

Don't stop believing

by Kim Fairburn-Baker

As a relatively new young mum I watched with delight as my young daughter played on a local playground. I enjoyed the opportunity to clear my head from all the other busy stuff in the world, to have the time just to enjoy being in Jayde's company. It was a clear, bright spring day and I smiled as I thought about what a perfect place to be to enjoy it.

I watched other mums chat away while watching their two young daughters play together. They were a little older than Jayde. I remember in this scene feeling a part of that important collective of motherhood. I encouraged Jayde several times to play in the space of these two children, however she was far more interested in moving quickly between, through, in and under all the play equipment.

It wasn't long before the two young girls asked their mothers for a swing. Diligently their mums walked over to them over, picked them up and gently began pushing them on the swing. When the two girls got off the swing, keen to join in the joy it had clearly given them, I called Jayde over and let her enjoy the experience. She obviously loved the lift and the capacity to go as high as I would safely allow. I still to this day can recall enjoying that moment.

After 10 minutes I became weary of pushing, so I stopped and gently allowed the swing to slow before unfixing the chain and enabling Jayde to play. As the two other girls were called back to their mothers, Jayde passed close by to them. With teddy bear under her arm, the older child called to the other, pointed directly to Jayde and boldly stated, "She's weird!"

To this day never had two words from a stranger broken my heart like these did that day. I had worked for many years with many individuals who have disabilities and their families but never had a statement cut me to the core. I had always felt angry about the injustice of stereotyping and negative assumptions but never as deeply as I had this day as a mum.

Did that four-year-old know what she was doing? No. She was simply repeating the messages, modelling and examples of society which like a cancer, limits, excludes and reduces those who are different to having no value. That day I remember sucking up the pain back to the car and sobbing all the way home. I was no longer just a mum, Jayde was no longer simply my daughter, we were suddenly labelled something else much less.

This was over 13 years ago and like many of you, we have weathered many wounds from ignorance, stereotyping and negative assumptions. For us, and perhaps many of you, inclusion is still often a daily challenge. I want however, to use this article to explain what tools we have learned to use. Tools, which have helped us avoid the wounds, heal and learn from them, and which have supported Jayde to have a good life. These tools have also enabled us not only to survive but to thrive. They have been adopted and developed during the different emotional stages of our family's life and some continue to evolve and be refined as our learning continues. Here they are:

A vision — write it down, share and refine it!

Seek and hold onto the vision you have for your son or daughter and build it with them. We had a vision for many years and although we tried to articulate this to others we didn't write it down for a long time. It seemed like a huge task and we were simply always too exhausted to do it.

Then with the help of Social Role Valorisation training (thanks Darcy Elks) and a keenness to overcome the accumulated frustration from our experience with services, systems and professionals (ever changing) we decided to do it. It was a powerful process for us to write it down with significant others in Jayde's life (Circles of Support). It helped us talk through our vision, and helped us to clearly clarify our beliefs and values.

Along with our vision we were then able to construct guiding principles, which enabled us to

Be creative — there is a way!

Trust yourself. Trust that there is a way to attain your vision of a valued life for your son and daughter. After years of defending, it is often difficult to approach each day or transition with new energy. Too often we are being tempted to settle for making the best of a bad set of choices, which if chosen would allow others to strengthen their low expectations of Jayde. Often systems think that quality is simply providing incident-free supervision; that planning is a five minute conversation with the coordinator before you are able to enter the service; that individualised choice is an entire group going to the local shopping centre and sending a letter.

As a result, I have just recently resigned myself to the fact that we need to find the energy and resources to create the services around our vision. We need to think creatively without the barriers of disability, move beyond the opposition of others or what they believe is attainable for us now. Challenge the system to make the burger you want to eat, rather than take the premade one and simply having that small insignificant choice of “wanting fries with that!”

At the risk of sounding “soft”, you need to believe miracles can happen! It takes boldness, patience and time but if you act on your values and beliefs to support your vision, you will fly above the prejudices and limitations of others. When we believe there is no answer, there will be none! When we give up hope, we fall victim to the devaluing and segregation. For example, when Jayde commenced Prep, we wanted her to attend full days at school. It wasn't however, until this year when she was in Year 10 that we attained this goal. We waited, we resisted many recommendations to go somewhere else, we thought creatively around the issues, stood our ground and attained this goal.

Find solitude... and celebrate

Holding the vision against the opposition of assumptions and stereotypes has often a huge emotional toll and finding time to reaffirm what and how we are doing is crucial. Time in prayer, church, meditation, walking or whatever it is that finds the peace you need to heal and to strengthen your resolve to keep going. This time has enabled us to reflect and celebrate the gifts Jayde brings, away from the overwhelming, negative images and messages others have of her.

I find the greatest role in my life is that of being a mother and a critical component of that is to show and demonstrate the high regard for my children and the significant gift they are in my life. As stated in the recent Social Role Valorisation conference “a gift isn't a gift until it is **received**”. We need to receive and cherish the gifts which our children bring, and show and advocate to others that they do have great value.

I remember being moved by a story placed in Mother Theresa's biography which told of a frail and aged woman who was dying and was carried into one of Mother Theresa's centres. This woman had been found left on top of a pile of garbage. The dying woman stated to Mother Theresa that her heart was broken not because she was left to die on top of garbage but because her son was the one who had left her there! Relationships are everything. How we value our children presents the strongest message for change.

I recently read that research has shown that disability does not stop development of our children in typical ways, it is the negative assumptions and stereotypes that dictate the way others treat them due to them having a disability (Lemay 2005). We are the key to advocating and modelling such change. Never give up your power to do this!

Having a vision, building your champions, being creative, finding solitude and celebration can support you and your family to give your son/daughter a valued life. It means living bravely, being resilient and having a strong determination to do and be what is right. We are all at different stages and phases of this but we must not stop believing we can have a valued life for our son and daughter. I read once that the greatest offence to humanity is taking something beautiful and making it ugly. I really believe this is true. Our Jayde is gorgeous and she is destined for great things, even if the world is yet unwilling to accept or believe what we know to be true. Cherish the journey.



Kim and Jayde

think through how we wanted such a vision to become Jayde's consistent reality.

Now we use it to help us establish relationships with others and services. It keeps us and others (especially services) consistent in supporting Jayde in a way dictated by her vision. It reduces conflict with others who assume that segregation is part of our story.

With new services and staff, it helps us to be proactive in identifying our expectations and clearly takes the pressure from trying to accurately retell these to others. It also allows us to follow up any supports, which have not met these principles, identifying clearly where they may be in conflict with what has been written.

So get your vision on paper, write, draw, do whatever it takes to record it in a way you can share and discuss it with others to achieve your vision. It might be the most important thing you do for your daughter/son and your mental health.

Build your team of champions

In the early years I spent too much time trying to change the attitudes and opinions of others. Inclusion is such an important principle to me that I wanted others to understand how wrong stereotypes and negative assumptions were. I wanted them to feel as passionate as I did about making it happen.

Unfortunately, I found there were too few "inclusion warriors" out there to try and move the masses. As a result, I learned particularly within systems, that we just needed to find a few others who shared the same beliefs and values and who could share our vision. When we found them, we looked after them really well and we took them on our journey with us. Then in their sphere of influence they spoke and positively influenced others and "one by one more" people started to get it! Not only did others get it but our vision was respected and defended in those places where cynicism of inclusion is rife.

These individuals also remind us of our vision, they pick us up when we fall, they coach us to the next level and probably more importantly, they remind us that there are great people out there wanting to support Jayde to support herself.