

A Letter to Parents of Deafblind Children

OREGON DEAFBLIND PROJECT Newsletter, Fall 2001, pp. 3-4. (2001)

By Wendy White

When I was asked to write this I had a difficult time focusing on the topic. The tragedy of September 11 made anything I wanted to say about deafblindness seem trivial by comparison. But, like so many Americans, the event itself inspired me to focus on “what really matters” and to lessen the importance of petty concerns. My son’s deafblindness has always been a priority, but my resolve to do more and be more effective in trying to help him was strengthened by the tragedy. I might not be able to lessen the grief of a child who lost their loving parent in the Trade Center or Pentagon, but I can potentially and positively change the course of my son’s life as he struggles to overcome deafblindness. Our freedom, independence and quality of life were challenged on September 11. We responded with grief, outrage, resolve and active compassion. As parents, our response should be similar to our children’s deafblindness. In every conceivable way, our children by nature of their disability, have been denied freedom, independence and quality of life through no fault of their own. Deafblindness is not trivial at all. This condition prevents our children from accessing information and makes it impossible for them to fully understand or enjoy life. They are isolated and locked within themselves. As their parents, we are called upon to interact with our deafblind children in unconventional and sometimes uncomfortable ways – but always in *ways they understand*.

Deafblindness requires “higher” communication – more conscious, more thoughtful, more creative. And we are the ones who must aggressively intervene and implement meaningful communication. If we don’t, we reinforce the disability and make it greater. How do we learn what communication methods are meaningful to our children and how do we most effectively implement them? I wish I had all the answers. I can only speak from my heart about what has worked best for our son. First, educate yourselves. But before you open a book or get on the internet, plug your ears and blindfold yourself and have someone take you some place you’ve never been before. Then, try to do anything on your own. You can’t without assistance. And even with assistance, I guarantee you’ll feel the world is being imposed on you, that you get frightened and startled and frustrated. You might want to cry and give up. This is our children’s world without appropriate intervention and communication. Empathy is a key to understanding your child. Without it, all the technical knowledge of

deafblindness becomes worthless. Then, seek out resources – specialists, professionals, consult the DB Project and log onto the DB Link website.

At all times, be patient with your child and strive to “read” the cues they give. One key learning for me was to stop thinking of education as a one way communication from teacher to student. My son taught me that I must be the student much of the time so he can teach me. While interacting with your child try not to assume anything about their intelligence or comprehension. (You know what they say about the word ASSUME – it makes an ASS out of U and ME.)

Provide your child with a stimulating environment. For our son, age/developmentally appropriate stimulation has been more important than “structure”. But a balance is always good. I suggest providing your child with as many of the same experiences as you would provide to your normal children – take them swimming, hiking, skiing – what ever is possible. I admit it is easier not to include them at times, but if we deny them normal experiences, how do we expect them to behave normally? Furthermore, we reinforce the disability instead of overcoming it.

Take every opportunity to include your child in activities with “normal” children – don’t hide them. Kids learn acceptance and sensitivity early if given the opportunity. Share the knowledge you have freely. Educate everyone who works with your child and insist that they be as consistent as possible with whatever “language” is most meaningful to your child. Explain the uniqueness of deafblindness and facilitate situations such that your child’s educators, caregivers, assistants, specialists and professionals can learn more about deafblindness. If your child has other challenges that may inhibit their ability to communicate, make sure you let them know.

Do not be intimidated by PhDs or MDs. Give yourself credit for knowing your child better than anyone, but be humble. We can always learn more. Weigh the validity of the advice you are given based upon your child’s response. (We were told that our son was completely deaf and blind, but his behavior clearly indicated he had residual sight and hearing. Later testing confirmed our observations.) Be nice but firm about the expectations you have of your child’s educators, assistants.... In a classroom situation, *your child needs 1:1 assistance*. A trained intervener is best. Insist that the assistant be committed to work with your child 100% of the time. Anything less than that and your child does not

have access to information and the environment and is therefore being deprived an education.

Advocate. Write personal letters to your congressmen/women and representatives urging them to maintain an enhance education budgets and to support laws and legislation that impact disabled children. Take any opportunity to speak out, break ground and lead the way.

Make frequent, close contact with your child. Touch is so central to their sense of security and confidence. If they feel secure and confident they are more likely to learn and interact. "Touch is love," to quote John Lennon. Let your children feel the love you have for them.

Have expectations of your deafblind child. It is difficult to let my son make mistakes. It seems so unfair to make him struggle when he's already severely challenged by his deafblindness. But I want him to be as independent and self-confident as possible. I have been called a "Drill Sargent" by a close friend and have taken it as a compliment. Despite my expectations, I don't think my son doubts my love for him.

As we all get back to the normal activities of our lives, let's remember that we are blessed to live in a country of relative abundance where freedom, independence and quality of life are valued – not just for one segment of our population, but for all. That includes our deafblind children. We have the resources available. Let's utilize them to help our children.