Small Family/Self Governed Collectives: Sharing the Learning About Working Toward Genuine Personalized Supports and The Roles Services Can Play

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Deb Rouget
Personalised Lifestyle Assistance

Introduction

Welcome to Melbourne and thankyou for listening. My name is Deb Rouget and I’m currently the Facilitator of the Personalised Lifestyle Assistance project. I’m joined today by Maureen McLeish who is the mother of Lauren and a member of the One by One project, Anita O’Brien who is the mother of Warren and a member of the Living Distinctive Lives project and Anthony Kolmus who is the Executive Director of Melba Support Services.

Before we start today I would like you to take a minute to think about on your own life. About your family, your schooling, your career, your friends and what you do for fun. Ask yourself the following questions: Did you go to a local neighbourhood school? Did you leave school and find a job? Did you leave a job to find another job and another job to find another? Did you make friends? Did you fall in love or out of love? Did you want to create your own life? Did you want to move into your own place? Do you live with people who love and care about you? Do you have hobbies that you’re passionate about (that others wonder why!)? Do you have rituals that are important to you? Did you ever struggle and face adversity? Do you ever need support? Do you have dreams and aspirations? My sense is that you have all done these things and followed them in your own unique way as you search for a fulfilling life. Just one more question: Did anyone ever suggest to you that you’re special and that you’re so special you need to go to a special segregated school or work environment, recreate or live with people like you away from community and that only professionals can support you?

For most of us, unless we break the law, as we grow and develop segregation and congregation is not even considered as an option. Nor is a dependence on professionals thought to be the only way to meet our needs. These choices are not placed in front of us by our career advisors, our families or our friends. We are automatically encouraged to pursue our abilities, interests, passions and friendships in the community or as Darcy Elks describes follow “natural
pathways”. Unfortunately this has not happened for most people who have a disability. History has shown us that time and time again they are offered segregation and congregation as the only alternative. To most of this would seem repugnant even if we needed support to get through the day.

Our humble beginnings in Melbourne started almost seven years ago around one individual and her family as we struggled with the question of how to assist her to pursue her abilities and talents in the community rather than in a congregate day service. We were inspired by people like Michael Kendrick to imagine better. Today we are going to share a small part of that journey. We do not believe it to be anything new, a magical answer to the struggles of life or easy. But what we can say is its not “rocket science”. People in communities have lived such lives and still do even as we speak! It’s very ordinary and what most of us take for granted. One thing that has helped us is to continually ask the question “if this were my life would I be satisfied with the options that have been presented to me and want to pursue them”.

Today Maureen will share her family’s story about how they assisted Lauren to pursue a life in the community and Anita will share her family’s story of how her family assisted Warren to move into his own place and pursue his own community life. Anthony and I will share our perspective of how as service providers we have encouraged and assisted people to get on with their own lives in the community with a range of informal and formal supports.

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 or say that those people don’t have significant disabilities. 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.

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 is the PLA project

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
- Have 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 advisory project that sits “with” people to imagine better around each person’s fundamental needs and aspirations in inclusive ways. We do not do “for” people but try and work out “with” people about 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 are seeking did not exist.

We have assisted many individuals and have also assisted in the development of a number of small grass roots collectives or projects where people with similar values wish to work together. These include One by One (a “post school options project), Living Distinctive Lives (a small “live in your own place project), 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 agencies, The Department of Human Services and organise 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 had its initial beginnings in 2000 and emerged from most of the families who were original members of Person by Person.

Today One by One is a small family governed arrangement in Melbourne that has seven members. Families have 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. This means each person gets to choose what they do in the community, when, where and with whom. This includes choosing and directing their own support workers if needed. 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 seven 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. Anthony will talk later about some of Melba Support Services learnings from hosting such semi autonomous projects.

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**

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 known 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!

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 seven 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 her son, Warren’s story.

Group Home or My Home – What will it Mean

Anita O’Brien

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 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’s 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 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.

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.

The rest is now history. As Cameron couldn’t be with us today he has asked me to read his paper. It’s called…
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 [Football Club] 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.

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 Tromp 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 his 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).

Some insights & learnings from Melba Support Services in regard to hosting individual and family governed, inclusive arrangements

Anthony Kolmus
Executive Director Melba, Support Services Melbourne

By way of background, Melba is an organisation that has provided a range of services (generally fairly traditional group homes, day services and employment supports) to people with a disability for just over 35 years.

In 2000, as part of a deliberate cultural shift towards exploring more personalised ways of supporting people we hosted a workshop by Michael Kendrick on the concept of Family Governed Supports. We were subsequently approached to and began hosting what has now grown to become a variety of self and family governed support arrangements and collectives.

In addition to the traditional services we still operate, we now host thirteen individual support arrangements that are led by the person receiving the support (and/or their family), three family governed collectives, an overnight attendant care service that is overseen by the people in receipt of the service and the Personalised Lifestyle Assistance Project (a resource project aimed at encouraging and supporting small grass roots efforts here in Victoria).

I should also make the point that Melba is not, by any stretch of the imagination, a rich organisation (so it isn’t the case that we’ve been able to do this because of substantial resources or cash reserves etc.). Any success we’ve had has been the result of our being willing to sit with people and to genuinely and honestly attempt to provide the supports they require in the way they want and in a way that they can largely control.

Given time constraints, I’ve tried, in the following dot points, to touch on and summarize what have been some of our key learning over the past seven years, each of which has been critical in terms of our being able to successfully host these types of arrangements.

BECOMING A SERVICE FACILITATOR RATHER THAN A SERVICE PROVIDER

This may just seem like a play on words but I think there is a subtle but important difference in the two concepts.

Our organization, and I suspect many others, used to think of ourselves as being a support provider. That is, we were the experts, we (and/or the “system”) had pre-determined what services people needed and that’s what
people had to “choose” from.

The increasing concern we had with this situation was that it was based on the premise that we knew what people wanted their lives to look like and that, even if we attempted to be flexible within that service structure, we ended up trying to make one model fit everyone’s needs.

In shifting to a mindset of being a service “facilitator”, we worked towards shifting our organisational culture to one where our focus was more about what the person wanted and needed rather than what we could directly provide.

A critical part of this was shifting staff’s perception of their role from one of being the “expert” to instead being a potential resource to people as they attempted to work out and pursue the lifestyle of their choosing. If it works out that we can provide what people are asking for, great. If we can’t then maybe our role is to assist them to locate and access that support elsewhere.

Making this shift helped us to accept the notion of playing host to people’s support arrangements. It wasn’t about what we thought people might want or need but about them determining how they wanted their supports and our using our skills and resources to work with and alongside them to make it a reality.

TKJ Inc in Salt Lake city used to use a nice example of thinking of people who use their services as “the neighbour next door” who like the rest of us requires support in relation to electrical work, plumbing etc but who may also require support in relation to their daily living arrangements. That is, the role of the organisation is not to take over people’s lives but to work with them, preferably as much in the background as possible, to empower them to pursue the life they want to live.

**LETTING GO OF THE CONTROL OF HOW SUPPORTS ARE DELIVERED**

This is perhaps the single most critical issue for service providers and, in many respects, the most confronting. It’s also a natural follow on from the notion of facilitating as opposed to providing supports and genuinely enabling people to take control of their lives.

From what I’ve seen of other examples here in Victoria, it is also, a common reason for the breakdown of the relationship between the person and the host agency in these types of arrangements.

It’s important to note here living a good quality life isn’t just about having individualised supports. It’s about self-determination, which for many people with a disability includes having control over the type and nature of the support they receive.

In other words, for hosted personalised support arrangements to be genuinely of benefit to people in pursing a “good’ life, they must be led and largely
controlled by, the people accessing them.

Historically, organisations have held the control of how supports will be delivered and this is largely the mentality that exists in the delivery of traditional models of support.

In our efforts to successfully host these types of arrangements and in order to even attempt to be true to the notion of people leading their own life, we’ve had to really focus on letting go of the control over people’s supports that we have traditionally had and begin to genuinely work alongside and with them.

The fact that people’s supports are delivered via our organisation (i.e they’re support staff are actually employed by us and then seconded to the person or collective) means that there are some limitations on what people can do. Certainly with the arrangements that we host there are certain non negotiable’s such as Award conditions and the treatment of staff, issues relevant to duty of care, police checks, payment of fees etc. These are outlined in the Agreement we establish with each individual and/or their family.

To use the TKJ example, this is normal in that any time we contract a service from someone there are invariably some bottom line expectations and responsibilities we each have in relation to that contract.

Fundamentally though, in order to successfully host individualised arrangements, organisations need to be willing to let go some of the control that they’ve historically held. This is something individuals and families need to be very clear about when looking for a host organisation. In particular, you need to gain a sense of whether or not the CEO / Board is going to be willing to hand over the necessary level of control.

**RISK MANAGEMENT / OCCUPATIONAL HEALTH AND SAFETY**

I don’t intend to speak about this issue too much here but I will say that, in my opinion, the increasing obsession that exists in relation to these two areas poses one of the biggest threats to the future of individualised supports.

Clearly there is a need for both issues to be dealt with, however they need to be dealt with in a reasonable way that would be acceptable to general members of the public in terms of the correlating impact on any given individual’s life.

Life involves risk. Living a life without some level of risk is, in my mind, not living. People with a disability have enough challenges in their lives to face without the impact these issues are increasingly having on their lives.

It is all too easy for organisations to cite OH&S in particular as being why certain types of supports cannot be delivered rather than sit down with people and genuinely attempt to work out a way of “reasonably” safely delivering the desired support.
ORGANISATIONAL STRUCTURE / SIZE

I’m probably about to make a gross generalisation (which I tend to be very good at) but I just wanted to make the observation here that smaller organisations seem to be more able to successfully host these arrangements than larger organisations.

The problem for larger organisations seems to be the difficulties they have in adapting their systems, and perhaps to a degree their thinking, to the needs and principles required in order to host a successful individual arrangement. I think larger organisations by their very nature need clearly established and consistent systems and processes in place in order to function effectively and that this tends to influence the culture of the organisation as well.

Being a small organisation doesn’t guarantee an ability to successfully host these arrangements (I’ve seen examples of this) but it does seem to be the case that a small organisation may find it easier to adapt to the requirements of individual arrangements a little easier than larger organisations.

As per usual, there will be exceptions to this rule, one being Jay Nolan Community Services in California and I’m sure there are others.

Ultimately, it comes down to people’s commitment to empowering people with a disability to take control of their lives and being willing and able to adapt to enable this to occur.

ADMINISTRATIVE REQUIREMENTS

One problem that we experienced along the way was that of achieving the critical mass necessary to enable us to create the internal supports necessary to support and monitor the arrangements. This is a little messy to explain but is an important point for prospective host organisations.

Essentially the problem was that when we first started taking arrangements on we were only making a small income from each arrangement (given that too charge too much would have undermined their viability). Obviously we needed someone to look after them within the organisation but it didn’t warrant creating a position specifically for the handful of arrangements we had in place. Initially, we had one of our Managers take on the role and provided her with an Assistant Manager in her area of the organisation.

Eventually we reached a point where we needed a full-time Manager to both support the existing arrangements we were hosting and to respond to the new requests we were receiving. The Catch 22 was that we weren’t generating the income necessary to create a full-time position and couldn’t generate that income because we didn’t have a full-time manager to support the additional arrangements required. Fortunately, given that the arrangements were precisely what the Victorian Government’s State Plan for Disability Services envisaged, we were able to negotiate some “bridging” funding that enabled us
to create the full-time position and thereby take on the additional support arrangements required (which in turn generated the income necessary to make the position viable).

This is something that funding bodies may need to be willing to consider if organisations are to be able to take on these models of support.

Another issue we had to confront was that we underestimated the difficulty we would have in adapting our existing administrative systems to being able to host, track and report on individualised supports.

Before Melba started hosting individual arrangements we had about thirteen cost centres within the organisation. At last count we now have about forty three, all of the growth being in the area of hosting self and/or family governed support arrangements.

Essentially, we needed to adapt our finance and HR systems so that we could track and report on all income and expenses down to an individual level, a significantly more complex task than doing so for group homes and day services. (Each individual arrangement / project is provided with a monthly report detailing their income, expenditure and overall bottom line. All of this is reported on entirely separately to our organisation’s core (i.e. traditional) funding streams.)

If I was to be really honest, the infrastructure required to do this was originally established on the back resources available via our traditional services and out of a long term commitment to this being the future direction of our organisation.

Whilst I was comfortable with this in terms of the flow on benefits we’ve seen for people accessing our traditional services, we’ve also had to be sure that, in the long term, the hosted arrangements are in fact “paying their way” and are not constantly drawing resources away from other areas of (and people served by) the organisation.

We currently charge 10% of funding received where we are simply hosting the supports. Where we directly manage the supports we charge 20%. On occasion, we’ve negotiated an alternative fee for particular arrangements.

I have no doubt that in the early days, we effectively subsidized the development of these arrangements, something we believed we needed to do in order to find a balance between covering our costs and keeping the arrangements viable.

We’ve now reached a point where we’re confident we’re covering the costs associated with hosting the arrangements. The next conundrum we are beginning to consider is how deconstructing our traditional services will impact on our overall financial profile.
This is an area prospective host organisations need to carefully consider in terms of their ability to cope with and resource such arrangements in a way that enables people to really "know" what their financial situation is like and therefore be able to make decisions about the resources they have at their disposal.

**START SMALL**

Given the challenges hosting individual and or collective arrangements can present to organisations, both structurally and philosophically, one positive is that you can literally start with one person and learn from there.

In our case, when we got started with the first family, I really wasn’t sure exactly where it was going to take us as an organisation or what it was going to require.

The point was that we believed in this model of delivering supports and we believed we could establish a relationship with the person and their family within which we could all learn and develop together in terms of our understanding of how this was going to work. I was confident that we could each make mistakes along the way without it automatically souring the relationship.

In a sense, for those of you who are thinking of pursuing this model of support whether from an individual, family or organisational perspective, you need to find people that are committed to the concept and who are willing to work alongside you in working out how best to set up an arrangement so that it works for everyone involved.

**STRUCTURE OF A HOSTED ARRANGEMENT**

The following is an attempt to diagrammatically present how the hosting arrangements are structured.

In a nutshell, for each of the arrangements we host, the government funding allocated to them is received by Melba on their behalf. (Meaning that the funding relationship is between the Government and Melba. This also means that, strictly speaking, the hosted arrangements are Melba services. On a day to day level, the autonomy and actual operation of these arrangements is very different.)

Melba then effectively delegates responsibility for how that funding is expended (i.e. more or less keeping in mind the Government parameters as to how the funding is to be used) to the person or the Governance Group of the collective. In the case of the Governance Groups, they actually register as volunteers of the organisation so that the delegation of power is legitimate and they are subsequently covered by our insurance.

The Governance Group and Melba then jointly employ the Co-ordinator. This person is an employee of Melba who is seconded to the relevant project and
subsequently reports to the Governance Group. The broken line between the Co-ordinator and the host agency represents the fact that the Co-ordinator is expected to liaise with the relevant Melba representative (generally me at this stage) both in terms of reporting on the activities of the group and as a resourcing opportunity for the Co-ordinator. As outlined above, the agreement between Melba and the Governance Group outlines the core expectations of how staff need to be managed and supported.

Direct support staff working in each person’s hosted arrangement are then jointly employed by the person receiving the support (and/or their family) and the Co-ordinator (acting at least in part as a representative of Melba as the employer).
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!

In conclusion I would like to share some other learnings;

- Genuine personcentredness can not happen in structures and frameworks that congregation people with disabilities together (people only get to choose from a limited menu and never have the flexibility to pursue their own life)
- Redesigning our models gave us the opportunity to work one person at a time but it takes much more than redesign to get a good community life. It takes passionate, determined, sometimes uncompromising people who are committed to people and genuine inclusion
- It takes a different way of thinking one person at a time and utilising natural pathways just as we all have the opportunity to do.
- There are no magical answers. There is no “Blue Print”. Life comes much uniqueness that requires thoughtfulness and hard work “one person at a time”
- People’s lives are not perfect and their lives are not without struggle (just as we had expected) but people are well on the way to living a more “typical” life in the community.
- 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 cannot emerge in segregated settings.
- Life doesn’t happen over night and it also 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!) so you need to be committed long term
- Sometimes we have had unrealistic expectations for people with disabilities. For example, often we have expected a person with a disability to leave school and have one job or live in one home for the rest of their life. This is not the case and nor is it for most of us!
- There is and always will be a constant struggle to resist the shift back to congregation, segregation and standardisation because it seems “easier”. It needs to be challenged with vigilance daily in ALL of our efforts with carefulness, reflection and thoughtfulness. You have to stand strong and resist!
- It does not necessarily take more money. Some people require less money than would be required to support them in a congregate care setting
- Services and Departments can and have done much to assist if they have good leadership that filters through all staff so that, genuine authority is delegated to people and bureaucratic process are kept to a minimum
• Small collectives aren’t for everyone but for those who are members of them, they appreciate the mutual support and exchange of information with people who share similar values. They can also provide a safeguard for the future.
• People with disabilities and families have much potential and talent to drive change. By sharing their stories of good inclusive lifestyles they are almost always the best at convincing people it can be done!
• Respect, honesty and trust is not an exclusive right it is a mutual obligation between ALL people
• Small can be significant
• Not all people get it even when you explain it to them. You have to assist them to live it!
• Most people need ongoing assistance to imagine and do better
• There has been undiscovered potential in ALL of us!
• It is only possible if you believe it IS possible!

Questions?