

Record

332

File Number

10298

Author: Simpson, Cheryl

Title: Perspectives on parents in advocacy

Original source: QPPD Access '93 Inclusion in Life Event 7-9 March

Resource type: Written

Publication Date: 01/03/93

Publisher Info: QPPD

**Abstract**

Cheryl Simpson, the parent of a teenager with disability describes the three traditional views that she encountered with the birth of her child. These are: the Medical View, the Miracle Cure View and the Tragic View. When her daughter was two, Cheryl attended a lecture by a parent of a 21 year old woman with disability. It was here that Cheryl first glimpsed a fourth way of viewing people with disabilities. The difference was that this parent had a plan for her daughter's future. **Keyword: Families**

## PERSPECTIVES ON PARENTS IN ADVOCACY

- Cheryl Simpson

Parents in advocacy - Why do we need them? - What happens without them?

To answer these questions, I really needed to look again at the past. Because I didn't think about these issues back then - I didn't have any idea. Only over the years have I been able to get a bit of perspective - To see a few patterns - To see some of the forest again in spite of the trees.

The past for me goes back 13 years when my daughter was born. It seems to me now that 13 years ago there were 3 major views you could explore if you had a child with intellectual and physical disabilities. I use the word "explore" rather loosely - There wasn't much time for the luxury of exploration - You had these views thrust upon you - You had little choice but to adopt some of them and your child's life was inexorably shaped by them.

The first of these views you encountered usually was the Medical View. It went something like this .... Initially your child was tested and found "wanting". Then there were more tests and more tests and more tests and pretty soon your child was broken down into bits and scores and parts and in the end you were handed this dossier of deficits a kangaroo couldn't jump over (deficits all duly recorded in hundreds of files much like a criminal record). It didn't end there. The results of these tests then dictated that your child be therapied and braced and counselled, monitored, splinted, IEPed, toiletted, lifeskilled and of course all this took countless hours - Hours to travel there and back - Hours to park - To outfit, to practice, to assess, to ascertain, to reassess - Hours on buses and in waiting rooms, hours before panels of professionals - In short, hours and hours away from who real children are and what real children do. From the start your lives were disconnected and segregated and in a sense you lost sight of your child and certainly many of the real needs of your child.

Then there was the second view - The Miracle Cure View - And miracle or otherwise, it ran the gamut from prayers to pills to movement patterns. I know at that time a lot of us were wrestling with that old Doman Delacato DEVIL. The miracle cure view was tremendously seductive. There were so many well meaning and convinced and convincing promoters of endless products. Needless to say the pace was hectic and guilt a constant companion. And in pursuing all this (whatever this was) you were once again taken out of the mainstream and again you lost sight of your child and many of the normal kinds of living patterns.

Then there was the third view which cut across these first two views. I call it the Tragic View. Society is still very much locked into this one. It has a long tradition and I personally find it more disabling than any disability. As one parent said to me "You know the minute you are caught up in this view, people suddenly lower their voices and begin speaking in hushed tones". There was a lot of sentimental

---

This article is made available by the Institute for Family Advocacy & Leadership Development  
and cannot be used except for the sole purpose of research and study

nonsense that emerged out of this view - A lot of charity you came to depend on - Loads of sympathy and sympathetic advice - Very little honest to goodness help. According to this view your life was Tragic - Your child was a tragic burden - A very special child with very special needs. Only those with special compassion and special expertise could or should really assist your child. As a parent of course you didn't need this expertise for you had been especially chosen by God, and consequently you were blessed with an especially broad pair of shoulders. (Either that or you were to be found somewhere in the throes of grief and/or guilt. In those days you were obliged to grieve at the drop of a hat. Kubler Ross had decreed ... "Thou shalt enter the grief cycle" and God forbid if you resisted! Then you were promptly labelled "A Parent in Denial" and we all knew about those parents). I digress.

Now all this may sound a bit over the top - But the fact of the matter is that these views really affected my daughter's life and they are still affecting her life. They are still affecting the lives of many people - And they all have common elements which obviously highlight why we need parent advocacy and what happens without it - Elements which obviously shaped the nature of parent advocacy today.

For in the end it didn't much matter which view you adopted. You landed pretty much in the same place.

It was a place apart from the rest of the world.

A place preoccupied with congregating and correcting.

There was little respect or little value for your child as she was.

There wasn't much interest at all in a child's gifts and capacities.

Instead, deficiencies were highlighted and a maze way of specialist services was set up to support those deficiencies. (At times it could seem that deficiencies were created to support services).

As a parent you were overwhelmed by it all. You learned quickly to defer to specialists. You lost sight of the ordinary dreams parents have for their children - Small modest dreams like - A sense of belonging - A sense of community - A nice place to live - A few good friends. Suddenly these dreams seemed unrealistic - even at times ridiculous.

That was 13 years ago - And as a young mother caught up in it all I had no idea that there might be another way - That there might be other views.

Then - It was 11 years ago when my daughter was two - I was asked to attend a lecture given by a parent. She was the mother, I was told, of a 21 year old woman who had "profound" (tragic view again ) intellectual and physical disabilities. I wondered at the time what on earth this had to do with my young daughter - Should I go? - Would this be yet another tale of woe?- Would I be able to cope?- I remember it was a bitterly cold night - We were living in Canada at the time - I did go finally - Reluctantly - I have never forgotten that night - I have never forgotten that parent.

It wasn't anything special really - as I recall it was a simple slide presentation and it wasn't just what this parent talked about that impressed me, but what she did not talk about - And the thing that quite amazed me from the outset (and this may seem strange to you now) was her matter-of-factness. There were no hushed tones. There was no deference. Of course I realise in retrospect that the three traditional views were very much absent. There were no winged miracles, no special treatment, no list of medical conditions, no IQ scores. Instead the thing that truly inspired me was that she actually had a plan for her daughter's future. She had a

vision if you like of how her daughter might like to live. Of course this plan of hers very much challenged the existing structures. And while this concerned her, it did not seem to faze her. She simply believed that her daughter had the right to a valued and respected life in the community - That she belonged there - And that it was her business to see that this happened. She didn't lay down the law about this - It was simply understood by what she said. Her emphasis that night was not on why it should be so, but on how she could make this happen for her daughter - How she was making it happen.

This was pretty powerful stuff for the mother of a delayed toddler whose life was rapidly being consigned to all the exit doors of her world.

I'll always remember the last slide this mother showed at the end of that evening. She said ... "I just want you to see this - It's not about anything in particular - It's just a lovely picture of my daughter - she has such dignity."

I remember I went back out into the night with my head just a little higher - I had the beginning of a new focus - I had the glimpse of a fourth view.

This was the first parent advocate I had encountered - And I realised then the power of parents in advocacy.

This parent is still vigorously advocating for her daughter. Last year she visited Australia. Some of you may have met her. Her name is Nicola Schaefer and her daughter, Catherine, is now 33 years old. Catherine recently moved into a nice place of her own in a welcoming neighbourhood in Winnipeg.

Such outcomes for our sons and daughters don't happen overnight. You are in there for the long haul and one person cannot do it alone. You need friends and allies along the route. There are many risks and costs involved in this kind of social change. And underlying it all one must have this unwavering fundamental belief that all people are valuable.

There are many Nicola Schaefers.

There are many here today in this room.

They reaffirm not just the value and dignity of our sons and daughters, but the vulnerability of their lives.

Through all the years of injustice they constantly promote the rights of the individual.

They persistently challenge traditional attitudes and practices. They lobby for change.

They take the initiative.

Through example they show us there is another way.

We are so easily channelled off down a hundred different side paths - At odds with one another and the world - Always competing with one another for scarce and often questionable resources.

If you like, sometimes we simply lose sight of the forest for all the trees. Parent advocates pull us back - Pull us together - Turn our focus back to the real human issues - Issues which involve us all - They encourage us to look at the bigger picture. They draw us into a deeper dialogue about our sense of social justice - About the values we hold - About the kind of world we'd like for our children, all of our children.

And so it goes down the grapevine. Sowing seeds - Sharing a vision - Gathering information - Joining forces - Challenging traditional views - Supporting one another - Involving friends and allies - Building alternatives - Changing the focus.

Parents in advocacy bring us back to the people at the heart of it all, our sons and our daughters.