Broadening our perspectives ~ families and vision building for socially inclusive lives and pathways

by Judith Ellis

Judith Ellis is Matthew's mother. She has been involved for many years in advocacy so that people living with disability enjoy and achieve valued roles and socially inclusive lives. Judith has also been at the forefront of influencing the Australian system — at government or non-government level — to make it possible for formal support to be personalised and individualised.

Judith now works with organisations and families to assist them to make the changes necessary so that people can live ordinary, real lives as full members of the broader community.

I caught up with a friend recently. She is someone I have known for over 18 years. She lives a bit of a distance away and we don't see each other often. It was a good catch-up. Before our conversation turned to what was happening with our respective children, we shared our recent holiday trips, hers to England and mine to France and England.

We both have three children — hers are young adults, mine are older. As friends do, we talked about how they were going with all the ups and the downs that life brings with it. My eldest son, for instance, has some health concerns. He also needs to find more customers for his small home-based business — a situation which is shared by his younger brother who also runs his own business. I chatted on about my daughter and her husband who had recently moved house. She talked about her elder daughter who had just left school and who is thinking about what she needs to do to get a job in child care in the future. At the moment her daughter has a part-time position with a local bakery — a position she found from doing work experience when she was in Year 12 at school. Of her two other children, her son is now at university and living away from home, and her younger daughter is just going through the HSC experience.

All very ordinary, really. Ordinary, everyday lives being shared.

Our catch-up reflected the expectations and norms to which most people aspire — that give meaning to life. Things like love of family and friends, belonging, opportunity, contributing to the community, a good education, a positive future, work which reflects our interests and skills, a home, security, good health, fun, travel, loving and being loved.

Our paths had crossed 20 years ago because we each have a child who was born with a disability. Her daughter is 19, my son is 40. When we meet, we invariably reminisce about what life could have been like for them and us had we not found a way to dream, to think differently and to pursue an ordinary life for them.

Like me, in the early days, families may find themselves losing a sense of a desirable future as they naturally look for diagnosis, advice and assistance. They become gradually dependent on the professional service system for all the answers rather than just some of the answers. The way my friend and I talk about it now is the difference between having dreams and aspirations about a "real life" — just as you have for your other children — and being conditioned to think that a "service life" is an ordinary life. While individuals within the system are invariably good people with lots of ideas, and often themselves passionate about making a real difference, sadly it's a system which puts individuals living with disability on a different pathway. In service land, the ordinary expectations are turned into programs and there is a "program" for everything — early intervention programs, therapy programs, special schools and units, work preparation programs, day centres, behaviour modification programs, independent living programs, residential facilities. And all these programs tend to group people together in places and spaces, which are not shared by typical members of the community; where families are expected to concede their natural authority and decision making, become beholden to the service and government system and be eternally grateful; where often, despite government policies and monitoring, individuals with disability end up isolated and lonely, separate from the community, on the margins of society, sometimes at risk of neglect and abuse.

Most families with whom I have had an ongoing connection often say that they felt, in their hearts, that they wanted something different to what was on offer. They perhaps internally questioned the programs to which they were referred, wondering why there were no other children except those with disability, wondering why they had to be "fitted in" to what was on offer, wondering why it was the case that their sons and daughters with disability were in respite services with children who they did not know, and with whom they had little in common.

Another friend of mine names this as "becoming an outsider" where there are only occasional glimpses of the lives that others enjoy.

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Thinking about a positive and desirable future does not mean that services are not needed.

Like many other parents who aspire for the "ordinary life", I am not "anti-service or anti-government". Those are simplistic and incorrect assumptions. Rather I know and accept that my son needs paid support. What I, and many would like however, is a service system which ensures that people are supported in a way which reflects their individuality and uniqueness and rids itself of the stereotypes of disability — not the least of which is that people who have a disability have more in common with other people with disability than they do with non-disabled people.

My vision building started with belief, a strong belief that my son could and should enjoy the good things of life. Where did this belief come from? I am not sure that I can answer that question. What I do know is that, after 20 or so years of accepting the segregated programs, I realised that my son did not have a life and he was not known by any members of the ordinary community. I realised that he would become more of an outsider and more vulnerable by having only his small family and paid service provision.

My innate belief, spurred on by these painful reflections, galvanised into action through meeting another parent whose daughter — who had very profound barriers to life as a result of her disability — was doing amazing things. I remember this parent explaining to me that she had consciously developed a vision of an ordinary life, that she had written it down on behalf of her daughter, and — as a start — she had shared it with others. I was inspired, intrigued, and a bit frightened and I recall asking to see this written vision. It stated, very simply, that she and her family wanted her daughter to have opportunities in life to meet lots of people in her life who got to know her, they wanted her to be supported to move out of home into a home of her own, to have choices, and to have a valued work role. This vision meant that her daughter needed support to be in places and spaces where she would meet people of her own age who shared her interests. It meant that, on her behalf, they had to ask different questions of the professionals and services she received.

That was it for me! I had to turn my belief into a vision of what my son's life could and should look like into the future and I had to share it with others and find others who would join me and other members of his family to make a difference.

These moments are not without their challenges. When we hear stories of the ordinary, everyday, it takes us by surprise because for so long we have relied on a different narrative. My friend calls it "staring down the "cookie-cutter" approach to life" — a cookie-cutter, which has been designed by others far more powerful than us and whose blueprint is based on notions of disability rather than individuality. The cookie-cutter designers are unknown to us and are certainly people who do not know, and never will know, our sons and daughters.

All this speaks to how families broaden their perspective, question the status quo, and start to aspire to, and envision, those things that make up a "real" life, a "good" life, actually an "ordinary life". This is where the "vision" word comes in.

In the face of the lure of the system and to stand against the status quo, my friend and I — along with lots of other families — found that spending time thinking about and developing a vision of a desirable future was the starting point. If we were going to swim against the tide, we had to strengthen ourselves, bring others in to help, ask ourselves and others different questions. We had to challenge ourselves and re-examine the decisions we may already have made.

For some parents of children, this moment develops as a result of meeting other parents who have already carved out some ordinary things of life — whose child goes to the local school, spends their early childhood in ordinary playgroups and preschools, plays in the local park with children who live in the neighbourhood, and gets invited to birthday parties by children who live down the street.

For others whose son or daughter is an adult, their decision to engage in intentional vision building came from hearing stories of people living in their own homes with the level of support they require; of spending time in ordinary, valued places where they became known by a wide group of people, some of whom have became friends; of working; and of pursuing their individual interests.

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So where to start?

Imagining means trying to put form to something that is unseen — something that is "over the horizon". Those who have done it, have hints to offer.

- Find people with whom you can have this kind of conversation, and hear from others who have a vision of an ordinary life, how they started, what they face and what differences have been made. Finding others who have done the same thing, who question what is on offer, is illuminating and inspiring.
- Understand that a vision gives you clarity. One parent talks about "vision" being the guiding star — the ones that seafarers used in past times to guide them to their destination. Another uses the analogy of a "compass" — giving you direction. Neither the star nor the compass take into account the difficulties experienced on the journey. A clear vision does, however, mean that you have additional impetus to meet the difficulties and challenges and find ways to move forward, even though — at times — the moving forward is slow. It helps you see a way around short-term disappointments and keep the longer term goal in mind.
- See that a positive vision helps free you up to search for other things, to think laterally, to forge new relationships.
- Take advantage of the fact that holding the goal of an ordinary life gives you a different way of speaking to others. Your language changes and you are able to bring others into an understanding of how they can help.
- Believe that — when others hear of the ordinary dreams and aspirations of people with significant disability to have their own home, their own place, to find work because of who you are — it frees them to come up with ideas. And the more ideas there are, the more opportunities emerge as possibilities.
- Realise that it gives you the power to say "no". As you listen to what the system has to offer, or what professionals suggest, you can be thinking "will this help achieve the future we are wanting?" If not, you can say "no". You can, of course, always say "yes", when funding or support or advice will provide you with the tools to progress your vision.
- Accept that bringing your dream and aspirations of an ordinary life to reality does mean hard work. Many people say, however, that fitting in to what is offered, losing control, having difficult meetings with service providers, becoming labelled as "difficult" is harder.

When lots more individuals with disability, parents and families are holding to the dreams and aspirations of an ordinary life, then government policy will change, funding guidelines get freed up.

When demand grows for the formal support to be shaped in a way to help turn a vision into reality, big changes will happen.

I know that the vision building, which we started about 20 years ago has been the compass we have used to stay on track. We, like others, have weathered many storms, sometimes over a long period of time. We have felt tired and disappointed, angry and impatient. Luckily sharing our vision brought to us people who have stuck with us, friends and colleagues who have helped us with ideas, support, advice — who have laughed and cried with us. We have found service providers who have listened to us and supported us to achieve our vision. We have never really thought of giving it up, as we have slowly but surely carved out the bits of ordinary life which we so value for ourselves and for my son.

My son — who lives with the effect and barriers of significant disabilities resulting in him needing support in all areas of his life, now lives in a home he can call his own. He shares his home with people whom he chooses, people who provide him with safety and security, who pay rent, people who do not have a disability. He has a small business enterprise.

He remains a valued and loved member of his family.

The decisions which are made about his life are made with him — that is — by people who know him and love him who listen to him even though he does not speak, and who base their decisions on his humanness, his identity, his uniqueness — rather than his disability. He has a close circle of friends who only came to know him once he fulfilled and achieved some valued roles. His paid team are invaluable, chosen by his family and him. They work in partnership with him helping him fulfil and enjoy his "ordinary life" which includes being the principal of a small mail delivery and collection business.

It takes work to keep it going, there are ups and downs, and it is not perfect. But it is "ordinary life".

My friend's daughter — a young woman with significant support needs as a result of her disability, has gone through the whole of her education in her local neighbourhood school. She is just starting out on life — a life about which she has dreams and aspirations, a life which reflects who she is and not her disability.

I always look forward to seeing my friend and I know she looks forward to catching up with me. We give each other ideas, energy, and a renewed enthusiasm. Our conversations are of the ordinary, everyday stuff of life. They would be very different had we not broadened our perspective and done some vision building.

Matthew Ellis

Despite the fact that my friend and I, our families, and the people in our families who live with disability, swim against the tide, we are proud of our and their achievements, proud of their ordinary life, and the difference this has made and will make into the future.

With acknowledgement and thanks to the many parents and friends whose experience of vision building has shaped this article.