

Belonging Matters' Podcast

Transcript

Episode 3: A Desirable Future

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Welcome to Belonging Matters podcast series. Now available on Apple podcasts, Google podcasts, Spotify, and www.belongingmatters.org. You can email Belonging Matters at info@belongingmatters.org. Episode Three, A Desirable Future. Lisa lives in Brisbane with her husband Terry and her three children, Amelia, Sean and Declan and works at Community Resource Unit as senior consultant. Lisa has a social work background and since the birth of her son Sean 18 years ago, Lisa has been actively involved in a number of parents support and disability advocacy organisations, including Queensland parents for people with disability, the Down syndrome association of Queensland, and Queensland advocacy. She is passionate about building communities which more routinely welcome people with disability and has a keen interest in bioethical issues impacting on people with

disability. In this podcast, Lisa shares the story of creating a desirable future for her son, Sean.

A few weeks ago, my son Sean celebrated his 18th birthday, or more accurately, began what is turning into a month of celebrations. Given how desperately ill Sean was when he was born, a month of party seems entirely fitting, though I am looking forward to the completion of the festivities alongside this socialising. This milestone has also led us to deeply reflect on Sean and how limited our imaginations were when he was born. I would love to be able to go back to the comfort and reassure the sad, terrified woman that I was in the days and weeks after Sean's birth to tell her that it would be okay and that she was about to embark on a wonderful adventure. Sean is a delightful, sociable young man who embraces life with a bigger than life enthusiasm, which makes most of us look like we are stuck in second gear. He is affectionate, kind, and frequently hilarious. And he has been a one boy introduction agency helping us meet lots of wonderful people. And yes, a few dodgy therapists, educators and medicos, who we could have easily lived without, our lives far from being blighted, or limited by his presence, as we then feared, have been made better and richer by all that we have learned from and through him. Initially, my vision was pretty much focused on fixing Sean. It took me some time to understand that while helping Sean to develop was a worthy goal, having Down Syndrome was absolutely okay. Sean did not need to be fixed or cured or changed. With this realisation, I was able to start again to imagine a different future. I was able to really think about the

elements which make up a rich and meaningful life, a life I would see as fitting for each of my precious children. I'm no longer sure exactly how we got from those dark, dismal early days to where we are now. But the most critical ingredient was to surround ourselves with people who nurtured our imagination of what is possible. I'm grateful for the people with disability and their families whose stories of lives full of relationship and contribution, sometimes against great odds have inspired hope, and an ambitious vision for Sean. Equally important have been the professionals and allies who have walked with us sharing frameworks or ideas, gently challenging us when needed, and helping us to refine, expand and have faith in our dreams. The vision word is much bandied about and doesn't always sit comfortably. But this description of a dream captures the essence. A dream is a compelling picture of a desirable future. Once invented by the imagination, it hovers over the person as a Luma towards the future. We need our dreams to be compelling, persuasive, and likely to have power over us and others. We can and should create detailed pictures of a desirable future because they are the antidote to the negative images and "special" places of exile given to us by our culture. Such a dream loses us, beckons us, encourages us and becomes our compass, directing our efforts to this destination, and helping us know when we risk going off course. At the simplest level, my vision or dream for Sean is that he will have a rich life full of opportunities to learn and contribute embedded in a community where he is valued and appreciated. I want Sean to be linked within a web of relationships connected to people who will be more than bystanders in his life. People who will know him well enough to

challenge him to do what he can do. And to support him in those tasks which he finds especially difficult. People who will know and care about him, and if he is not travelling well, be prepared to act in his best interests.

I dream and trust that with our efforts and support, that he will experience love, belonging, and a sense of himself as the valuable and precious individual he is. Achieving any dream is challenging. We face barriers and obstacles, particularly when our dreams such as a home of his own regular meaningful work, love and marriage, regular holidays, opportunities to pursue his own interests and passion and to experience a sense of achievement have all historically been denied people with disability. The business of daily life leaves little time for reflection and planning about how our vision can be enacted in our current circumstances. So refining our vision and gathering people around us who can neutralise the naysayers and help us feel competent in that vision is critical. It's helpful to know our bottom lines and what we will and won't accept. Being crystal clear, for example, that a sheltered workshop is not an acceptable work experience option has been such a time saver, we waste much less time and fruitless discussion, and more time on our bigger vision for Sean. This enables us to explore potential jobs, which will help Sean create more local community connections, allow him to contribute his gifts and be seen in a positive role, and also build on his natural aptitudes and skills. I'm mindful, however, that many people with disability experience rejection and exclusion. So we do need to do more than just hope for the best. Our dreams need to be anchored in planning and intentional actions, which move

us closer to that vision. I'm very conscious about looking for roles and activities which helps Sean to pursue his interests. I share his gifts, and I look for opportunities to develop and preserve relationships, particularly connections in our local community. While our efforts in this regard are imperfect, we do work at maintaining contact with long term friends, such as friends from primary school, and as a family we also try to be active and visible in our community. We do this in recognition that investing in Sean being known in this way will have long term benefits. For almost two years we've had a support circle for Sean and this is one strategy we use for keeping the momentum going. The magic of the circle has been that now not every bit of forward movement relies on his tired parents. Support circle members have generated ideas, made the phone calls to find out about available services or courses, found Sean work experience opportunities, briefed employers and support workers, helped us develop job descriptions for support workers, stepped in when support fell down, found new groups and roles for Sean based on the goals we developed, shared time with Sean. Help with Sean's birthday party helps him to develop new skills and they've been a valuable sounding board. All this has been freely given and achieved without any application or accountability forms for us to fill out. It's worth contemplating whether seeking this range of support through formal disability services would have even been possible, let alone achieved in such a timely way, without cost, frustration, formed billing, or regulation. Al etmansky challenges parents to think of one thing that you're currently doing for your son or daughter, that could be done by someone else. Like many parents, this has been a struggle for me. For six months after

setting up the support circle, I thought I needed to implement every idea the support circle came up with. Luckily, some of the members got tired of me hogging all the jobs, and called me on it. One thing that has been very central for us in planning Sean's life has been that we want him in the real world, not the disability world. In short, we want him to have a great life, a life comparable to other young people without disability, and not just a pretty good life for a person with disability.

We still face the gap between what I would desire for him and the current reality. Sean enjoys lots of great relationships, but he is still home with us more than other teenagers. His social life is more planned than spontaneous. This last factor isn't necessarily a problem. But we hold on to that dream for more. To this end, we push ourselves to be flexible and take up last minute invites because we recognise the power of saying yes, even to last minute social opportunities, which might require us to juggle other commitments. For me, it never made sense for Sean to be outside regular sittings, trying to earn his way into the mainstream community. The foundation of this and his inclusion has been inclusion in local school. Growing up in a country town and then living in an inner city neighbourhood with strong community ties meant that being local was very important. As a former community development worker, I knew that building strong relationships is aided by geographical proximity, along with the time and intensity needed to cement a relationship. This means that people need to be regularly together and engaged in common interest to maximise the chance of a relationship forming. For us, this meant that when

we looked at where Sean would go to school, where he would recreate the activities he would join, the local options would be top of our list. Setting our campus to local where possible, where the local options were equal or more valued, helps us to form the web. The local options mean Sean is more likely to be there with school friends, and to run into those same young people in our local shops, cafes and parks. Another bias was that we looked for those activities which made sense for his age and gender. It helped that Sean was our second child so school was easy to choose. But with an older daughter, I wasn't always sure where boys of his age might hang out. So I relied heavily on other parents for this information. During his primary school years, Sean joined the swimming club, played soccer, took circus classes and learnt jujitsu. A real benefit of being in the local school was that it became easier to find allies who would support Sean being in other regular community settings. Basically, the kids he was in with within those activities accepted and knew how to support Sean already, and their parents were the coaches, referees and timekeepers. Having these regular opportunities has helped Sean to be perceived as similarly with other children rather than his differences. I can certainly remember many occasions where other children were variously impressed or envious of Sean's soccer trophies or new uniforms. It's a great reminder of the power of inhabiting roles that are highly valued, because let's face it, the role of a disability service client is not one any of us aspire to. It is worth spending time really intuiting our family members interests and what makes sense for their age and stage. Because so often we don't do enough research to make a good match. I remember meeting a mother desperate for friends for her son,

but because she couldn't at that time figure out where he should be spending time. Her 30 year old son was hanging out, and happily for all, at her ladies craft group. Well, this mismatch may seem obvious, I think we can all think of other examples where the age gender interests match have been wrong. Unfortunately, many people then count that as evidence that relationship between people with disability and other community members don't work. Rather, we've forgotten some of the fundamentals of how relationships are more likely to develop. I see one of my major tasks as a parent is to be a detective in scoping opportunities for Sean, to remain in regular, typical age appropriate roles.

This has been particularly relevant for high school where there is less parent contact with the school to know what is happening and when teenagers socialise become less structured and directed by parents. To discover the group's activities, rhythms and rituals of school, I use formal contact with teachers. But I also use the school newsletter website tuckshop duty and contact with parents I know. We have recognised that some opportunities won't work for Sean, as he shares the family's genetic lack of musical ability. So although his school has an excellent music programme, we needed to give that a miss. He does, however, attend rugby training travelling out by train with hundreds of other boys to the school ovals, he directs the water boys at games, that's a long story, loves school dances, sports days and camps, participates in the school photography competitions, volunteers for door knock appeals, is an active volleyball supporter, participates in

the seniors barbecue roster, and is a member of a number of school spirit and service committees. A big part of our detective work is finding what depth David Wetherow calls the sweet places in our community... places where people are not just consuming, but open to relationship and where people can have a valued role and contribute. Sean's youth group is exactly like this. There are great leaders modelling respect, a program which suits Sean, because it includes fun and physical games, (as well as talk) a shared meal which Sean can help to prepare and set up and young people who are open. We are thrilled when Sean initiates social contact on his own or is invited out by friends. But many things do not just happen. They require our involvement. So we know about them, get him there well prepared and sometimes ask or negotiate his involvement. Frequently we lack the capacity to chase up an opportunity and I try not to feel guilty about that. Having the support circle helps the momentum and guards against us feeling that it's all up to us.

But still we face the reality of constant monitoring and continuing to invest in maintaining the positive roles and relationships he enjoys. Many years ago now Joel Satherly, a young man with disability who has sadly since died, identified one of the major barriers to a good life when he said life should not be boring and predictable every single day. Just because you have a disability. Don't assume something that they want to do is too unrealistic. Because chances are this is code for I'm too scared of helping them try. As family members we must face how frequently are many varied fears do limit what is

possible. I can still find myself immobilised by fear that Sean will be rejected. Even though I have evidence that while community can be rejecting, it can also be wonderfully welcoming. There is not a human being on this planet that has not experienced rejection at some time, it is quite possible to survive it. Sometimes our fears make us doubt that real friendship is possible - and so we unwittingly ignore evidence of when it is on offer. We fail to nurture the seeds which might take some time to develop. We take people out of the regular settings where the possibilities are present. Believing friendship and inclusion is possible helps us to be ready. And nothing ventured, nothing gained. When we fear rejection we need to "feel the fear and do it anyway." - and go into the regular community spaces armed with our compelling dream, and able to share with others, our aspirations, and our family members' gifts and potential. Sometimes even good people say insensitive things, or don't know how to include someone well, so we need to overcome hurt, not harbour resentment or write people off too quickly, but turn our attention to the task of business. A very useful metaphor for us in choosing what makes sense for Sean, is Wetherow's 'empty calories' description of many disability programs with a community access or recreation focus. These are often programs that keep people busy, but do nothing to create valued roles or relationships, or give people a purpose. Usually, they isolate people, often erode rather than build a person's skills and self worth and send a message about where people with disability belong. So we give these empty calories a miss. You are in a time where there is a lot of enthusiasm and expectation for a National Disability Insurance Scheme. But unless we are

guided by a dream worth pursuing, we risk investing in more disability programmes which are dead ends for our family members. Much of what will add value to people's lives cannot be bought. Therefore, funding will always only be an adjunct to rich, meaningful life. There is also a danger that we will see a market in special programmes or therapies, which will only strengthen a separate path. We risk perpetuating and indeed expanding a menu of disability services which will continue to fail people because we risk asking the wrong questions and looking in the wrong places, places which isolate people with disability into day services, music therapy, etc. We risk forgetting what we as human beings all need, love, purpose connection, to be seen as someone of value. Sean is now in year 12 at a local Catholic Boys School in walking distance from our home. He loves his new senior white shirt and tie which he wears proudly with his blazer even in the Brisbane heat. He studied five subjects and has a half day of work experience each week. In the last year has worked in a bakery, a tourist office and a refugee settlement service helping to set up their catering and training rooms. He will now spend a term in his dad's legal office which is his vision. This week he will go on retreat and next week he will take part in the Seniors' Commissioning Assembly. During the week he says he attends swimming squad

three times a week, attends jujitsu trains at the gym, supports the school volleyball, rugby or basketball depending on the season, goes tandem cycling with his dad, and attended church youth group. He bosses his younger brother and

cousins around, phones his friends and spends too much time on Facebook and YouTube. He walks to and from school and is becoming more independent around the home. Though, as with many teenagers these skills seem to fluctuate madly, it is a pretty regular teenage life. Our precious baby is now a young man, his wondrous life is still evolving. Our challenge is to keep strengthening and sharing our dream, so that this dream and not the old disability story... becomes not just persuasive, but completely irresistible.

Since I wrote this article on a desirable future. Sean has left school. He has been working at multicultural Australia since early 2014. And for the past four years. He's also had a second job at the Brisbane Convention and Exhibition Centre. So he's been working five mornings a week. He has moved into his own home 18 months ago, where he lives with a flatmate who is a teacher. And he's now a youth group leader and has been for many years in the youth group that he joined during those high school years. He continues to shake us all up in terms of our complacency, too. He continues to have a wide circle of friends and to be living his best life, and we're immensely proud of him.

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