

The Impact of Services on a Vision for Life

Suzanne Tuttle, from Innisfail, describes herself as a wife to Chris, and mother of their ten children. Her values are based on the experiences of her childhood and early adult life. Suzanne has been involved as an advocate for people, particularly children who are marginalised, for over thirty years. Here, she reflects on vision, and the impact of services and bureaucracy upon the vision of families.

“This is no child with a child’s face;

this has no name to name it by;

yet you and I have known it well.

This is our hunter and our chase,

The third who lay in our embrace.”

Extracted from Judith Wright’s poem Woman to Man

Long before the birth of our children, we have a vision for them; we know them in the way only parents can. We have hopes and dreams for them based on our experiences and needs. But on a more universal plain we all share some pre-conceived certainties of what we want for our children: health; happiness; shelter; and to experience a life where love is freely given and received.

With support and love from a caring family most of our children fulfil this universally held parental vision with minimal problems. Few parents ever articulate this innate vision and many are, on a conscious level, unaware they hold it and measure their children’s successes and failures by it.

When we have a child who has a disability we not only have to own and be aware of our vision for that child, we have to be able to articulate it, justify it, and advocate for it. Why?

Because although no westernised society today would attack the civil rights of a child who has a disability, our vision for our child is vulnerable and is often under attack.

Unprepared we are thrust into an existence of recognising we have a vision, keeping the vision alive in spite of all the outside influences. Visions like everything else in a parent’s life need nurturing. Maintaining, expanding and modifying the vision, without compromising that vision, becomes a central theme in the life of the parents.

Our vision for Dominic is not different from the vision we hold for his siblings. For children who will both give and take from their communities, society accepts that it is reasonable to have a vision, which encompasses health, happiness, shelter and love, in a community of their choice. These people all function at a level that society in general, values. Their contribution is valued, and consequently, so too is their existence.

Comparatively what Dominic is able to contribute is seen as minimal. People consider he is taking from his community. Therefore, through the loose intellectual and moral associations people make, members of his

community see his existence, his contributions, and his place in his community as of less value. Our vision for him is therefore not a vision shared by the general community. Western society, I would argue, is a “value” based not “values” based society.

For Dominic to receive medical or therapy services we must be prepared to articulate, and defend our vision for him. The simple vision of a parent that this child has the same needs and wants as his peers, and that he offers a unique contribution to society, is challenged by well meaning professionals. Like most parents, I have been patronised, treated as a mushroom, an imbecile, and a person of questionable character. Fortunately, I am not easily undermined. In the worst possible scenario, I am grudgingly allowed my opinion and nothing is considered, recommended or done to Dominic without my permission. The best scenario occurs when the professional involved and I, are able to participate in an exchange of ideas and ideals, which leads to positive outcomes for all concerned.

The education system creates a particular challenge to vision through its minefield of consultations, explanations, and recommendations. These are, in my experience, all in the best interest of the education authority rather than the child or family. I remember simply stating our case to the school that Dominic had an enormous amount to offer the school community and I needed to know why they would reject that opportunity. We were convinced that their community would benefit from a relationship with Dominic. It was often a difficult line to hold: they could use all the politically correct language; they held all the politically correct concepts; and they knew their legal position and legislated rights. Our beliefs and vision were vindicated when, at the end of grade twelve, Dominic had the night of his young life celebrating his graduation with his graduating class. His peers arranged the graduation so he could attend. This was no small feat as he needed air conditioning and wheel chair access in a non-air-conditioned Shire Hall. They celebrated with him in a compassionate and inclusive manner.

As each new threshold is approached, the vision needs to be the focus of our thinking. Post-school opportunities and support to be part of the community comes at enormous cost to families. Every assessment form to obtain services or funds requires a frighteningly negative picture to be painted of them. This filling out of forms for a panel to assess or a cumulative number to be attained, gives no opportunity to enunciate the vision. Faceless panels weighing up the unweighable leaves a pervading sense of hopelessness. Negativity suppresses hope. Our present systems to support community living are based on negativity.

Hope is the nourishment of parental vision; it may flicker very low on occasion but it is never extinguished.

“This is the maker and the made;

This is the question and reply;

The blind head butting at the dark,

The blade of light along the blade.

Oh hold me, for I am afraid.”