

Challenging the Myth that One Size Fits All Community Resource Unit Conference, QLD, February 2007

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Deb Rouget Personalised Lifestyle Assistance project

Deb Rouget has lived in Melbourne all of her life and has two children. She has spent over 25 years supporting adults who have a disability and families in various capacities. She is currently the Facilitator of a small grass roots project in Victoria called the Personalised Lifestyle Assistance (PLA) project. The PLA project assists individuals with disabilities and their families to develop, initiate, and sustain small consumer/family governed, socially inclusive personalised support arrangements and projects. 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 will share some stories and share some of the lessons that have come from individuals and families as they seek unique lifestyle enriched by community. The Personal Lifestyle Assistance Project is an ongoing Statewide independent consumer/family assistance that has been supported by the Victorian Department of Human Services.

The danger of myths

The Oxford Dictionary, 2001 states that a myth, is an old story about ancient times or an untrue story or belief i.e. something that is actually false or incorrect. The problem with relying on myth is that it may lead one to believe that it is the actual truth.

It is fortunate that we have people amongst us who search for the truth. Scientists and others who persistently ask, "what would happen if all I believe is right might actually be wrong"! They push the boundaries and in doing so dispel many myths.

For example how many of you think that the chicken breasts we purchase for cooking today are larger than a few decades ago because of the hormones they put into chickens?

According to research Dr Ian Godwin has found that hormones have not been given to Australian chickens in over 40 years. Chickens today are four times bigger than they used to be due to improved breeding programs, feeding and farm management (in Kruszelnicki, 2005). It's claimed that 80% of Australians believe that chickens are injected with hormones. I certainly did!

So what then does all of this mean for us as we support people who have a disability? Simply there are potentially many myths that we may see as truths that may prevent us from searching for better. One such myth is that people with a disability are generally safer in “special settings”. Research has indicated that this is not generally the case. Sobsey and Mansell (1990) found the risk of sexual abuse in institutional settings i.e. residential and group homes is two to four times higher than the risk when the individual is in the community. This is not to say segregated settings are unsafe but we need to challenge the myth that they are automatically safer than the community.

Another myth is that “one size fits all”. That just because you have a disability you need the same solution as all other people who have a disability. This, as Jane Sherwin suggested is like saying all people who wear glasses need to live together. You could also say that all blondes should work together (imagine the type of work that would get done!) or all men should live together (that may seem appealing to some)! You may laugh at this but sadly in reality, for many people with disabilities, the attraction to view all needs of a particular disability as the same, has led to many standardised responses that can't possibly meet the uniquely complex needs of each individual. No one needs to be with “their own kind” rather every human being needs to be supported to lead their own uniquely fulfilling life.

Clearly we have missed something in the lives of people with a disability as many individuals and families continually appear dissatisfied with their lot in life. What if we began to question that all that we previously believed to be correct a myth and there could be other answers? That perhaps we have been misguided by the perpetuation of certain myths and assumptions. What if we believed segregation and congregation was no longer the answer? Would that open us to searching for new ideas and solutions? What if we believed that people with disabilities could lead a uniquely tailored, personally fulfilling life in the community like most people take for granted? Perhaps that would open us to the questions of how might we achieve this.

Introduction

Our humble beginnings in Melbourne started almost seven year ago around one individual and her family. I must admit we did not actively set out to challenge such myths. But we challenged by people like Michael Kendrick and begun to ask questions about how we could assist people to work towards lives that were personally meaningful, relevant, inclusive, well supported and guided by the people themselves. Today Maureen, Anita and I are going to share with you only few stories of some of the people's lives we have been involved with and how with a different way of thinking, in our own small way, we challenged some of the myths that exist today that prevent many people with disabilities having the same opportunities as each of us in this room take for granted i.e. to study, work, recreate, live in one's own place, enjoy a range of relationships and have fun in the community.

In doing so we are very grateful to people for opening up their lives and sharing them with us. Due to respect for people we will not describe every detail of their life or the many areas in which they need assistance. Thus we

ask you not to dismiss their stories as insignificant or unlikely to work for others. We had no criteria for the people who asked for our assistance other than a desire to lead a good life, their own life, in the community.

You may say that the people we support do not have significant disabilities – that is not true. You may say all of those people have very active families – that is not always true. You may say people do not have medical needs – that is not true. You may say people do not have physical disabilities or autism or mental illness or need 24-hour support – that is not true! You may say it would take more money – that is not true. You may say the service systems you have in Victoria are better – that is not true (although we have had some very good support from some services and the Department of Human Services). You may say we have had it easy – that is not true. You may say that wouldn't work for my son or daughter or the people I support – We can't answer this and perhaps we don't know until we have tried! We ask you today to set aside these thoughts and ask yourself how it could be done for the person you love. Just as we did.

It must be acknowledged that in the scheme of things our efforts are small and embryonic. We continue to learn from the many experiences and wisdoms that come from people with a disability themselves, their families and allies. This in essence is what drove our efforts from the beginning and what continues to drive them today. We do not claim our efforts to be a panacea but in their own small way they provide significant learnings for the future.

Our Vision

“The PLA project believes that **all** people should have the opportunity to pursue a *unique* lifestyle that is *personally meaningful, relevant* and *typically* intertwined in the *community*.”

What the PLA project does

The PLA project is a small, assistive resource project that is funded for approximately 25 hours per week. It stemmed from people and families who wanted to:

- Create “typical” lifestyle responses and supports (that foster community inclusion)
- Create personalised (**one person at a time**) supports
- Give people genuine influence and self determination over all aspects of their own lifestyles

We are not a service as such. We do not do “case management”. We are a small, grass roots assistive project that sits “with” people to imagine better around each person's fundamental needs and aspirations in inclusive ways. We do not do “for” but try and work out “with” people what might be needed to get a good inclusive life.

Many times we have had to assist people to design things from scratch because what they were seeking did not exist.

We have assisted in the development of a number of small grass roots collectives or projects. These include One by One (a “post school options project), Living Distinctive Lives (a small “live in your own place project), Yoorooga (similar to Living Distinctive Lives but in country Victoria), EQAL (a small business and community lifestyle project) and NightLife (a flexible mobile night time assistance project similar to Mobile Attendant Care in Brisbane). These projects do not belong to the PLA project. They were stemmed from the people themselves to address particular needs and thus they belong to the people who are involved with them. People only gain assistance from us when required. We also provide assistance to individuals, agencies, The Department of Human Services and organise certain leadership and training events.

The PLA project has tried to ensure is that it is not just about what is provided but “*how*” it is provided. Thus a great deal of time is spent not only on developing people’s visions but creating sound *principles and ethics* that restore each person’s unique personhood and way of life in the community.

We would now like to share with you some stories because at the end of the day it’s what is done in people’s lives that count!

The One by One story

Deb Rouget

One by One emerged from most of the families who were original members of Person by Person. It started in 2000 with some inspiration from Michael Kendrick and a particular family who had wanted to create meaningful community life for their daughter. At the time there few options for people with disabilities if they wanted to create their own unique life in the community. Eventually as her life in the community developed, this one example provided some inspiration to develop a small family governed project. We developed a vision and framework with guiding principles and proposed a structure to the Department of Human Services, which was eventually supported. Gradually 7 other individuals and families joined.

Today One by One is a small family governed arrangement in Melbourne that has a vision to create highly tailored personalised support arrangements around each of their daughters so they can follow natural pathways e.g. work, recreate, study and develop friendships in the community. Each person (together with their family and advocates if necessary) develops their own vision for their future and has influence over their allocated funding and other resources to craft a unique support arrangement that is personally relevant and fulfilling. In this sense no two individuals supported by One by One do anything together because they want different things out of life.

The individuals supported have now taken up many valued roles within the community that were previously not available because of the standardised or congregate supports generally offered by traditional services. Such individual roles include work, volunteering, further education, recreation, membership of

specific interest groups etc. This has also led to the development of many valued skills, relationships and networks.

One by One have also chosen a Coordinator, Adele Braun to assist in the lives of each person and the project as a whole.

As people and families did not want to become burdened with the fiscal and legal responsibilities of receiving their own funding directly, they employed a "host" agency (Melba Support Services). The host agency stays in the background while taking care of administration and legal requirements. The host agency has become a strong ally for the project and its vision. The people and families of One by One have demonstrated (over a five year period) that *small* grass roots efforts are sustainable, financially viable and often get closer to what is actually wanted and needed by people. Thus counter balancing the notion that services need to be large and maintain a corporate image to remain viable. It has also demonstrated that high degrees of influence/governance at both an individual and project level by people who have a disability and their families/advocates can be created and maintained via a hosting arrangement.

I would now like to introduce Maureen McLeish who's family is a member of One by One. She will share Lauren, her daughter's story with you.

One by One – Assisting Lauren to Enjoy a Good Community Life

Maureen McLeish

Maureen McLeish has three children - Lauren, Carly and Cameron and two grand children. She and her husband, Murdoch lives in Glen Iris Victoria and have a small printing business. Lauren is nearly 23 years of age and although she has Cerebral Palsy it has not, with the right supports prevented her from pursuing her passion around film, movies and television in the community. Lauren and her family are members of One by One. One by One is a small family governed arrangement in Melbourne that aims to assists people primarily with intellectual & multiple disabilities & their families to imagine & create lifestyles that are unique, based on each individual's aspirations & enriched by genuine inclusion in the community.

Lauren is a wonderful young woman. She is nearly 23 years of age and is a movie and television buff.

Lauren's life did not have a smooth beginning! She has Cerebral Palsy due to complications at birth when she had a stroke. For the first 12 years of her life, Lauren had intractable epilepsy that has since been stabilised with brain surgery known as a partial hemispherectomy, where she has had 2/3's of one side of her brain removed. Due to the stroke, Lauren has limited use of her left hand. So you can imagine that life was not all that easy for Lauren and us as a family.

On leaving school Lauren went to TAFE to explore further education and with the thought that she may be able to find mainstream employment. She

participated in a Transition in Education Program at two different TAFE college but was not able to find anything that really appealed to her and would assist her in employment, or to get an inclusive life in the community. Frustrations grew as Lauren was unhappy with the congregate ‘schooling’ arrangement.

It was at this point that we were looking for other ideas and options. With a group of friends who were thinking along the same lines, we became part of One by One. This is a small family governed framework that assists Lauren to participate and achieve a flexible, inclusive lifestyle in the community. One By One is a semi autonomous, family governed body that employ their own Coordinator who assists each individual member and their family. An important principle of One by One is to ensure we focus our energies where they are most needed. That is to work towards a good life for each individual supported. To enable this to occur we have an agreement with Melba Support Services who “hosts” our project. Melba Support Services take care of certain tasks for us. For example, administration, receiving and acquitting of funding, employing our support workers (which each person and family choose) and other legal and reporting requirements.

Lauren does receive some individualised funding (Futures For Young Adults) and it is this funding that pays for some of Lauren’s support. The funds come from DHS and are “hosted” by Melba Support Services in a separate account for Lauren.

The flexibility of One by One enables Lauren the opportunity to pursue her own voluntary position in the community, her hobbies and interests. Through such contribution to the community Lauren has the opportunity to continue to grow in confidence and to become more independent.

Lauren is passionate about TV. She loves watching it. Initially the thought of trying to find something genuinely inclusive, that would encapsulate her hobby, appeared challenging. So some creative thinking around her hobby was important. It took some support to think outside the square and *imagine* where her interest could be pursued in the community, as it was something you often did by yourself or in a program with other people who have disabilities!

Some work experience at a local Video store was the first step. Then Lauren applied to be a volunteer at ACMI in Federation Square where she got the position as an usher in the cinema on a Monday. Then she applied to work as a volunteer in the Marketing Department on a Tuesday. So her life kept building on her interest in TV and movies.

At first, Lauren was supported in her job by her own Support Worker, but as her confidence grew the support came from her colleagues at ACMI and the Support Worker was able to step back. This enabled Lauren’s Support Worker to start investigating other things Lauren could pursue in the community based on her vision and plan.

Lauren then applied for a position as a Program Seller at the Playbox-Malthouse Theatre. This was a paid job on the occasional Saturday and Lauren needed support to attend. It was challenging for her as there was money involved and this is not a skill Lauren excels in. As the job progressed she was offered another position in the cloakroom, but she found this isolating and this role has since faded away. We could see that Lauren was even developing a sense through experience of what she really wanted to do with her life.

In trying to assist Lauren and keep her life flexible and interesting, she pursued many of her interests. She is a keen sports fan and a member of the North Melbourne Kangaroo's football club. She attends regular Weight Watchers meetings where she is included in a very supportive group of friends who help her make healthy choices with her food. She has a walking companion one afternoon a week and participates in fun run/walks on a regular basis.

At one time, I thought it would be helpful if Lauren learnt to cook. Her Support Worker researched an appropriate venue and Lauren was all set to go. She then decided she would rather learn to dance! So a dance class was researched and she was supported by her Aunt to go dancing every Saturday. After a year of dancing she decided to learn a language and give up dancing! So she went to a night course to learn to speak Dutch. Soon she is going to Holland to practice what she learnt! Now she wants to do a wine appreciation course.

Lauren was also a performer in the closing ceremony of the Commonwealth games in Melbourne. This was an amazing experience for Lauren. Along with other performers she was sworn to secrecy about the performance. She was not to tell anyone. Even though I tried extremely hard to illicit this information from Lauren she would not tell me! She along with hundreds of other people practiced for hours and performed as Dame Edna!

This is where Lauren's life and plan must be flexible and appropriate for her, not for me! Remember I wanted her to learn to cook! Like her siblings, Lauren doesn't always agree with her parent's point of view!

There are still lots to work on, and the future is always challenging. Building and maintaining Lauren's confidence is always something we need to work on. We are trying to find an appropriate youth group for her to join. Learning to travel is a huge part of Lauren increasing her independence, but seeing the way she has learnt to use the phone and make some of her own arrangements with the One by One Coordinator is most rewarding.

With this assistance for Lauren, she has grown as a person. In doing so we have also been able to find time to pursue our own interests and also spend time with our other children and grand child as well.

Felicity's story

Deb Rouget

Felicity and her family joined One by One in 2000. At the time she was living with her family and attended a segregated TAFE program. We developed a vision around Felicity and in the beginning she had two hours of paid individualised support. With some creative thinking and persistence around Felicity and her community seven years on she works in Safeway, volunteers at a number of community houses, has had her own market stall, volunteers at a nursing home and is well know in her local community.

She has recently just moved into her own flat and is now a very proud homeowner. This is an amazing achievement because seven years ago we thought this would never be possible!

Cameron's story

Deb Rouget

Cameron is a great young man who lives in country Victoria. As he approached adult life he wanted to move from his family home like his brother and sister but due to not getting supports right around his disability (both an intellectual disability and mental illness) several attempts had previously failed.

We started with assisting Cameron and his family to build a vision and design his unique supports based on his needs and desires. Although his family's original thoughts were for him to share with another person with a disability, when exposed to other life sharing options Cameron clearly articulated he was more interested in a person's qualities rather than their label! It also seemed that sharing with a person without a disability had many advantages. For example, it would give Cameron an ordinary experience of sharing with a person of his choice and he would gain the supports he needed in a natural, unpaid capacity thus saving on costly resources and avoiding a life of "staff" driven supports and rosters. Cameron also wanted to get a job.

Cameron's parents did not want to run a business to assist Cameron to get a life so they use a local agency to "host" his resources and take care of the administration, reporting and legal aspects of receiving funds. This arrangement has worked well with mutual understanding and gives Cameron and his family authority over his resources. This includes how they are used i.e. where, when and with whom. To cut a long story short after submitting a proposal of Cameron's vision with the assistance of the PLA project to DHS, Cameron's proposal and vision was supported with much enthusiasm.

The rest is now history. As Cameron couldn't be with us today he has asked me to read his paper. It's called...

Escaping Mum and Dad!

Cameron Skinner

Hello ladies and gentlemen my name is Cameron Skinner and I am speaking today about getting my own place and my story. It all started when myself Mum and Dad and a lady called Deb Rouget from Personalised Lifestyle Assistance project had a meeting about what I wanted to do in the future.

I told Deb that I wanted to live in my own house with a friend and to have a proper job, but we didn't know how to go about this. I told her that I am a sports nut and follow football and cricket. My football team is Collingwood.

A few months later when we got the money from the Department of Human Services to help us we started to look at finding a house and a housemate and someone to help me find a job. The first house we looked at we got and I lived there for 2 and a half years. Then we found a housemate Caroline who lived with me for 1 year. We then looked around for another housemate and we got Brian, he is a baker and we get on really well. He is a volunteer at the CFA. [Both Caroline and Brian receive free rent for the support they offer Cameron].

Early this year my landlord, Murray, who has become my friend, needed his house and Brian and I had to move. Murray helped us find another house and it is just across the road from Murray's house.

I have a support worker called Denise who helped me find a job. It took us nearly a year to find a job, which was a traineeship at the beginning but is now permanent. I am a receptionist at a company called the Jerimiah Group. I love my work and I have been working at Jerimiah for 18 months.

I work part time for 4 days a week and answer the phone, see people when they come in and some data entry into the computer. My job is ongoing as everyone is happy with my work. I work with 10 people and we get on really well. Whenever I need help with things they are happy to help me. Sometimes they get Denise, my support worker, to come in and help me if it is a bit hard.

I'm really glad that I moved out of Mum and Dad's into Warragul, because there are more things to do, like bowling, the movies, visiting friends, social group and I go to a self development course.

My friends from work came to my 30th birthday party last year as well as my family and other friends. There were over 60 people. I organized it all myself and we had a terrific night. My work friends gave me a Collingwood jumper and the next week they asked me to bring in the jumper to work to show someone. They asked Dale Thomas the Collingwood player to come in and meet me and sign my jumper. That was the best thing, he gave me his autograph and I had my photo taken with him.

So to people with a disability and their parents and the people that work with them I say have a go, work out what you want in your life and make it happen. You can be like me and escape your mum and dad!

Several months after Cameron moved into his first home his parents were able to fulfil their dream of travelling around Australia for twelve months. Cameron's family created a circle of natural supports (i.e. family and friends) around Cameron to assist him during this period. This circle of support has endured over time offering Cameron an important friendship and a vital safeguard for the future if something were to happen to Maggie and Greg.

Living Distinctive Lives (LDL) Deb Rouget

Living Distinctive Lives (LDL) is located in the Eastern metropolitan region of Melbourne. It's a small, semi autonomous, family governed hosted project. It was established to support up to 10 people to live in their own place with a range of informal and formal supports. It also aims to support each person to become a valued member of his or her community.

Living Distinctive Lives has formed a Governance Group of families and they have chosen and employed a "host" agency. They have selected a Project Worker who assists families on both an individual and collective level. There are currently five members building their *own* visions and each person has plans to move into their own place and pursue a unique lifestyle in the community.

Anita will now hear her son, Warren's story.

Group Home or My Home – What will it Mean

Anita O'Brien

Anita and Alan live in Doncaster in Melbourne. They have two sons, Mathew and Warren. Anita will share their family's journey of trying to find a lifestyle with Warren so that he could have the same opportunities as Mathew. That is to live in his own place, develop relationships, lead a valued lifestyle and follow his aspirations. Anita has a passion for not only assisting her own son to follow his dreams but to assist other families who are interested in community and natural pathways. Her family are members of a small family governed project called Living Distinctive Lives.

Who is Warren

Warren has a delightful nature, a good sense of humour, is caring and sensitive to the needs of others, loves to socialise and has a strong sense of justice. To thrive, Warren needs to be in environments where he wants to be! And with people who value him, who talk to him, with whom he relates! He needs lots of different relationships.

In 2002 after Warren participated in a 20-week live-in independence program we decided we would help him to be as independent as possible, living in the flat below our home. But Warren's anxiety increased, and he was sometimes physically ill in the mornings - he was lonely! Where to now!

Well I was so excited:

- I found a family governed group home set up by a parent I already knew, and there was a place for Warren. It wasn't in our area unfortunately, but at least I felt that we would have some say in the way the home is managed.
- I had been working for ten years to do this myself, so this was at least start towards our own group home.
- I thought he would have people to share his day with.
- It wasn't perfect, and I felt a little uncertain, yet what other options were there? I decided to work with it.

You might ask why we would we take our son out of a group home that was family-governed and not governed by the system, a place, you might think, in which he was safe and had friends to go out with.

Why would we take him out of an ATSS day program at the same time and place him and ourselves in a situation where we knew we would have to be very creative, without any funding to start with, to provide him with a meaningful day.

Simply put, our son was not happy and although he always tried to make the best of each situation in life, he was telling us this is not what he wanted for his life by his demeanour, anxiety, and actions. He was not presenting at his best – personal hygiene was not good enough! He was very anxious! One day when I took him back to the house he would not get out of the car. The next day I took him out for lunch and he ended up being physically sick due to his anxiety over not wanting to be where we were asking him to live. Choices were limited!

Eventually, through the influence of many people, such as Deb, the Deohaeko families from Canada, and finally the Mamre Conference in 2005, I saw the possibility of Warren living in his own home, and having a high degree of influence over the kind of life he wanted – in community, where it all happens.

So we developed a VISION for Warren to have the life of a typical 30 year old, one that saw him on the natural pathways of life, in valued roles that make sense for him. In July 2005 we had a conversation with Warren about where he wanted to live, giving him options, and he chose to come home to the flat below the family home and the community in which he lived. Why? He gave the simple reply: "because it's better". He returned home late 2005, which meant removing him totally at the end of the year from his ATSS as well, a step in faith.

Everyday happiness for him was restored when he returned to the community he grew up in and started the journey to an *ordinary life*.

Our challenge was to do it better, for him to have his own home, to seek housemates and develop a life in the community, assisted by a Circle of Support. This meant a time where he had no funding, and whilst we needed to be creative he did have freedom to choose! Whilst Agencies can assist and often do well, we are not relying on them for our son's future happiness. We wanted to have people who care about Warren in his life, and assist him to develop many different kinds of relationships, because we believe it is people that will keep him safe and help to maintain his 'ordinary' life.

Sharing my home with housemates

Warren returned to our Doncaster East to the family home eighteen months ago. He is living in a two-bedroom/two bathroom flat on the lower level of our home.

Twelve months ago a young married couple came to share his home as housemates, and provide the individual support he needs for daily living.

- Warren, Ashley and John (and now Molly born on 29th December) are all enjoying each other's company.
- Warren is developing friendships with their family and friends and it has enriched his life.
- Ashley and John work very hard to 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 are very sensitive to him and listen to him with the heart and the head.
- They go out for coffee, Warren has lunch out with John, he has a drum lesson with John's brother, and sometimes Saturday lunch with their family, they sometimes go to church together, they have friends over for a meal.
- There are still struggles and challenges, particularly around helping him to communicate his feelings, but he is most definitely doing that now. The other day he told me, then John, then Ashley, then his father that he did not want to do something we had arranged for him. We thought it was a good idea and Warren agreed initially, but we had not talked to him enough as we did the organising.
- Having his flat below our home has its own challenges of course, and we need to keep open the lines of communication to ensure the intentions of Warren having his own place and being supported in his new life are a reality; and to ensure the well being and happiness of everyone.

In developing a range of both formal and informal supports we have found that:

- The inclusion of housemates as part of the support structure for a person with support needs is most beneficial and renders the budgeting of available funding affordable.
- The natural support of housemates can be targeted at the times and in the way that it is required.
- The arrangement provides opportunities for the development of natural relationships and friendships.
- Housemates can be a pivotal link to other supporters (both natural and paid), and they can provide invaluable insight when participating in the 'Circles of Support' that is a crucial element in the support plan.
- Whilst it may not be for everyone, this is one of the most valuable ways to support an individual with a disability in their own home, so that they can live a life that is typical of others in the community.

Circle of Support

In this journey, we felt that a Circle of Support for Warren, and us his family, was essential to help him accomplish his goals. The members of the circle include family, friends and others who have been involved in his life, and who have agreed to meet together on a regular basis. They are not paid to be there and are involved because they care enough about Warren to give their time and energy to help him overcome obstacles and increase the options, which are open to him.

We started by inviting the people who we were aware made Warren feel loved and valued and related well to him. We asked them to come to an evening to share in Warren's recent successes and talk about ways in which he could continue to pursue his interests and dreams. We explained that he had commenced pursuing a more independent life, with new work and activities, and was living in his own flat with housemates. It is the Circle's purpose to create the best possible community lifestyle with Warren.

In 'get-togethers' we have:

- Celebrated with him
- Agreed on a Circle objective
- Identified who Warren is, his passions, interests, skills and abilities
- Identified what gives him energy and what doesn't
- Focused on a passion or interest and explored all the possibilities, such as events, groups that meet, work, volunteering
- Talked about his fundamental needs, such as freedom to make choices, self worth and recognition, maintaining a sense of belonging.

We are gradually searching out opportunities, and learning how best to conduct the meetings to help Warren feel comfortable and assist him to contribute his ideas and communicate what he wants to do.

What Warren's week looks like today

Since September last year, Warren has been volunteering on a Monday at St Vincent' Hospital in Melbourne. He works in the Executive Department doing their shredding and other office duties. Jenny, his support person, carefully assists him to make the connections and to develop the relationships – she knows it is his job and is very careful to stand back when not needed. Recently he was asked to volunteer at the Grand Prix and it is anticipated that more opportunities in his volunteer capacity will arise.

Warren also volunteers one day a week at lunchtime at The Salvos Coffee Shop. This is at his church - a place he loves to be – where there is a chance to develop and nurture relationships.

Warren is *passionate* about the police. One of the ways we commenced the connection with the local police was to attend their open day. He loved being there and his interest was obvious – even asking a question of the officer who took our small group on a tour the Station.

For six months Warren was given the opportunity to regularly visit the local Police Station as a volunteer, where the staff were wonderful in their approach and made him feel so welcomed. The day that he went there was the day he was up on time preparing for the day ahead. It took careful planning and sensitive on-going management to ensure everyone involved understood the needs and was appropriately supported. After trying out a couple of jobs, including cleaning out the cells, his job as 'chief shredder' was established. This was a dream come true. His self esteem ski-rocketed on Fridays. He was delighted to be asked back to a Christmas morning tea where he very easily chatted to the staff and felt quite at home. He even told the sergeant he should give him his job back. He has also been asked to be involved and contribute on their Open Day this year.

Further research for Warren to be involved in some way with the Police continues, as this is his area of passion. He will shortly commence a job delivering the 'Neighbourhood Watch' newsletter.

The Circle of Support, his family and friends will safeguard Warren's vision for an ordinary life. These are people who care about his fundamental needs - for love and belonging, self worth and recognition, freedom to make choices, to have fun and feel secure.

Sharing our Insights

- Warren thrives on being in environments that are meaningful to him and in which he feels valued. Connecting and relating to people are important to him, and he has the ability to develop relationships when supported by a person who understands and embraces the principles of community inclusion, belonging and contribution.
- Housemates for Warren has meant a new family and friends in his life, and people who listen to him carefully. It is important that there are intentional times of just being together, just like any family.

- By linking to his passion around the police, an opportunity arose that gave him great self esteem.
- The natural support of his housemates is targeted at the times and in the way that it is required, compared with competing with the needs of six other people in the group home.
- When seeking work for Warren we need to ensure he has a visual experience of the workplace, and the opportunity to refer to photos of his own work experience as visual cues for discussion.
- We need to listen carefully to Warren; what we think he needs may not be what he wants
- His Circle of Support, which includes family, housemates, friends, supporters will and do make a difference as we work together to ensure the quality of his life is comparable to any other 32 yr-old, and will safeguard Warren's vision into the future.
- It is a journey, that requires imagination, hard work and courage but, it is better and it is worth it.

EQAL (Empowerment for Quality Active Lifestyles)

Deb Rouget

EQAL is in its development stages. It's a small, family governed community-based project located in the Eastern Region of Melbourne and now supports 5 individuals. It was designed to identify and facilitate uniquely tailored business, lifestyle and social opportunities in the community around each person supported and their unique passions and abilities. It was developed from the visions of two families, The Nye and Trompf families whose sons have struggled to find or "fit" traditional employment or support options as they have quite complex needs.

The EQAL project is not about creating a business or a lifestyle option for a group of people with disabilities but it aims is to assist each person to craft a unique support option based on their passions, abilities, wants and needs.

Scott's story

Scott is a very talented artist. His vision together with his family is to assist him to pursue his role as an artist in a very valued, creative and flexible manner so that he can create his own business in addition to pursuing a fully integrated lifestyle in his local community. He has held two art exhibitions at the Warrandyte Community Centre at which he has sold his work at "artist" prices. Scott also sees himself as a labourer as he is very active. He has a small paid job at a plant nursery and mud brick making business. He also volunteers for the State Gardens and Nursery and Monsulvat, which is an Art Gallery and Reception Centre.

NightLife

Deb Rouget

Nightlife is another project we have assisted that was created and initiated by people who have a disability. It was originally inspired by Mobile Attendant Care in Brisbane. It aims to create a flexible mobile night-time service for people with disabilities living in their own homes in the Southern Region of Melbourne. With the assistance of the PLA project a small committee of people with physical disabilities has been established to create a service that not only aims to be an emergency over night service but a service that liberates and gives “ordinary” life to people. It will enable people with disabilities to live as independently as possible in their own homes and enjoy an inclusive lifestyle that most people take for granted (especially in the evening).

Conclusion

Deb Rouget

Today we have only had time to share a few stories with you and encourage you to talk with us more about what we have learnt and still have to learn!

We do not want to create any more myths today so we need to say:

- There are no magical answers. Life comes much thoughtfulness and hard work
- People’s lives are not perfect – just as we had expected
- The community is not perfect and should not be idolised. But at the end of the day it is what we all have and if well supported it can provide many opportunities and resources that may not emerge in segregated settings.
- People’s lives are not without struggle but people are well on the way to living a more “typical” life in the community.
- This comes of course with times of joy, struggle, new friendships, loss of friendship, uncertainty, development, growth, doubt, change, pain, risk, and love and loss of love. Just as life in reality is for each of us!
- There is and always will be a constant struggle to resist the shift back to congregation, segregation and standardisation. It needs to be challenged daily in our efforts with carefulness, reflection and thoughtfulness.
- It does not necessarily take more money – just a different way of thinking *one person at a time and utilising natural pathways* just as we all have the opportunity to do.
- Services and Departments can and have done much to assist if they delegate, genuine authority to people and their families.
- Respect, honesty and trust is not an exclusive right it is a mutual obligation between ALL people
- Small can be significant
- Most people need ongoing assistance to imagine and do better

- There has been undiscovered potential in ALL of us!

By the stories we have shared we have supported the notion that ALL people are unique. Today we ask you to challenge the myths that have surrounded the lives of people with a disability. Believe that the community will accept individuals with disabilities if people share their common aspirations, are invited, encouraged and well supported one person at a time.

Its up to each of us, in our own small and thoughtful way to challenge the myths of today and imagine and create better even for one person that we care deeply about. That would make a significant difference!