! Coming back from a great holiday in Sydney in January, feeling all refreshed and quite enlivened, Margaret seized on the

energy and said that we ought to get going and get the move happening before full-time teaching recommenced at the end of the month. I protested that I really didn't think that I was ready: I had just said goodbye to my 20 year old daughter, who was going to spend a couple of years in London! Margaret's response was "better at 54 than 74, Roseann!" And the gentle push was on.

### *House hunting*

Initially we had to decide which to get first, the house or the flatmate. We eventually decided on getting the house first, as even though this was more of a financial risk, it would secure the place for Dan. We used the normal channels of real estate agents and internet searches. A house quite close to me put "for rent" signs up, both an agent's and a private sign. I contacted the owner, who showed me through. It seemed great in many respects. It was very close to home, opposite a bus stop, had built-in cupboards, large living spaces, a no-maintenance yard, and even low benches in the kitchen and a low clothes line. In many ways it was just right. I decided to reveal to Rosemary, the owner, that I was looking for a place for my son, who has Down syndrome, and asked for her response. She stated that, in that case, she would want my name on the lease. From that I gathered that she had no further objections. So, after we had all looked over the

place, and went through various other places around, we decided to take it and put our application in to the agent.

The owner, without any explanation, rejected it. This was a huge blow to me as we had now lost a lot of time and I was due to start work within days. I wrote so many letters to Rosemary in my head, it was incredible. I had an absolute flow of words at times and one-liners kept screaming around in my mind.

It probably took me a week to regain my confidence and determination, and proceed again with the search for a house for Dan. Eventually we found his home and he moved in at the end of February. It is not quite as close to my place as the previous one but still within walking distance. It is a nice older 3 bedroom home; Dan is able to catch all the same buses as he did when he lived with me, and he is even closer to his Monday night washing up job at the local pizza restaurant.

#### ***Flatmate Wanted***

Our next step was to advertise for a flatmate. Ad's were put on the University and accommodation websites and also in some parishes' newsletters. By now it was near the end of February, so most students would have already had their accommodation organised but we got a response very quickly, and after speaking with the young man for a while, I enquired as to whether he had noted that Dan had a disability. His response was that that was irrelevant. He subsequently came for an interview

and wanted to accept on the spot. He had never had anything to do with anyone with a disability previously.

Ivan is a 20 year old man from Moscow who is studying at Queensland University of Technology. He told us he spends little time at home, but as we have no expectations of care from him other than being a flatmate, that was fine.

#### ***Letting go***

Missing Martha, experiencing "empty-nest syndrome", and needing

rather than have me assisting him. This has been a further "letting go of control" process for me as a parent. Sometimes "we find me" very resistant to this! Dan has now been in his own place for seven months. The agent and the owners are very happy with him as a tenant, and Ivan and he get on well when they see each other. Ivan has told me Dan is very kind, and very peaceful to live with, and he has no intention of leaving at this stage. Dan now has a support worker help him with the cleaning, shopping, rent paying etc. and cooking one

***"Like most families of people with disability,  
I have issues with asking people for help  
and support"***

something to look forward to, prompted me to organise to meet Martha in Turkey for my 3 week winter holidays. Leaving Dan was a huge step, but support was put in place for the things I had been assisting him with since his move, such as cleaning, shopping, rent paying etc. Again this was a further step in the "letting go" process, and giving up more control. We organised a social schedule of people visiting Dan, and Dan visiting for dinner. We also organised for Dan to cook and take dinner in to his neighbours' one night.

The results? Dan absolutely thrived in my absence, grew in confidence and wanted to continue having the outside support when I returned,

night a week when he invites friends over. Whilst initially needing extra financial support in order to set up his unfurnished house, Dan is now managing to live on his disability support pension.

Mamre has truly honoured and respected our family throughout the whole process. It is an organization in which I really trust and under the gentle guidance and promptings of Margaret Rodgers, Dan's desire to have his own place, live within the community and attain relative independence has been very successful to date. One day at a time.

Roseann Schoch shared this story at the "Inspirit Conference" organised by Mamre in Queensland, September 2005. Printed with kind permission of the author.

# False Realism and the Unexplored Potential in People's Lives

By Michael Kendrick

We live at a time when there is much emphasis on seeing people with disability as being people just like everyone else. This is a most welcome development, as people with disability have suffered greatly in not being seen as fully human, and not being treated as unique and interesting individuals in their own right. All of the attention has seemingly gone to endlessly evaluating what people are not, rather than better unleashing the hope and potential in people's lives. It is almost always true that people will tend to underestimate, rather than overestimate, what could be possible in life for people with disability.

A key factor in much of this is the extent to which most of us are limited by what we have not yet seen, experienced or believed to be feasible. Our beliefs about what is actually practical, and within the realm of reasonability, tend to be things which are already part of our life or theirs, rather than options which are as yet untried or unfamiliar. So, what we consider to be "realistic" is most often more of what has already happened rather than what has not yet happened. In many cases, we may be deeply sceptical of what is new simply because the old is so comfortable, even if it is not all that satisfying.

What we may forget in our ardent "realism", is that much of what today is now possible in life for people with disability was once considered "unrealistic" by many people, and more or less had to prove itself before people granted it the credibility it deserved. The option had actually been "realistic" all along, it was just that our previous sense of "realism" did not allow us to be sufficiently open to its potential. We were suffering from "false realism", insofar as we were actually wrong in our beliefs, given that the option was ultimately proven to be quite sensible. Now if that can happen in the past, it should be obvious that it is probably happening now in much the same way. The interesting question in all of this is, of course, what in the world are we dismissing as "unrealistic" today that will also, in the future, prove us to have been wrong yet again.

The alternative to "false realism" is not to abandon scepticism and a careful appraisal of whether or not something new and unfamiliar lives up to its billing. This would leave us unprotected against all manner of possible folly. No, the remedy is actually something quite different. It is in seeing that we need to be open to the unknown, because somewhere in its depths are ideas, options and potentials that are genuine and authentically good for people with disability. It is not sensible to walk away from

options that bring valuable benefits into our lives. Yet, when we take no time to explore and try such options, we are actually depriving ourselves of advantages that might well make a striking difference for the better in our lives. By all means we should fear the unknown, because of the dangers it may contain, but we should also be wise enough to recognise that the unknown and unfamiliar may also be a very good friend.

In order to be able to sort out what might be good in the unknown from what might be worrisome, we need to accept responsibility for entering the unknown, and seeing what it has to offer. This is what some people might call "imagining better" or "dreaming", in the sense that this is the way that we link the possible potentials in the unknown and unexplored to what is still missing in our lives, or the lives of people with disability. A "dream" is really just an image or picture of what might conceivably improve life, but it frequently is a crucial step towards eventually attempting something in one's life that offers the promise of fulfilment of our hopes, wants and needs. It is also the way in which we can try on the unknown for size, and see whether it is actually what we need or want.

If today's "reality" is not really meeting the needs of a person

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with disability, then it is logical that we should question today's "realism" as it is obviously not a reality that is helping. The question that then forms is "what might possibly be better than we have today?" When we take the step of wondering what might be better, we start becoming practical problem solvers. By not being married to what there is in life now, but rather by looking past today's reality to what ought to be there for people, we become engaged in the creation of new possibilities. In fact, we will make more progress if we are actually "sensibly unrealistic", insofar as we reach for something we cannot yet prove is realistic. We can, however, assume that there must be something awaiting us that will indeed prove to be good and beneficial though it is not yet part of our lives.

The best guide to what these options might be can usually be found by considering more carefully what it is that satisfies the needs and wants of people who do not live with a disability. In most cases, with a few adaptations that take account of the impairments that people may live with, highly "ordinary" options that work for all other people will normally prove to also work for people with disability. Even if those options are unknown or untested with people with disability, they are clearly

"proven" already with most of humankind. This is why it is highly likely that they will also work for people with disability, given that they are people like everyone else, with all the diversity and potential that being human offers.

***"When we take the step of wondering what might be better, we start becoming practical problem solvers"***

We might never attempt what is being suggested here if we become unduly preoccupied with what a particular person cannot do or be, as that negative emphasis will divert our attention from the more positive question of what the particular person would enjoy in life. Almost always, when this hopeful exploration is the emphasis, people's lives will expand in the direction of their true potential. What the person cannot do or manage might simply be done by others, thereby eliminating this as an issue. We are all dependent on others in life to take care of many things, so

even the need to be supported is quite typical, and ought not to be seen as being somehow unusual.

"True realism" as opposed to "false realism" comes about whenever we both give in to hope, and look beyond the moment to the promise of what life might yet offer. It in no way requires us to wear rose-coloured glasses or to ignore the many hardships and difficulties of life. It simply asks that we not become so preoccupied with the barriers in life that we no longer dream. When we resign ourselves to "reality", we forfeit the chance to taste the benefits of other unconsidered realities, many of which may be just as practical as any reality we rely on today.

There is a saying that "where there is life there is hope". This is most certainly true. Nonetheless, when hopes and dreams are ignored, or are undernourished, then life and its potentials will elude us. As we know, many dreams will not always come to be, but this should not stop us from dreaming. We dream not because we are assured that what we explore will be guaranteed, but rather that dreams link us to the deep promise of life and its potential. It is this potential that rightfully belongs to people with disability as much as anyone else. We must be very careful when we deny this to them in the name of realism.

# A Personal Reflection on Making 'Authentic' Change

by Deb Rouget

*Deb Rouget is the facilitator of the Personalised Lifestyle Assistance (PLA) project in Victoria, an initiative that empowers people with disability to lead valued, meaningful lives within their local communities. She has been involved in similar projects since 2001. In this article, the author explains why and how she started questioning the types of supports that are traditionally offered for people with disability, and how she got involved in supporting the "dreaming" of a person with disability and her family.*

As a professional, I had reached a point in my career when I began to question what I was doing. What was my purpose and role in all of this seemingly endless world of bureaucracy? I seemed to be continuously distracted by superficial advances, prestige, deadlines and priorities. I had lost sight of what I was meant to be doing. So I had to review my own passions, my strengths and what I felt I was put on this earth to do. It seemed that no one could tell me what to do... where are all those people who have all the answers when you need them!

For almost 18 years I searched a maze of technologies, ostensibly progressive practices and models and whatnot, and I couldn't find a key to unlock the mystery of assisting people who have a disability to gain "real" meaning in their lives. Like most, I was easily lured by the usual superficial changes and technologies such as congregate living, person-centred planning, segregated "inclusion" and so on. But my conscience kept telling me that there were so many inconsistencies between my life and that of the people I supported, no matter what technology we imposed. I knew that life had to be better for the people I supported but somehow I was stuck in a rut and I had lost my way. Even with good intentions, I had contributed and invested in what seemed to add up to disappointingly

superficial solutions and couldn't envisage any sort of change that would endure. Even though we seemed to ask the people we supported what their aspirations were, we seemed to lack the support arrangements and frameworks that would endeavour to support such visions in reality. At times we managed to support people with glimpses of community participation while the rest of their lives were a disaster.

So, I continued my search for change that was more real... not a change for the sake of change. I had to ask myself some tough questions and get to the essence of what really mattered to the people and what was unimportant. This led me to seeking out moments in life that I had actually already witnessed that were wonderful and true and then somehow build a vision or plan around the essence of them.

It was about this time that I was introduced to Michael Kendrick, who had often spoken of the existence of such instances where people who have a disability, together with their families and other allies (including some committed staff and people in authority) had created real changes and found some measure of progress and meaning in their life. Their essential claim was that people with disability and their families can be hugely positive and even innovative when the sense of what was needed

and possible was allowed to be an active and decisive force. A key caveat was that this was most likely to occur when they were *properly supported* in their "dreaming" or visioning.

It would have been easy to accept such advances without question. But all ideas need questioning and careful analysis. As I listened carefully and spoke to families and individuals in such personalised arrangements I could hear a sense of truth. As I listened to my heart, I could hear clearly that these options gave hope for a different version of life and achieved much of what was hoped for.

These examples and projects were not perfect and came, like all things in life, with ongoing challenges of their own (just as the people with disability and their families had claimed!) Unlike so many things that had been presented to me before as being seemingly complete solutions, these examples were a bit more of a paradox. People's lives were clearly improved in comparison to the past, yet they commonly spoke of life still being a struggle. So their story was more one of significant *progress* rather than *utopia*.

Around this time I also met a family who were also seeking some meaning in life for their daughter (who has multiple disabilities). So we embarked on a journey together



to seek a better version of community life for their daughter. The questions were – How could we make it happen? How could we create a vision that would build on their daughter’s unique gifts and abilities in the community and provide support that was arranged and influenced by her and her family rather than a service provider?

At times I felt like we were about to take a wild leap into the dark or abyss. We were nervous, uncertain and unsure but we had to take a risk on creating change that would save further

*together.* The courage of this family and their daughter, and other individuals and families, constantly amazes me. Often such families have been labelled as “trouble makers” but as I see it they have a gift of determination to create something better. They are *champions* who pave the way for other individuals and families to follow if they so desire.

I believe all people have the ability to be champions for themselves and for other human beings, as life is full of opportunities to be seized. Being

Being a champion of change means following your heart, doing what makes you most happy and taking risks... It’s about finding what gives you most meaning in life.

From the original vision and lots of hard work, a small family governed project was founded. Other families who wanted to create their own visions for their sons and daughters based on each individual’s unique talents and abilities gradually joined the project. Each person’s arrangement is considered unique and the model of support is negotiated with each person and their family so that they can lead a relevant and fulfilling life in the community.

***“Being a champion of change means following your heart, doing what makes you most happy and taking risks... it’s about finding what gives you most meaning in life”***

suffering and create meaning in life for their daughter. Once we made this decision and took the first steps we were off and running. We now felt like we had no time to lose. We had to go after their daughter’s vision with courage, energy, commitment, conviction and persistence otherwise it could be dismissed on a whim. We could no longer afford to spend time sitting on the fence otherwise we would be left behind. We also had to proceed with caution, create and foster good relationships and had to explore the “what ifs” in the form of a contingency plan. As you can guess, taking personal responsibility for things, rather than waiting for the system to define the rules, is quite a shift!

But as I reflect on these uncertain times at least I knew we were in this

a champion does not occur, however, if we are too tied up in ourselves, too lazy, afraid of what others might think, scared that someone may say no, afraid that our effort would only be considered a “drop in the ocean”, believe we have to be in a position of formal authority to make things happen, too scared of failure (mistakes are an inevitable part of life that help one to make better decisions for the future) or too scared of not getting things right. One should not get too tied up in dollars, although realise, like all people, people with disabilities live within a budget. But it was not necessarily about how much people have or don’t have but more a matter of what is done with the resources available.

In *The Alchemist*, Paulo Coelho, 1988, suggests that pursuing one’s ‘personal legend’ or dream is within the reach of *all* human beings, not just those who can perform alchemy (or the extremely talented and mystical). But the pursuit of one’s ‘personal legend’ takes courage, focus, persistence, guidance, reflection, determination and struggle. However, as the shepherd in *The Alchemist* pursued his ‘personal legend’ he was not only surprised by what he found in himself but the gift that the most unexpected supporters brought to his journey as they recognised his gift. I wonder if the shepherd would have realised his ‘personal legend’ without such encouragement and guidance from others. We cannot only pursue our own ‘personal legend’ or dreams but be with others as they pursue their own.

This article is an extract from Deb Rouget’s paper ‘Some Personal Reflections in the Bringing About Change More Authentically “with” People who Require Services’, presented at the “Can Dreams Become Reality” seminar in May 2002. Printed with kind permission of the author.

# Everyday Happiness in Heart, Home and Community

By Anita O'Brien

*Anita O'Brien lives in Victoria. In this article, she explains how she got inspired to better help her son Warren pursue his aspirations and the lifestyle he wanted. She details the steps the family followed to achieve the independent, rich and happy life that Warren enjoys now, and encourages other families to take this journey that leads to 'everyday happiness'. Anita and her family believed that Warren could participate and contribute to the life of his community, and be a valued member. Their belief is now a reality.*

Everyday happiness was only reclaimed for our son Warren when I decided that history was not going to dictate his life. As Professor Steve Trumble, Editor in Chief, Australian Family Physician, has said, "We have a dark history of segregating people with disabilities from the rest of society, ostensibly to allow each group to be happy in their ignorance of the other. We have condescended to people with disabilities through unwarranted allusions such as calling them 'eternal children', or 'God's special people.'"

I have been inspired by many people who have made substantial ground on supporting people with disability to pursue their aspirations and have similar opportunities that most people take for granted - to live in one's own place, work, have recreation time and make genuine friendships in the community. In early 2000, I attended a seminar by Michael Kendrick and both my heart and mind agreed, but I wasn't sure how to achieve the dream of assisting our son to have his own life and not one dictated to by systems and in traditional settings. At the same time, Deb Rouget of Personalised Lifestyle Assistance was encouraging parents to dream of something better. It was not until 2005, after attending a seminar in which the parents of the Canadian accommodation and lifestyle model 'Deohaeko' presented their story, that I saw the exciting possibilities. This was followed up by linking

with a family governed project, participating at the Mamre conference in Brisbane, and spending a weekend with the Community Living Project in Adelaide.

The light had dawned that it was possible. Warren did not have to continue on the path that was expected by society, or wear the client role; we dared to help him dream of a life of choice, of feeling happy, and of being valued. We believed he could participate in, and contribute to, the life of his community and be appreciated for the person he is, with his own unique gifts and abilities.

Warren is 31 years old. He has a good sense of humour and is very caring and sensitive to the needs of others. He enjoys being with other people who share his sense of humour and fun and therefore naturally connect with him. He is passionate about music and art, and he is very interested in the city of Melbourne and its architecture. He enjoys taking care of his small dog, Bono, who helps him in accepting responsibility.

Due to his disability, Warren needs support to plan, work and travel. Knowing his surroundings and being able to negotiate within them independently is very important to him. Some years of planning and training have helped him increase his independence, identify needs and

prepare for an individualised approach to support; however, due to lack of funding, this choice has not eventuated as yet.

Warren has spent much of his time in segregated settings, and in the last three years this has happened to a greater degree by living in a group home as well as attending an Adult Training Support Service. He does not need 24 hour support, in fact much less, but does require support that is focused on his individual needs. He was missing the friends he grew up with, spending quality time with his family, and his church family; even though we tried to make some of this happen for him, he was aware that there was something better.

Whilst we were grateful for the welcoming and caring people providing assistance in the home, being in a congregated disability setting most of the time was dragging him down. Some residents, in their supportive way, were taking over tasks that Warren needed to be doing himself, and he had one person who was always telling him what to do. This was increasing his anxiety, and though he was bravely making the best of it, he was not happy.

Last winter we had a conversation with Warren about the different options of places to live. He chose to come to the flat below the family home, to the community in which he

lived. Why? His response was simple and clear: "Because it's better." Three months later he moved out the group home, and at the end of the year he left the training support service as well: a step in faith. This meant a time where he had no funding – whilst we needed to be creative he did have freedom to choose!

Since February 2006 he has been in the flat with his housemates Ashley and John, a young married couple who provide support in lieu of rent and enjoy Warren's company as he enjoys theirs. Ashley has experience as a support worker: I had some conversations with her about Warren living in his own place and pursuing his aspirations in the community. When I asked whether they would be interested in being Warren's housemates, her eyes lit up and that was the 'start of a beautiful friendship'.

Warren is developing friendships with his housemates' family and friends and this has enriched his life. His housemates ensure the relationship is as natural as possible, encouraging Warren to participate in tasks around the house, and providing the prompts and assistance he needs. They listen to him with the heart and the head.

Warren has recently been granted some funding that helps with the rent and some support for activities in the community; however, it has been necessary to be quite creative to ensure his days are meaningful and affordable. This means that we need to draw the community into Warren's life.

Apart from spending a day at a

funded arts project, he is working with an artist and they have set up a studio in the home. His friend Chris helps inspire his art by tapping into Warren's love of the city, by visiting places of interest, taking photos of

***“Making the vision happen’ has led my son to commencing the journey that will allow him to have the lifestyle of his choice and the natural friendships, relationships and supports that follow”***

buildings and scenes, and frequenting art galleries.

Warren is also currently realising a life long dream. He has always been a passionate supporter of the police. After a few months writing letters and conversing with staff at the local police station, Warren was given the opportunity to regularly visit the station as a volunteer, where the staff have been wonderful in their approach and made him feel so welcomed.

One important thing to remember is never sit back and say: "Well, that's organised," because it not only takes careful planning but sensitive ongoing management to ensure everyone involved understands the needs and is appropriately supported.

This recent decision to 'make the vision happen' has led Warren to moving back into the community where he grew up and commencing the journey that will allow him to have the lifestyle of his choice, and the natural friendships, relationships and supports that follow. It is a gradual development from building his skills within the framework of some community roles, and some activities that are in supported programs. The people in his 'circle of support' that we have just started will help with ideas born from their own interests and contacts, and also contribute in a meaningful way from their knowledge of Warren, some over years and others who have just come into his life.

For us as parents it is new journey, and it is a continuing work to help him redesign his life. Helping organisations and people understand that Warren wants to contribute as a volunteer is often a challenge, particularly for people who may have known him for a few years and see him as someone who needs to be looked after.

Warren has adapted well to circumstances in his life and is usually the one that lifts the feeling in a place and makes comments that cheer others. However, he is now experiencing a sense of everyday happiness and contentment that has been missing for quite a while. We still have much to do and areas to improve, but it is better and it is worth it!

Be brave. Be prepared for hard work. Don't be afraid to ask. Sometimes 'no' means "try a different way". Remember it's a journey. Expect happiness!

**family**  
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## Family

Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

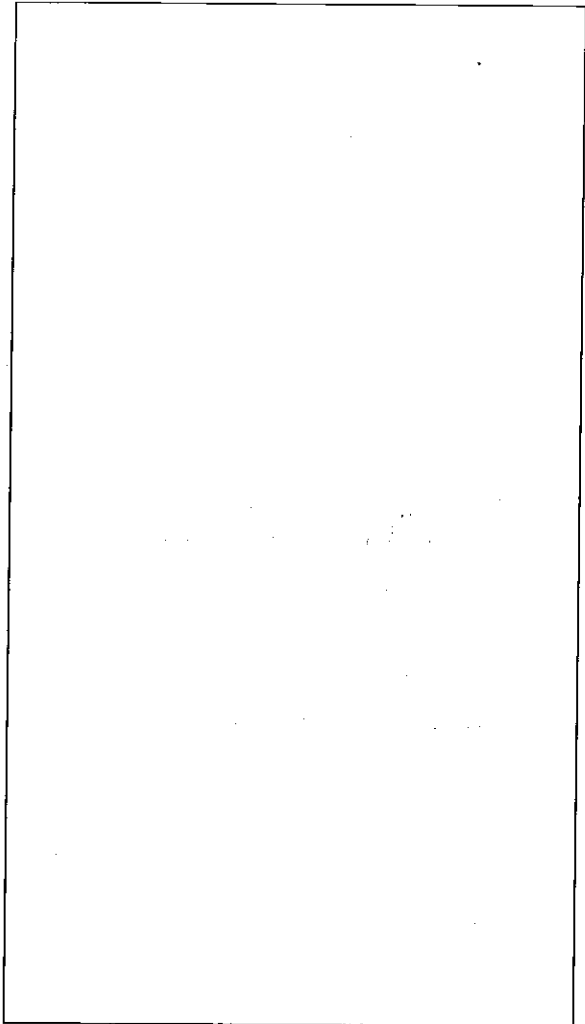
## Advocacy

Standing alongside an individual who is disadvantaged – and speaking out on their behalf in a way that represents the best interests of that person.

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