

Families for Change

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

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ADVOCACY

The Odyssey... A Journey Of Enrichment And Possibility

Through the mail in any given week, Family Advocacy receives numerous emails and fliers advertising conferences and workshops relevant to the disability sector. In the main, these events aim to assist attendees to *manage clients, develop programs* and implement *best practice* among other things. They focus on the mechanisms of the services rather than the people the services are created to support.

In October 2007, Family Advocacy hosted *The Odyssey... a journey of enrichment and possibility*, a conference which unashamedly considered and featured people, not programs. At this conference, the presenters talked about vision, creativity, courage, tenacity and love - ingredients that enable people to flourish and grow and live valued lives in their community. People with disability, their parents and allies, told their stories of how they have created a better life which is not dependent on the disability service system providing everything. The stories were inspiring and will hopefully encourage families and professionals alike to reflect on the ideas and attitudes about what can be achieved for people with disability, the beliefs and expectations about what people with disability bring to society, and the day to day practices of supporting someone to live a valued and meaningful life.

Family Advocacy is part of a world wide network of people and organisations who believe that people with disability should be supported to live lives full of enrichment and possibility. We want more people to share this view. We hope that *The Odyssey* Conference created an environment in which this view could be expressed and families could tell their stories of how they are creating a rich and vibrant life for their family member with disability, right here in Australia.

Many of the families associated with Family Advocacy have created opportunities for their sons and daughters that are not at all commonplace in the disability support sector...yet. We know from past experience that the most powerful tool for change is demand and we hope that, through events like *The Odyssey* Conference, we can stimulate demand for something different, something better. We hope that the ideas expressed at the conference inspire families to 'be the change that you want to see in the world', as Gandhi said.

"...the presenters talked about vision, creativity, courage, tenacity and love"

In her paper, *Clarity of Vision: A Compass for the Journey*, Wendy Stroeve challenges us to dream of a better life for our family member, because without the vision of a better way, it is impossible to leave behind the well-trodden disability path. Anita O'Brien, in her article *Home: A Place of My Own Where I Belong*, encourages families to realise the importance of having a home, a place of acceptance and security, and how this can lead to a better life, embedded in the fabric of the local community. Sally Richards was inspired to create a business for son Jackson, and in the story of *JACKmail: More Than Just a Mail Service*, writes of the positive associations that employment can produce. Meg Sweeney explores the importance of relationships and why families should encourage numerous activities that create connections in *It's A Numbers Game*. In his paper, *Meaningful Leisure: Pursuing Interests and Exploring Possibilities*, Joel

Satherley writes about the importance of supporting people with disability to lead challenging and interesting lives.

Despite our best efforts, the ideas and opinions of people with disability and their families are often ignored or dismissed, so that people with disability and their families endure a procession of services and programs coming in and out of their lives, that just don't fit their individual circumstances. Most of us feel a sense of frustration with the lack of creativity and flexibility in the current New South Wales service system. But if we take heed of the advice of the contributors to this journal, we should seek to embark on our own journey. Perhaps the best life for people with a disability is not necessarily linked to service provision, even though some support may be required and should be provided, but based on the dreams and the gifts that people with disability have to share.

For the complete version of the edited papers included in this edition of Families for Change, and other information from the *The Odyssey... a journey of enrichment and possibility*, please go to our website at www.family-advocacy.com and click on *Conference 07* or contact our office.

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The Management Committee and staff of Family Advocacy wish you much happiness for the festive season, and peace and empowerment in 2008.

Clarity of Vision: A Compass for the Journey

Wendy Stroeve

Wendy Stroeve is the mother of two teenagers and worked as a teacher in New South Wales secondary schools and in TAFE from 1981. Her son Alex has high support needs, multiple disability and autism. The Stroeve family's support of Alex has always been driven by a belief that Alex makes the world a better place.

In the Pirates of the Caribbean movies, Captain Jack Sparrow has a compass that is rather special in that it points only to that which the user most wants to find. In a way, that is the kind of compass I am talking about... something which will give us direction and keeps us focused on what we want to achieve for a person with disability.

We hear stories about good things happening in the lives of people with disability. When we do, you can pretty much guarantee there will be one thing all the stories will have in common. They will have in common a vision.

Good quality of life, in connection with family, friends and community, with jobs and interests and opportunities and variety, does not just happen for people with disability by accident. It may happen, for particular individuals, as a result of clear vision and determined action.

Some people think the word 'vision' sounds a little evangelistic. But what I am talking about is having a clear idea and some positive dreams about what we want someone's life to be like. We actually dream all the time about positive lives for ourselves and people we care about. Some of the dreams are so basic and fundamental we hardly even fully articulate them. But when most of us are asked to say what we think are the most basic elements of a 'good life' there is a surprising similarity in what people say:

~ relationships: partners, friends, acquaintances; people who care about you

~ home: a sense of security and belonging

~ work or leisure: capacity to pursue skills and interests

~ making a contribution

~ enough money to give security/not living in poverty

~ ideally, good health.

We could say these are pretty 'ordinary' dreams. Having a vision for the life of a person with disability is really about claiming for that person the right to the same kind of ordinary dreams. Put simply, having a vision means believing a person with disability can have the same kinds of dreams and will need the same things in their lives everybody else does.

A vision will reflect a view of what is possible for people with disability that represents a completely altered mindset from the common ideas in our society. From birth, the idea of 'separate paths' can become well entrenched for people with disability. Other kids go to the park and playgroup; a kid with a disability might go to early intervention and therapy. Other kids go to the neighbourhood school and play in the street or backyards after school; a kid with a disability may be taken across town in a bus to a special school and never see much of other kids in the neighbourhood. Adults might attend workplaces, socialise with co-workers, join sporting teams and have people over for barbecues. Adults with disabilities may spend their lives in congregate care facilities, attend work training programs or leisure programs or 'independent living' programs.

These essentially separate paths can be maintained throughout life and can be seen by many people to be the inevitable reality for people with disability. People with disability end up congregated together, and in disability-specific 'programs' separate from the rest of the community.

There is something that happens to our thinking where disability is concerned. I will give you an example of how we think differently.

I know when my son Alex was young I was urged, again and again, by well-meaning individuals and professionals, to take him to Riding for the Disabled (RDA) as a leisure activity. This was in spite of the fact that I kept repeating that horses terrified him and he was not interested in riding. But people were convinced that "if he got used to it" he would begin to enjoy it. And some were quite determined to change my mind.

Now, I hate flying. I am terrified every time I get into a plane. However, no-one has ever suggested to me that I should join an aero club and that once I 'got used to it' I would love flying. In fact, most people are quite at home with the idea that I might submit to what ever flying is necessary, but that I am not going to go out of my way to make it a leisure activity.

There is a difference in the way we think about what activities and places are appropriate for people with disability.

Another part of the same story, is the fact that I have had some strange looks from people when I have told

them that I would like Alex to join some woodworking groups when he leaves school. He loves woodwork at school because of the sound of the machines and has always loved wood and wooden percussion instruments and beating out rhythms.

Of course, the strange looks are because people understand that Alex will probably not do much of the actual woodworking. He would probably need substantial support to learn any of the most basic elements of the craft. So they cannot see him being there. I could point out, of course, that he would not have been riding a horse in RDA without being supported to stay on the horse or without someone leading the horse.

The crucial difference is that RDA is a disability-specific environment so people immediately accept Alex can be there. It certainly would not be a natural environment for Alex as an individual to be in, disliking horses and riding. It would be about as natural as my joining the aero club. The woodworking group is a much more natural environment for him, since he loves the machines, loves the wood. Support can just as easily be delivered there as at RDA, but because that environment has not been specifically set up for people with disability that is much more difficult for people to 'get'.

What happens is that society's expectations about where people with disability can be and will be supported begin to shape people's lives and experiences. People expect to see Alex, with disability, at RDA where they expect support is provided. They do not expect that woodworking can be a supportive environment. For a lot of people with disability, this thinking just logically leads to horse riding. People's actual interests or desires become irrelevant when we have already determined the places they can be.

When we start developing a vision, we should not immediately put limits on a person's, or our own dreaming. Our aspirations are limitless when we

start out in life. It is not uncommon to hear kids say they want to be Olympic champions. Some of us still have a vague financial plan based on winning the lottery! It is human to dream sometimes big, unlikely, uplifting or optimistic dreams and all too common to limit our expectations for people with disability.

***“At times of difficulty,
the clarity of your vision
can offer a source
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resolve.”***

When we start to dream with people with disability it is important NOT to say about the things desired, “but I can't see her ever having a friend” or “there's no way he could have a job” or “there's no point in going to woodwork if you can't use the machines”. Wonderful things can happen in the lives of people with disability. Around the world we are seeing individuals with all kinds and levels of disability having work, living in their own homes, enjoying social connections and the other ordinary things people see as important elements of a good life.

Articulating a vision is the necessary first step. What does this person want? Some people with disability may be able to articulate some of their own goals themselves, with help and support to do so and possibly lots of help to implement these. Others may only need some guidance about how they might live their life.

Others may need us to dream a positive future on their behalf. What do we want for them?

Beginning to flesh out a vision of what a person wants or you want for them could mean, for some people, getting together a circle of support or a 'think tank' to help develop a clear picture of what a person with disability wants in their life. Maybe you can invite others in your life to help you do some dreaming. You could start fairly

general with big, core shared issues and/or you could start exploring possibilities in much more individual detail, making a plan of action as well. For many people it could be helpful to write down a vision statement.

When we first did this, when Alex was very little, many of the statements were very general, like: “We want Alex to be involved with lots of different people. We do not want him to be lonely or isolated, but to have friends and acquaintances like other people.” We wrote things like: “We want Alex to be seen as a person with an individual personality, strengths as well as needs and gifts to bring to others...” As time has worn on, these ideas have become completely internalised; and you may never need to look back at the paper. We kind of make a contract to pursue the things we want in the person's life. Over time we have worked in things that are a part of what he is able to communicate to us: his love of company, of music, of wood, of water, to the more practical elements of what we do.

I am very grateful that I was encouraged, by other parents, to develop a vision very early in Alex's life. It helped us reject the 'separate path' from an early age. The one thing we knew was that our dream of Alex living a life included in the community and with other people meant that he could not afford to head off on the separate path.

Early intervention delivered in a segregated complex? No.

Early intervention services tailored to Alex getting the best out of his experience of preschool and delivered in the preschool setting in the context of the sandpit or water tray with other kids? Yes.

Early enrolment in a special school at age four? No.

Extra days at preschool then a tailored approach to school orientation? Yes.

The choices you make are facilitated by the clarity of your vision.

After putting our vision for Alex on paper, we began to talk to people we knew about this vision. My parents and parents in law thought we were unrealistic, because they come from a different generation and were still apt to view everything to do with disability as tragic. But people come to understand you are committed to a good life and this is something that, eventually, most people do 'get'. You can start to answer the questions people have about a person's life and future with the consistent communication of the vision. We might quite often have said things like, "I don't know how we'll get there yet ..." but people have always known what we were aiming for. People may have all kinds of private reactions to that; people might see us as engaging in wishful thinking or developing a head-in-the-sand approach. I am sure many will be sceptical. We have probably all had to justify our choices, sometimes to virtual strangers, but with a clear vision, it becomes as simple as repeating your vision of what you want and where you are headed.

Another thing that happens is that unlikely people can come on board. Sometimes people you expect to support you do not; but invariably people you never expected do get enthusiastic about another way of looking at the lives of people with disability. This can be a really exciting development. It is not necessarily the people we choose to socialise with who are the best at helping us with this. Other people we do not necessarily spend a lot of time with, but who value Alex, can be really wonderful.

To return to the idea of a compass, once you have created a vision of a positive life and begun to articulate it to others, you also have created a compass for navigating your way to that outcome. The actual navigation can, and probably will, be fraught with difficulties. The compass may point you in a particular direction, but insurmountable obstacles, mountains, gullies, may stand between you and getting there. A parent may know, for example, that they want their

daughter in the regular class at school, but they face a wall of professionals continually steering her to a support unit. A person wanting tailored support for a young person to pursue interests and make connections in the community may find the only kind of support arrangement available in a town, upon leaving school, is a congregated adult day program.

It is vital for us to recognise that if we seek a good life, an ordinary life, for people with disability we are moving against a powerful societal current that will constantly try to drag us back to the set path deemed suitable for people with disability. This 'set path' is limiting, where your vision is enabling. The usual options may be congregated with other people with disability, where your vision sees the person with many relationships with people in the community who have the capacity to help stimulate and support the person's life. Services may segregate people from other community groups, where your vision is about being included in the life of the community, in the local music group, library, art class, and workplace.

Clarity of vision allows us to evaluate choices that may be placed before us. You ask a simple question of things: "Will this choice bring the person closer to the desired outcome?" If I was evaluating the option of Riding for the Disabled against my vision for Alex's life, I would ask.... "Does this activity and grouping get Alex closer to the life I want for him, pursuing his interests and making relationships with other people from the community who have the potential to enrich and support his life?"

My answer would be "No".

Could the woodworking group provide him with possibilities to pursue his interests alongside other people who share that interest and can get to know him as an individual? "Yes".

At pivotal points in a person's life it may be a good idea to re-examine and reassess the vision and the paths being planned to achieve it. At present,

we are thinking seriously about life beyond school. If our vision for Alex is that he have a range of freely given relationships with people and that they get to know him as Alex instead of as a person with a disability, it becomes crystal clear that as he is on the brink of leaving school he must, despite his level of disability, join in with other people in ordinary community activities. We will be asking "What does he like? Where will he meet people who share his interests? Would he like to go swimming at the local aquatic centre, to listen to bands at the pub? Join the folk club? If we can bring people into his life through some work role then he needs to have one...what could it be?"

These are fundamentally different questions from "What programs exist for people with disability?" Our questions are in line with the vision, and are about making the life a person wants. The question about services is common but may be very limiting. Programs and services are not the answer. Programs and services may provide some funds and supports, but they alone cannot result in the life you want. Unfortunately, for many people with disability, programs and services supplant their lives. People end up having nothing else in their daily lives; they have programs instead of a life.

Without a vision as the guide, families can unfortunately misdirect their energies, insisting that more funding, more services, more programs are what is needed for people with disability. But, as they are commonly delivered, these things often drive out the person's vision, any hope of dreams, the involvement of family and the building of a natural supportive community around the person. Then, of course, they are seen to need more programs and more services to take the place of other, disconnected areas of their lives. It can be a really vicious circle.

A vision alone cannot guarantee anything. It must be accompanied by constant vigilance and lots of work to keep it on track. In the case where you have been forced to divert, you may be able to put strategies in place

to mitigate some of the negative impact the path might have. For the parent who is more or less forced to place their child in a support unit at school it may be necessary to really step up the effort to increase the connections a child has out of school, through sport or other clubs or by inviting neighbourhood kids in the afternoons. These could be strategies to pursue while you work on getting into the classes you do want. People who, years ago, had no choice but a congregated specialist day program for a person, may decide to work hard at increasing community connections at other times of the week, while they work out how to change the support arrangements over time to reflect their vision for the person's life. We should

all expect that there will be obstacles. That does not mean we ditch the vision. It means that we need it more than ever to help us work out other paths to the destination. And it means work.

People with disability and families are in the best position to consistently articulate a vision. Others, like workers or professionals are likely to get bogged down in other day to day organisational aspects of the journey. Their loyalties may be divided; people with disability and families can have their eyes on the compass. The vision keeps the destination in mind, but the vision alone is not enough. It must be used to examine choices, bring people in to help, provide guidance around barriers, reject inappropriate practices, work against opposition.

You may receive little encouragement and even some derision. At times of difficulty, the clarity of your vision can offer a source of inspiration and something to steel your resolve. Find others who share your view of what the lives of people with disability should be like. Remind yourself to question - what can be so wrong about wanting a good life for a person with disability?

If this is what you want and you believe it IS possible, you have yourself a real, authentic Pirates of the Caribbean compass - it will point to that which a person most wants and it is a pretty reliable means of charting your course through all weather.

It's A Numbers Game

Meg Sweeney

Meg Sweeney has been involved in advocacy for people with intellectual disability for over fourteen years. She is the mother of three teenagers and a passionate promoter of inclusive practice.

This paper could have also been called *The More the Merrier* or *Come One, Come All*, as I believe the number of typical people we encounter in our lives enhances the opportunity for relationships, commitment and even love to develop.

I am sharing the very personal story of my family that comprises my three children – Daniel, Joscelyn and Monica and my husband Todd. Todd and I have been totally committed to making decisions together in relation to our family.

When Joscelyn was born, we knew that life was going to be tough for her. We were being told by various professionals and well meaning people what Joscelyn needed. I was also on a personal search for information. I devoured journals, attended workshops and conferences and accosted many individuals with endless questions about why everyone thought life should be so different for my daughter than for my son.

This search was the foundation of our own personal numbers game. Being a very small family, I decided we were too vulnerable and needed more allies, hence the arrival of Monica, our third child.

“We have always chosen ‘regular’ everything – simply because that is where everyone else is.”

I was extraordinarily lucky that my search led me to excellent events and people who gave me confidence and faith in my daughter's future. I learned that not only are there barriers in Joscelyn's life due to her own personal manifestations of intellectual disability but also due to the centuries of baggage that each one of us carries around with us in relation to people with disability, subsequent fear and lack of expectations.

At one event I attended, there was an overhead that outlined the things that vulnerable people need protection from or advancement in. I loved the way the points were all interconnected but what spoke to me was the second point – “Sense of Personal Security, Acceptance, Love, Belonging.” This overhead became our family compass. Someone was talking my language at last.

Relationships were the most important thing that Joscelyn needed and this became the focus for all decision making from that time on.

Our family was the obvious place to start. Love them or loathe them, our families are the backbone of our lives and taking the time to make these relationships as right as they can be is worthwhile although it can be emotionally draining.

We shared our vision constantly through demonstration of our love and

respect. Social events and gatherings became very important. We made contact with any distant family and let them know how valuable all our children are. We have also paid particular attention to our children's relationship with each other.

I have been conscious of helping to develop collective and individual relationships between our children. Our mantra as a family is that home must be our sanctuary – the place where we all can relax and do not need to be on guard. This has given Joscelyn a strong foundation of self worth and identity to take into the world.

Outside our family is where the numbers of people really come into play. We have always chosen 'regular' everything – simply because that is where everyone else is. Our kids have always attended preschool and school together, in regular class, enhancing and embedding Joscelyn's belonging, acceptance and identity.

All our kids now attend our local State high school. There are about 1200 students and 80 adults. Being part of such a large crowd reduces the intense pressure and constant scrutiny that Joscelyn can experience.

Joscelyn has developed wonderful relationships with the friends of her brother and sister. She has developed a large informal group of acquaintances and a small group of close friends. By the time Joscelyn

leaves high school she will have encountered over 2000 young people and 150 adults. This has been a massive opportunity for Jos to know people and for people to know her.

Because of our small family, we have to create the relationships that others may typically have through family. Our neighbours and friends are very important to us. Our family is a very welcoming neighbour, helping where we can with baby sitting, tool lending etc. This has led to numerous casual friendships where all our children are known and Joscelyn enjoys support or assistance if other family members are not around.

It has also led to a number of close and ongoing relationships with families still in the street and other families who have moved away.

Like most families, we have facilitated birthday parties and out of school get - togethers. We encourage other kids to come on our family outings and host billets when out of town students need somewhere to stay. We have also embraced opportunities – like securing a personal trainer to develop Joscelyn's swimming skills rather than accepting a segregated swimming class – an option that did not fit comfortably with our compass. The personal trainer is slightly older than Joscelyn and a valued member of their school community. This relationship affords Joscelyn the opportunity for other connections.

Joscelyn also has friendships with kids she has known since infants. In order to find these few gems, Joscelyn has been right 'out there' amongst it with her peers.

Friendship is a two way street. Not a lot of people will embrace Joscelyn's friendship and she often rejects the offers of friendship from others. Friendship cannot be purchased, arranged, brokered or organised. Friendship, love and enduring affection are gifts that we give each other freely.

The more typical, valued, roles Joscelyn has, where everyone else is and the more people she meets, the more opportunities there will be for relationships to form.

It is the layers of Joscelyn's relationships, so delicately interwoven, that create a web of support, invisible to the casual observer, that provides her with the personal security, acceptance, love and belonging that I hoped for when she was a baby. Our journey as a family is just under 16 years along. With our compass, knowing that the distance already travelled was in the direction we anticipated and with increasing numbers of fellow travellers joining us along the way - the horizon looks good for fair sailing.

Meaningful Leisure: Pursuing Interests And Exploring Possibilities

Joel Satherley

Joel is a young man of twenty four who is passionate about music and theme parks. Despite facing multiple intellectual and physical challenges, Joel lives life to the full. In December 2007 Joel won the Personal Achievement Award in the Federal Government's inaugural National Disability Awards. Joel hosts a popular weekly radio show, has released a CD of his original music, regularly shares his story at disability conferences and recently scaled the sacred mountain, Wollumbin (Mt Warning) near Byron Bay, with help from family, friends and complete strangers who wanted to support his dream. Next year he plans to produce a play he has written and go on a tour of UK theme parks. Joel's family believes his inclusive schooling laid a strong foundation for his current life, embedded in the fabric of his local community.

I began school in a special education class. That was a disaster for me.

Mum tried very hard to get me out of there but it wasn't easy. She had to go to dozens of meetings and give up her job but in the end she found a school where I was welcome.

After finishing high school I went to university for a bit and then to TAFE. I am still at TAFE two days a week doing a visual arts course and preparing for a solo exhibition in a local art gallery.

I do lots of other things through the week that are fun and exciting, too. I go busking down the main street of town, do a radio show and belong to a frisbee golf social club. Sometimes I go to the gym, swimming, fishing, sailing, bowling or bush walking.

Often I will have a dream about something really special I want to do and then I pester mum over and over again until she organises it. Sometimes it costs a bit of time and money but I tell her that "sacrifice and serving others is the path to spiritual enlightenment". Ha ha! It works every time!

So that's how I got to ride in a helicopter, climb Mt Warning and go to Euro Disney. Next I am going whale watching, swimming with dolphins and to a special theme park in England that I want to visit called

Blackpool Pleasure Beach. I love going on rides and designing roller coasters, using computer software, more than anything else.

In my life I have found it is important to have a dream, a clear picture of what I want to happen and a strong belief that it WILL DEFINITELY happen, no matter what anyone else says.

"Families need to be open to new ideas, new options and new potentials"

When hopes and dreams are ignored, when no-one cares about your hopes and dreams, then all the good things in life you want to do will never happen. You will watch from the sidelines as your sisters and brothers, friends and relatives all follow their hopes and dreams. But for you, nothing will change, even if you wait forever. Day after day life will be boring and mundane. This will just make you feel sad and empty and sometimes even angry.

I know that not every dream I have will come true, but it doesn't stop me feeling happy dreaming and imagining what my life could be like and getting excited and looking forward to all sorts of possibilities.

People sometimes tell me "no you can't do that, it's just not possible, so forget it" - like climbing Mt Warning - because I can't walk properly or having a radio show because people can't understand me. They try to protect me by putting limits on me and telling me what I want to do is "not realistic". But if THEY wanted to do the same thing, they'd soon find a way to make it happen, wouldn't they? No barrier would be too great.

I find that people around me (even those paid to support me) often make excuses for not helping me to achieve things I want to do. Sometimes they say it costs too much, or it's dangerous, or we'd need to ask too many people to help, or I could hurt myself, or they decide it is too hard for me or not in my best interests, or it would take too much organising, or it is an occupational health and safety issue. The excuses are many and varied.

Sometimes they don't know how to start and won't ask anyone for help or advice, so they do nothing. But mostly they are just too busy living their own lives to be bothered with helping me live mine - and that sucks because without their help and support, I can't achieve anything on my own!

So I have learned to be persistent and not to take "no" for an answer. I am

lucky because I can speak but some of your sons and daughters might not be able to speak and I wonder who is listening to their heart's desire - because they will have dreams just as I do.

Please listen to their silent voices. See in their eyes what makes them happy and help them find activities that bring more of that joy into their lives.

Families need to be open to new ideas, new options and new potentials. I am not saying you have to take big risks, but taking small, carefully planned risks can be OK.

Let your kids dream, but dream with them. Build a vision of what could be a more interesting, challenging and fun life for them – a life that could make them happier and more fulfilled. Life should not be boring and predictable every single day just because you have a disability! Find out what ordinary young people their age are doing and see whether it is something they, too, might want to do, or see, or be.... and THEN figure out the HOW TO MAKE IT HAPPEN part.

Don't assume something they want to do is "too unrealistic" because chances are that this is code for "I'm too scared of helping them try" and once you have helped them achieve it, you will see it was quite realistic all along anyway. It was only YOUR fear holding THEM back.

I believe you can create your own reality and manifest personal dreams

and goals in life if you JUST WAKE UP AND DO IT with passion, single mindedness and belief in yourself – and that is true for all of us.

Climbing the Mountain

Ever since I was a young teenager, I have wanted to climb the sacred mountain Wollumbin, also known as Mt Warning, near Byron Bay. For me, it was my Mt Everest. I dreamed about it, and talked about it, and pestered everyone who would listen about it – and never ever gave up dreaming that one day I would stand on its summit.

My family tried several times to make the climb with lots of helpers but we never got very far. Each time we failed they told me it was just not possible and that it was an unrealistic goal, that it was too hard and too dangerous.

But I had a dream in my heart and wouldn't let it go. One day mum agreed to give it one last shot. Thinking a climbing harness might help save me from breaking my neck, she did a Google search and picked a climbing gear store in Bendigo, Victoria to ring. The owner, Steve Morris, was a climbing instructor, who, to cut a remarkable story short, volunteered to fly up and help me get to the top of the mountain. We all met Steve for the first time at dawn in the carpark at Mt Warning when he and his wife and two children teamed up to meet our 30 other volunteers - some friends, some family, and some complete strangers, like Steve and his family, who just turned up to help.

Steve brought mountains of ropes, shackles, belaying pins and stuff I'd never seen before, to help with the climb, which took 10 hours with teams of two people taking ten-minute shifts all the way up and down.

Half way up we could not see a thing as the mountain was enveloped in cloud and it was raining, making everything even more dangerous, frightening and slippery. But mum said my gleeful cheers and constant encouragement kept everyone's spirits high.

It took weeks to recover but it was a day to treasure and remember forever for us all.

I learnt that day that you can create your own reality and that your passion, single-mindedness and belief in yourself can help you manifest your dreams and goals in life when you hold that vision clearly in your heart and believe in yourself, even when others doubt you and say it is not possible.

My family learned, too, that it is not only your friends and family who will come to your aid, but that there are wonderful people out there in the world who may be total strangers and yet they are prepared to give an enormous amount of time and support. Everything is possible when a community of people come together with a single purpose.

JACKmail: More Than Just a Mail Service

Sally Richards

Sally Richards is a teacher, trainer, writer and advocate and her third son, Jackson, has an intellectual disability and autism. She represents families on various government and non government reference groups, steering committees and boards. Sally facilitated the creation of JACKmail, a business that employs Jackson five mornings a week.

My son, Jackson West, is the man at the centre of JACKmail, a family owned, sole trader courier business which operates in Canberra, Australia.

People establish small businesses all the time but Jackson is a young man who would never normally be able to find a job. Jackson has a profound intellectual disability and autism due to a unique chromosome abnormality; he has an extra terminal band on the long arm of the 22nd chromosome. What this means is that he has very high support needs; Jackson has no verbal communication, no concept of danger and needs others to attend to his every need.

Jackson is a person who is easily overlooked, and often totally ignored, by others. He is in danger of living permanently on the fringes of society, marginalised in the parallel disabled universe instead of fully participating in life with its rich experiences and relationships.

Some years before Jackson finished school, I started to put several things in place that might assist him to have a life of his own; a life in many aspects not dissimilar to the lives his three brothers enjoy. The elements of this long term plan included forming a family governance group with two other families, creating a website, forming a circle of support, establishing some partnerships and finding him a job.

As stated above, it was highly unlikely that anyone would give Jackson a job, but that didn't mean that he couldn't work. I firmly believed that he had the capacity to work. It just had to be the right kind of work with enough of the right kind of support. The right kind of work for Jackson was going to have to be built around him, his abilities and the things he enjoys doing. The right kind of support meant one-on-one support by a

particular kind of person – a person who would put Jackson first, promote him as a person, foster relationships, develop his skills and enjoy being with him.

In the early hours of one morning as I was lying sleepless in bed, I mentally catalogued Jackson's abilities and loves, and the solution came to me in one of those rare moments of clarity and certainty – he just had to be a courier.

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But not just any courier. The work had to be regular and predictable with Jackson delivering to the same businesses either every day or, at least, every week. One of the most important aspects of the business was that Jackson would get to know people and that people would get to know him.

So, JACKmail was created to employ Jackson part time. JACKmail primarily collects mail from post office boxes and delivers it to businesses. But occasionally the business delivers tender documents and couriers small items between businesses.

JACKmail has been operating since February 2007 and was officially launched by Ms Katy Gallagher, the Australian Capital Territory (ACT) Minister for Disability, on the 2nd March. Every week day morning Jackson makes his deliveries with his driver, Jamie Richardson. Jackson has gradually been learning new skills associated with his job.

So far JACKmail has achieved the following:

- 19 businesses use JACKmail either regularly or occasionally
- Jackson has a legitimate and valued presence in the Canberra business community
- Over 25 people in offices greet Jackson every morning
- Jackson is doing regular, predictable and appreciated work
- Jackson is missed - people want to know where he is if he is sick (the mail still gets delivered but without him)
- Jackson is known - people in the street say “Hi”, stop for a chat, wave, smile
- Jackson has learnt and is learning some work and social skills
- Jackson is earning money
- Jackson has a purpose and is busy five mornings a week
- His employment subsidises the cost of his care
- JACKmail has established some working partnerships with organisations and businesses
- JACKmail has been nominated for the ACT Chief Minister's Inclusion Award in Small Business.

The business has been a great success if you disregard the financial side of it which, in the grand scheme of things, is not really that important compared to getting Jackson a life.

I continue to promote the business through speaking at workshops, training days, conferences, the ACT Women's Chamber of Business and Rotary Clubs.

To find out more about Jackson visit www.jacksonwest.org

Home: A Place Of My Own Where I Belong

Anita O'Brien

Anita O'Brien has worked as a volunteer in the disability field since the birth of her second son Warren, who was born with cerebral palsy. She recently joined a group of families to create a family governed arrangement called Living Distinctive Lives that aims to support individuals to live typical lifestyles in their own home, in the community, utilising a range of support.

When one is with like minded people it is not unusual to say: "You have made me feel at home". Home is a place where you feel comfortable, valued and respected. Home is a place to be you, to share one's life – its joys and pain – with the people you choose to live with and who understand and care about you.

There is a song with the lyrics that say:

*I feel home, when I see the faces
that remember my own,*

*I feel home, when I'm chilling
outside with the people I know.*

So home is also about the relationships and friendships that you have the opportunity to develop.

Home is not just found in the house in which I live though, and the people with whom I live, but also in the community in which I have chosen to live. A sense of belonging can be found when home is in a community where you find connection to people and places and are able to participate and contribute to that community.

A quote from the L'Arche Community is worth repeating:

Whatever their gifts or limitations, people are all bound together in a common humanity. Everyone is of unique and sacred value and everyone has the same dignity and the same rights. The fundamental rights of each person include the rights to life, to care, to a home, to education and to work. Since the deepest need of a human being is to love and to be loved, each person has a right to friendship, to communion and to a spiritual life.

When I have these things I am at home in the world.

When our sons were born, we had dreams for them like everyone else. And

as they grew they had their own dreams. Are they just as entitled as each other to have some, if not all their dreams come true? Our elder son enjoys such things as a home of his own, a wife with whom to share his life, valued roles in his work, leisure and in his community. He has meaningful days and many different friendships and relationships. Warren, our younger son, indicates he wants and needs the same things, not a life lived in segregated settings and controlled by systems and people paid to be in his life.

"To thrive, Warren needs to be in environments where he wants to be and with people who value him, who talk to him and with whom he relates!"

Warren is 32 years old, has 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 and with whom he relates! He needs lots of different relationships. His disability is cerebral palsy, with an intellectual and some physical disability, which limits his capacity to plan, work and travel without support. It also means that knowing his surroundings and being able to negotiate within them independently is very important to him. He struggles with an anxiety disorder which is particularly debilitating when he is experiencing high levels of stress or emotional pain.

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?

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 I believed that we would at least have some say in the way the home was managed. I also thought there would be an advantage in that Warren would have people to share his day with. It wasn't perfect, and I felt a little uncertain, yet what other options were there? We decided to work with it.

You might ask why we would take our son out of this group home three years later, a supported 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 Adult Training day program (ATSS) 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. Although Warren always tries to make the best of each situation in life, he was telling us that this is not what he wanted by his demeanour, anxiety, and actions. He was not presenting at his best: his personal hygiene was not good enough, he was very anxious and his choices were limited!

Eventually, through the influence of many people, such as Deb Rouget, the Deohaeko families from Canada, and finally the presenters at the Mamre Conference in Brisbane 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. I linked with a family governed project *Living Distinctive Lives* which grew from the initiative of parents who believed their adult sons and daughters have the right to have a meaningful lifestyle, typical of other members of society, which includes accommodation arrangements of their choice, rather than living in disability service settings.

A whole of life approach is taken by the families. Individuals seeking to set up their own home are simultaneously aiming to form relationships, develop long term networks, and have meaningful roles within and beyond local communities. We believe this holistic approach is the key to living safely, successfully and happily in their own homes.

We had 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 the options, and he chose to come home to the flat below the family home and to the community in which he had lived. Why? He gave the simple reply: “Because it’s better”. He returned home late 2005, which meant removing him 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, yet unique life. Our challenge was to do it better; for him to have his own home, to seek housemates and to 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.

Warren is now living in a two bedroom/ two bathroom flat on the lower level of our family home. Almost two years 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, 2006) 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 sometimes go out for coffee, Warren has lunch out with John, and he has had drum lessons with John’s brother - just ordinary, everyday things.

“Whilst agencies can assist and often do well, we are not relying on them for our son’s future happiness.”

There are still struggles and challenges, particularly around helping him to communicate his feelings, but he is most definitely doing that now.

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

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.

In our ‘get togethers’ we have celebrated with him, identified Warren’s passions, interests, skills and abilities and what gives him energy, explored some work and leisure possibilities, and talked about his fundamental needs, such as freedom to make choices, self worth and recognition and maintaining a sense of belonging.

Warren has a vision and often dreams. Warren and his family and friends must keep their eyes on that vision, and keep returning to it, because we can so easily find ourselves compromising the dream. I believe the safeguards to that vision should be kept by the family; we can be supported by an agency and their staff, but we must not rely on them to protect Warren from change. For Warren, and his family, to have this high degree of ‘say so’ returned is indeed empowering.

When changes come, and they have – some more drastic than others - the good days cannot be taken away: the days where Warren is living a more meaningful life, in his own home and a welcoming community, are days that we can treasure. It has been well said: “You don’t stop planting a garden, just because winter comes. Each time a flower blooms you bring joy and encouragement to others.”

It is a journey that requires imagination, hard work and courage, but it is better and it is worth it.

family
A D V O C A C Y

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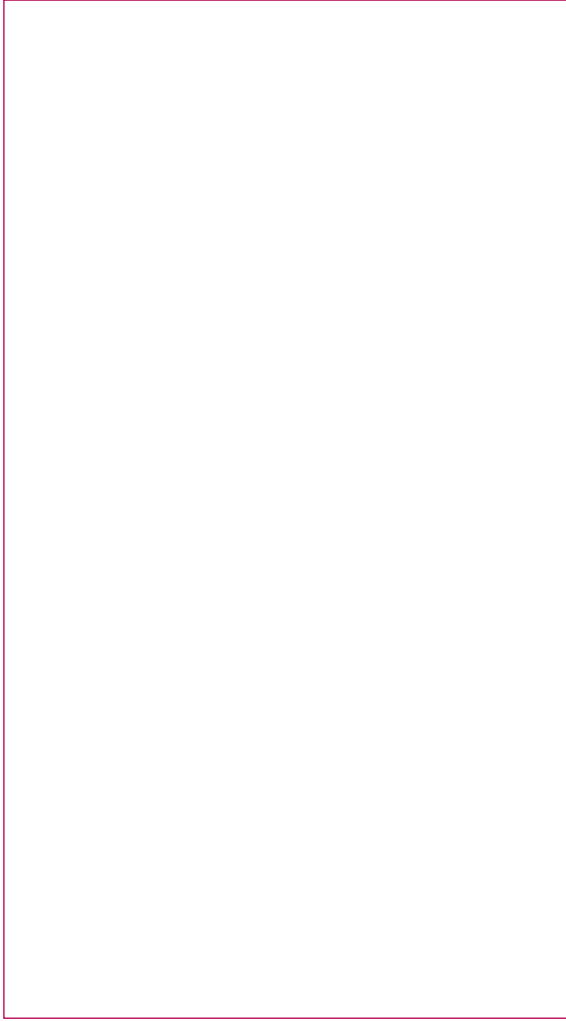
Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

Advocacy

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

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