

family

A D V O C A C Y

One in all in

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Our family's story begins when our daughter with an intellectual disability was an infant. We found ourselves being directed to a professional disability environment that encouraged us to believe that the people offering specialist knowledge and assistance knew what was best for us and our daughter. As she was just a baby and our parental role was still fragile it is not surprising that we found our family's natural and proper role in raising our daughter diminished by this experience.

As the disability specific environment is so powerful, many families comply with professionally base decision making on behalf of their child without question. This often takes families on a journey to a separate, congregated, disability specific life. A typical pathway often follows including special playgroup, early intervention preschool, special school or support unit, respite programs, recreation programs, sheltered employment and eventually a group home¹.

Many families remain unaware that a typical, ordinary life in the community can be lived by people with disability - regardless of their capacity. Families are so ensconced in the segregated, congregated pathway that they do not get exposed to another alternative. Unfortunately, many first question their family member's segregated life path due to suspicions of abuse, their impending death or sheer luck.

Our family was led to believe that only those with a shared experience of disability would be able to understand, empathise or lend support to us. It is true that many families turn to others in similar circumstances in order to share stories, experiences and expectations and this can be very helpful. However, when families attend the special needs playgroup, the opportunity to attend a mainstream playgroup is diminished. Then special school P&C takes precedence over the mainstream school. Fundraising - for respite and other services - is time consuming too. Over a few years, families often end up only associating with or knowing other families with children with disability. This then leaves families with a child with disability and families without at a distance from each other.

¹ The author recognizes and respects the fact that some families intentionally choose this pathway.

Often then, families with a child with disability become isolated and limited in the help they can naturally call on for baby sitting or a general hand as most of the other families they now know are equally stretched. Conversations about child raising then revolve around disability issues due to the collective families being isolated from developmental processes in typical families as children grow up. This cycle often continues until paid support is vital in families' lives - usually in the form of respite - due to the absence of natural supports that the family can call on.

Equally, typical families are accused of not having empathy or accepting people with disability in the community. How can people show empathy or understanding if they aren't given the chance to experience someone's life and grow in knowledge and understanding as we do? I think to assume that typical families cannot understand and empathise with the situation that families of a person with a disability experience reflects a fundamental flaw in thinking.

It is the essence of community life to remain connected to family, lifelong friends, workmates, sporting team members, faith community, neighbours etc and bring them along on your family's journey with you. Many families become isolated over time because the duties that relate to the disability-specific, segregated, activities are all-consuming. There is no time for once typical relationships which, as a consequence, gradually ebb away.

Due to luck, mentioned above, we met other families that encouraged us to take action early to keep our whole family connected to the community. We learned that if we did not take action we would most likely become isolated in the way I have outlined. Even though we were flying by the seat of our pants, we created opportunities for our daughter and whole family to continue and develop relationships at different levels of life - within family, with friends and neighbours, with the broader community and as individuals.

Family

At the family level we set the scene by explaining to our extended family what we wanted for our children and why it was important. We accepted that our extended family would take time to learn and grow as we had. As there was a sense of good will we tried not to be too harsh in our expectations of their acceptance and understanding. The reality is that most of us live a long life so relationships have time to grow. We appreciate that family relationships are extremely important to our daughter and this continues to make our efforts worth the energy and patience required.

All our children attended the same primary and high school, enrolled in regular class. They travelled by bus to and from school with other children in our neighborhood. This helped our whole family stay connected to each other in a

typical way. Being surrounded by regular families kept us grounded in ordinary childhood and family development.

I, as mum, had to learn to let go and appreciate that men do things differently and support the unique relationship the children have with their father. We consciously make room for 'Dad' things even now the children have grown up.

Our son has moved to Canberra so we arrange things to see him and his friends regularly. We have started attending music festivals as a family as one of the ways to keep connected. Our son has invited his sister to come and stay with him for a few days. Although we are worried that she might not receive the support we think she needs we have to trust our son's judgment that he and she will be fine. Now young adults, they are finding a new way of relating; as parents, we have to leave room for that to happen.

We really enjoy all our children and love each of them unconditionally. We publicly show our regard for each other and people respond positively to that joy we share.

Friends and neighbours

In relation to friends and neighbors we looked for ways to encourage closer relationships with them. We do ordinary things however try to 'value add' to what we are already doing rather than doing something else on top. Some of our ideas include the following.

Offering lifts to many children for sporting or other events. Whole families being invited to our children's birthday parties so people could engage with our family and daughter with intellectual disability in our own home. When some of our son's friends moved into a share house we invited them over for dinner every Monday night. This arrangement not only provided support for our son and his friends but also let them experience our family and our daughter as we are together.

We send out Christmas newsletters to everyone we know - even if we don't get them in return - to keep them up to date with how our daughter's life is progressing. When we moved house our daughter was turning 18, so this rite of passage was combined with a farewell party for the whole family and about 60 people attended. We mow the lawn and wash cars at the same time as our neighbors to enable casual conversation to occur. We also loan our trailer, tools and the like. We hosted the first street Christmas party and continue to have impromptu gatherings such as neighborhood barbecues and casserole nights. Other neighbours are now hosting events at their homes.

Community

We participate in as many local community events as we can. For instance our daughter joins the 'Santa Ride' each year with her father and neighbors. As a fundraiser for Marine Rescue, hundreds of Santa's cycling down the road are quite a sight. We are all members of the local Golf Club and try to attend the meat raffle as a family on Friday nights. When the children were at school, we hosted billets and home stays whenever there was an opportunity. We always use the local shops and supermarket for our shopping. Although it costs more, the gain we make in the broader community knowing our daughter is more than worth it. Our daughter owns her own car with personalised number plates, even though she needs someone to drive her about.

Individual

We support our daughter to be known as an individual as well. When we moved house she repeated Year 11 and completed her HSC in regular class at the local school thus enabling her to meet local young people. Consequently, many young workers in the community know and say hello when she is out and about.

She has assistance to keep in touch with her friends via Facebook and sends birthday cards to loved ones and important people in her life on a weekly basis. Her friendships are fragile as she finds it difficult to show reciprocity, so supporting her to keep in touch is very important.

Her life has a routine that allows for people in the community to get to know her in a predictable way. For example, she buys a magazine at the local news agency at the same time, on the same day, each week. Once she understood where to locate her magazine and how much it cost she could do this without support. This small routine has enabled her to get to know the lady in the news agency really well. They shared the same favorite television shows and chatted about celebrities. Our daughter is great fan of the Royal Family so Donna recommended a magazine with all the Royal gossip. As a result of their shared interest our daughter invited Donna to her celebration of the Royal Wedding that she was delighted to attend. Since then all kinds of opportunities to connect have occurred and now Donna invites our daughter to many things - like handbag parties, lunches and afternoon cooking sessions.

Our daughter is now known by a vast number of typical people in the community as a much loved and valued young woman. This brings a safety to her life that we alone cannot provide as the eyes and ears of the community are looking out for her. This enables more freedom for her to get about independently; this then increases the opportunity for relationship to develop with ordinary people. We

know we are heading in the right direction as more and more people whom she knows but we do not stop her in the street and have a chat.

Governments, funding and services cannot keep people safe on their own, nor can they replace the richness of typical, freely given, relationships. People keep people safe and personal relationships are the key. I encourage families and support workers alike to continue finding ways to initiate, embed and sustain freely given relationships for people with disability - in family, with friends and neighbours, in the broader community and as individuals as these relationships sustain us all.

This presentation was given at Family Advocacy's 2012 The Odyssey Conference...celebrating achievements, progress and change.

You can also read [Strategies to invite others in](#) for more ideas on building relationships

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