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## **Imagining better: a first step on the path to a good life.**

**By Jane Sherwin**

'Imagining better' is an intriguing phrase. It makes us wonder, better than what? The short answer is, better than what many professionals and well intended community members might expect is possible in the life of someone with a disability. Ann Roveta<sup>1</sup>, in reflecting on the time before the birth of her son who acquired a disability at a young age, said, 'I dreamt of a life for him in which he would know friendship, feel the fulfillment of achievement, be able to follow his interests and that he would be respected and happy'. Anne is not alone in recalling that the dreams that she had for the life of her son are the same dreams that parents have for all their children. What is it then that happens when the diagnosis of disability is given? Deep in the fabric of our community lies a perception of disability as a negative thing; the expectations that flow from this perception include that the son or daughter will be a burden and that not only will they not meet their milestones in early life, but they will never make anything of themselves in later life.

Well-meaning family members, colleagues, neighbours and friends may have been socialised into the tragic view of disability. Professionals may have adopted a deficit view of disability. Some parents are not immune to sharing these beliefs.

As a consequence, ordinary dreams and positive expectations are smothered. Alternative beliefs and ideas rush to fill the vacuum that is created. These ideas include that only the special system can meet the needs of their son or daughter, and that they are happier with their 'own kind'. One of the things that contribute to the 'special' dreams of 'more therapy' or 'more services' is that the doors in the special system readily open. For many, sadly, frustratingly, the doors to ordinary life and to regular systems can be harder to unlatch.

Meghan Sweeney<sup>2</sup> has a response to the belief that her daughter belongs with her own kind. Choosing to interpret the belief not how it is commonly intended, Meg says that her daughter Joss belongs with the Sweeney kind.

Let us re-imagine the dream. The dream that existed before birth was the same dream as that held for older brothers and sisters, the same as any child without a disability. These are the dreams about happiness, fulfillment, potential, being the best that they can be, having people in their life who love and respect them, having a reason to get out of bed each day, being a good citizen, and a valued human being.

Some parents say that they merely wish for 'happiness' for their child, however 'happiness' is a two edged sword. On the one hand, keeping someone happy through not making demands on them could lead to a life as a 'child forever', without important developmental learning. On the other hand, happiness also comes from our relationships, the roles that we have in our life, and a sense of continual learning. The latter sort of happiness is a great vision.

Having a sense of what a full, rich and valued life might look like is crucial. This vision becomes the filter for all future decisions. If, for example, the vision is that

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<sup>1</sup> Anne Roveta is a parent who presented a paper about her son Craig's life in 'New identity – a worthwhile life' at 'The Challenge of Inclusion Conference', Brisbane: Community Resource Unit Inc, 2005.

<sup>2</sup> Meghan Sweeney made this point at the Family Advocacy Conference in Sydney, 2012.

relationships are important, then as Susan Beayni<sup>3</sup> says, all future decisions about where her daughter Rebecca spends her time will be made through the filter of 'Will this bring relationships?' If the vision is that purpose is important for someone who is leaving high school, then the roles that are encouraged for post-high school must meet the criteria of bringing purpose and contribution.

### ***What things help 'imagining better'?***

A key step is to dare to dream and to take disability out of the equation. Think ordinary. This means that we need to think about how anyone else of a similar age or gender spends their time, where they spend their time, with whom and of what the range of things are that are important to them at any particular stage in life. This also means that we need to think about a son or daughter in the first instance without a focus on what things they can't do (don't worry, we'll come back to it later) and consider the character and qualities of the person. Personality, likes and dislikes are some of the clues for the imagination about what a good life could be.

Mary Oliver, an Irish poet, encourages us to ask the question, 'what is it that you plan to do with your one wild and precious life?' Isn't this a marvelous question? It encourages us to create a vision that is big, full of hope and enthusiasm.

Some people worry that if the expectations are too high, then the person might feel a failure. Michael Kendrick<sup>4</sup> reminds us that we should be optimistically realistic. This means being very hopeful about what is possible in someone's life, while being mindful of some of the limitations. The key point here is that we should not be limited by our sense of a person's shortcomings or of those around us. At some stage we do need to 'put the disability back in the equation'. However, we do this at the time when we start to get practical, not while we are creating a vision for a better lifestyle.

**Eight things are outlined below that are likely to help parents to imagine better and to assist them in sustaining their vision for their son or daughter:**

#### ***1. Believe and see***

For some parents, it is enough to believe that an ordinary life is possible because it *should* be possible, just as it is for all other children.

Mike Duggan is a man who many would describe as having significant physical disability. Mike<sup>5</sup> says that we 'need to emphasise the "ordinariness" of disability. We need to forget the "labelling and packaging" process. What has to be remembered and stated quite categorically and unequivocally, is the simple fact that we are people/human beings!'

#### ***2. See and believe***

For some parents, seeing is believing. Therefore searching for examples and stories of where a better life has been possible for someone that you can relate to will be an important strategy.

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<sup>3</sup> Susan Beayni is the mother of Rebecca. <http://www.tmw.to/members.php?uri=rebecca-beayni>

<sup>4</sup> Michael Kendrick – a well respected teacher, speaker and writer in the disability area [www.kendrickconsulting.org](http://www.kendrickconsulting.org)

<sup>5</sup> Mike said this in a paper at a Disability Awareness Week celebration, Gold Coast 2012

### **3. Share the dream**

Telling others about your dream for your son or daughter is a way of making the vision 'live'. It moves from a place that is close to the heart to the space where the imagined life lives and breathes.

### **4. Spend time with like-minded others**

If we accept that the path to an ordinary life is the harder path, then it is vital that parents join with others to strengthen their commitment to the harder path. These could be family members, friends, or parents on a similar journey who all share a vision of an ordinary life and who have values like hope, high expectations, and who perceive the son or daughter as worthy of the good and decent things in life. These people can bolster your resilience, just as you give them hope and strength.

Not all family members and community members have had experiences where they have seen people with disabilities have ordinary lives. For them, the sense of a better life may seem unrealistic. These people can be kept at arms length until they are ready to join the path.

### **5. Spend time with people who are down the track**

Parents get ideas and hopefulness from the stories of those who have put things in place so that their son or daughter has a rich and meaningful life. Some people might be those who are a long way down the track; their stories are great examples to aspire to. Other people might be those who are just a bit more progressed; these stories are helpful for ideas and encouragement.

### **6. Keep your relationships with families and friends as much as possible**

Sons and daughters having ordinary lives start with what happens at home. Being a brother or sister, grandson or granddaughter, the child of a family friend and so on form the basis for long term relationships and ordinary life experiences. These relationships also keep parents connected to ordinary life, when the pressures towards isolation and a service life are strong.

### **7. Be prepared for a harder path**

The things that seem to happen automatically in the lives of sons and daughters without disabilities take additional efforts to happen in the life of a son or daughter with a disability. As Margaret Ward<sup>6</sup> said, 'It is harder and better. Harder because you are going against the tide; better because the outcome is very likely to be better for your child.'

### **8. Look after yourself**

Looking after the body, the mind, the heart and the spirit can fortify parents to play the roles of dream holders and path makers.

### **Final comments**

Without imagination, we become stuck. We start to believe the messages from others that lead to a place of separation and a disability life. With a positive vision as the cornerstone, parents have been able to assist their sons and daughters by crafting lives of joy, purpose, fulfillment, relationships and a foundation for life beyond their parents.

May imagination be with you.

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<sup>6</sup> Margaret Ward, a well respected parent and activist, lives in Brisbane Australia.