

# *Back From The Future – Early Diagnosis in Hindsight.*

I am the proud mother of two beautiful children. They spark my life every day with new horizons and mold me into the mother I have always wanted to be. My five-year-old daughter has autism. She was nine months old when it was first suspected she had a different developmental path. We found ourselves alone, fearful and unsure of the future.

**I would like to share what I learned in the hope that this may help another family find a way out of the turbulent maze of the world of disability. Much of what I have learned came as a result of my involvement in a national training program called Partners in Policymaking.** The year-long training program included numerous presentations by the country's leading disability advocates. My point of view flows from what I learned from their expertise. Though I held these views prior to my involvement in Partners in Policymaking, I

was not able to clearly articulate what I believed to be true until I completed my training. My classmates also played a huge role in the content of this article. They are amazing parents of young children with disabilities and are adults who themselves have disabilities. They fill me with hope, excitement and a belief that anything is possible for the future. Although I don't think there is an adequate substitute for going through a Partners training program, my aim is to offer you hope in your situation.

When my husband and I first contacted Early Intervention Services we felt very uncertain of our future as a family. Even though we are fairly confident people, this new challenge made us question our every move. **The temptation is to delegate health and family decisions to the “experts” who have academic credentials.** It is my belief parents just want Early Intervention to come in, take charge and make everything better in a blink of an eye. Desiring life to return to “normal” is understandable. But what is “normal”? Dur-

ing the time of early intervention our goals tended to be very long term or very short term, without a clear process in mind. I learned it is essential during this time long-term goals are built on short-term goals. Both are incredibly important but they are mutually dependent on each other.



As time went on it became easier to focus on small steps for my daughter that was leading to a brighter future, even though that future was constantly changing in my mind. I discovered the goals I set for her needed to fit her unique qualities. People who are involved in the life of a child need to realize our children are not some mile marker on a chart. People who are involved in the life of a child are not the ones who decide what our children must become one day. **Our children are born with unique interests and talents which they will discover in due time with the aid of a loving, nurturing parent.**

The very first step in sorting out how to identify and provide for the unique needs of your family is to realize, as the parent, you have the power to make the final decisions for your own family. You have the power to search out and implement your own solutions for the unique obstacle you are facing. **As much as the advice of a professional is valuable and practical, it must be weighed against your own instincts and intuitions as a parent.** Have you ever heard the quote: "Professionals

built the Titanic, amateurs built the Ark?" As a parent, no one else on earth spends as much time with your child and is more invested in their success than you are. Therefore, there is no one more qualified to make decisions that impact your family than you are. The other side of the coin is that parents have to be aware of areas where they lack the expertise and seek advice from professionals in order to utilize it in making decisions.

This is a difficult step to take. People often struggle with the fact that it is more convenient to follow the advice of the professionals - it saves time and absolves the person of a certain amount of responsibility for mistakes. The fact is the parent knows their own child the best and their experience will lead them to make the best decision. It is a great undertaking, because the parents are the ones who will have to live with the consequences of any decision they make concerning their child.

Many concerns will enter a parent's mind when they suspect or find out that their precious child might have a disability. The following come to mind:

FEAR: Which stands for False Evidence Appearing Real. It is time to believe that definition! In the Early Intervention days, fear can be overwhelming, crippling, and paralyzing. The fear will pass as parents learn more.

**Facts help us move**

**toward informed actions, which help us realize our ultimate goals for the family.** There are certainly plenty of facts out there to be found. One can rely on professionals to distinguish between fact and fiction, or critically analyze the data and decide for yourself what may or may not be



worth the risk. Rely on the scientific method to discover whether the fact is something worth believing and then act on it.

**Independence:** As a parent it is scary to envision that a child may always be dependent on others. The fact is that there is not one person on the planet that is completely independent. Ponder this: people depend on a car to take them to work, depend on the grocery store to feed them and on shelter to keep them warm. This child may have a different set of dependencies than another child but none of us are completely independent. Since we are interdependent, the job then becomes to start building a network of support that will suit the child's needs for years to come. Eventually the job of building and maintaining that network will pass to them as they get older; parents need to make sure their child knows how to do it and has had practice doing it.

**Institutionalization:** There was once a grave concern that as everyone got older there might be a time when institutionalization would be the only option. Looking at the facts will uncover that this is no longer true in this day and age. Institutions are rapidly becoming a thing of the past. There is a tremendous network of advocates working tirelessly to get people out of institutions and replace that model with community-based inclusion. It costs \$194,000 per year to house a person with a dis-

ability in an institution. It costs \$67,000 to \$94,000 per year to have them live in a community with appropriate support. This not only saves money, it allows people with disabilities to lead a more fulfilling and independent life. The less expensive option is the one they would choose if they were asked! Look up local advocacy efforts, join them in their efforts and speed up the progress. There is no reason for children in this day and age to ever consider an institution as a part of their long-term future. There are states in this country that do not have a single, functional institution. They are taking care of people with disabilities in an inclusive community environment.

**Education:** Many times, doctors give a prognosis to young children with disabilities in order to answer questions for the parents. However, no person, as good intentioned as they are, has the ability to

predict the future. This can be the most frustrating part for parents. Everyone feels more secure and prepared when they know what to expect. The fact is, there is no way to know the future. Furthermore, the outcome will depend on the attitude of the people involved. This is why the phrase by Ginny Cook resonates with such truth and wisdom: "As we think, so shall we speak ... As we speak, so shall it be." Most pediatricians, unfortunately, make assumptions about the capabilities and accomplishments a child will have due to their disability, and pass these to parents as fact. They will most likely be right if the child lives his life enclosed in the glass bubble called "disability."

**The most important job for the parent is to prepare their child to function in the real world! Do not**



**expect special treatment; rather, expect reasonable accommodations.**

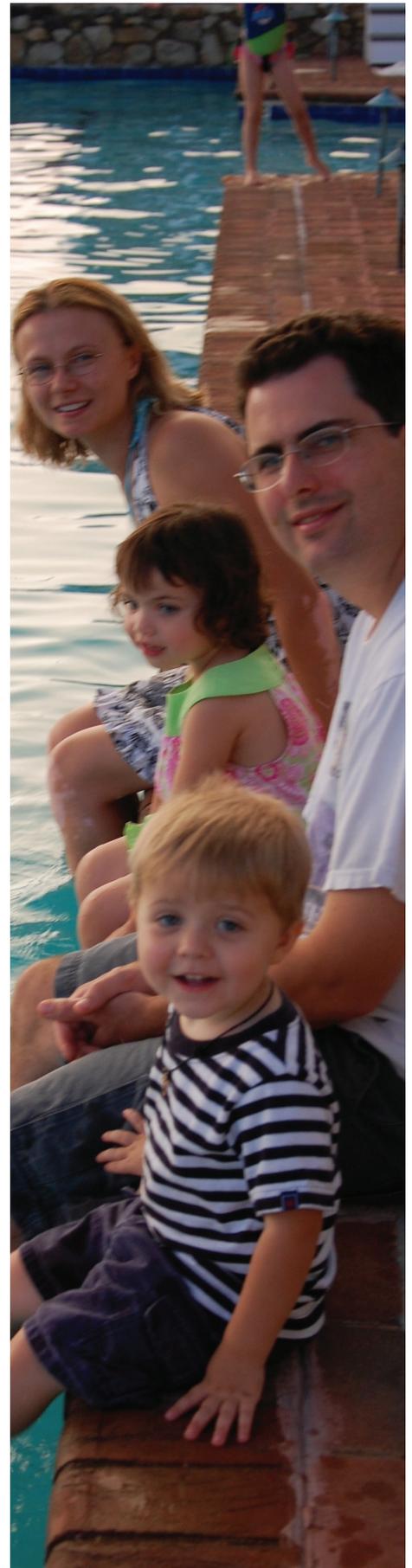
Success happens when preparation meets opportunity. There should be a strong belief that these opportunities will come as they come to everyone. If you do not believe this, your preparation will more than likely fall short. Please take the time in early childhood to prepare your child! They will build self-assurance by knowing that the people around them believe they can do anything.

Your child will need life experiences in order to understand the world around them. If one has never seen a tall tree, one cannot imagine what the tree in the Garden of Eden would have looked like. Furthermore, if there is no foundation of experiences, the inability to synthesize original ideas is significantly impacted. Original ideas have the power to give flight to success. Expose kids to camping, fishing, flying a kite. Broaden their view of the world so they can use those experiences to move forward and apply what they have learned to whatever natural talents and interests they have. Some parents may think their child is not responding. Though this may be a concern, your efforts will not be in vain. It is far more damaging not to provide the tools for success than to think providing them was a waste of time. Kids are people with amazing potential and one day there will be evidence of all

these efforts. **Drop the expectations and continue to give them all the possibilities.**

A child will need to know how to deal with all kinds of people with dignity and respect. There is a need for a clear understanding that how other people behave is a reflection of themselves and not this child. They must know that they can't expect to receive respect, patience, and kindness unless they give it. Children learn by what they see. The adults around them must believe and demonstrate to them every day that they are beautiful, talented, intelligent individuals. And in turn, they will show you that they are all this and so much more! It will be hard work, but every child deserves it!

Happiness: How can a person be happy if they have a disability? Many people assume if someone is not living the same way they are, then that other person must be unhappy. The truth is a human being needs only a few key factors to be content. Once there is contentment, happiness is all up to that individual person and their attitude. The following are the building blocks of contentment: A person needs to be able to provide something of value to another. They need a sense of community around them and the ability to make choices concerning their own situation. They need something joyful to look forward to in the short and the long term



future and they need support during difficult times and not to be ridiculed and given “extra therapy” for not being able to handle difficulties better. When most people have had a bad day they get encouragement cards and warm thoughts from others. It is hypocritical for us to think a person with a disability is somehow expected to be even-keeled all the time. Furthermore, when they have a bad day, they are labeled as “behavior problems” and are removed from the community and seldom given another chance. A family needs help in developing and identifying coping skills that help a child. They also need to encourage the child to use these coping skills! I do not mention appropriate coping skills, because it is so difficult to decide what is appropriate for an individual. These coping skills simply need to be safe and effective for the task at hand. **Teach your child that it’s okay to be vulnerable and how to ask for help when they need it.** Guard against being vulnerable and isolated. This is the making for a disaster. Make certain your child is being heard and that their needs and wishes are understood and considered. Did you know that 75% of all communication to a person with a disability is in a form of a question or a request (demand)? What would life be like if that were true about your life? It is best to have conversations with

a child, even if there is little to no response from them. When a child misbehaves and a conclusion must be made as to the motivation, assume it is a normal part of the developmental age and not the disability. They are a child first! The conclusion will be right more often if the assumption of why the child misbehaved points to the age of the child and not to their disability. This will preserve a child’s spirit and allow them to retain confidence in the face of the disability.

**The question then becomes: how can a parent of a child with**

## **a disability raise a self-sufficient adult?**

In order to be self-sufficient, a child will need to be empowered to make her own decisions. This starts with little things like choosing what to wear and grows from there. A child has to believe that he is capable of accomplishment and that making independent decisions is indeed within his capabilities. This empowerment is not built overnight; rather, it is cultivated within every interaction the child has with her surroundings. If people around them constantly broadcast the message that “you could not do that yourself,



you need help from me,” that is what this child will live by. There is a conflict in the disability system between cultivating independence skills and that system’s mere existence. If a child is taught from an early age to value independent thought and action, the system falls under threat of becoming obsolete. The quote by Albert Einstein comes to mind in illustrating this, “We can not solve the significant social problems of the world at the same level of thinking that created them in the first place.” If there is hope to influence the fact that there is a 75% unemployment rate among people with disabilities, there needs to be a change in thinking and in the way we approach raising children. **We**

**need to make certain that a child’s drive to achieve is not snuffed out day by day or hour by hour in an attitude of pity and unwillingness to believe that they can accomplish much if given the chance.**

Looking back, we saw our world change when the doctor gave us our daughter’s diagnosis. Its almost like we refer to our life before and after the diagnosis. **The ability to focus came when we finally realized**

**our little girl did not change the day she got her diagnosis. WE CHANGED!** Do not allow the outside world to dictate how you, as a parent, perceive your precious child! The truth is, you still hold the same sweet little baby the day of their diagnosis as you held them the day before. There is a way to help us simply loving our children for the individuals that they are, while helping them achieve their full potential. I urge you to discard your assumptions and excuses about what your child can or cannot accomplish. Let go of the milestones they may not reach and move forward with the ultimate goal of raising a self-sufficient adult.

My mother once told me that if you reach for the moon, in the process of getting there the least you can do is land on a star. And landing on a star is an amazing accomplishment in itself. The point is that to land on that star you had to reach for the moon, and you have to believe that you can get there. The day the parents of young children with disabilities realize that this is what they needed to strive for is the day they exit the world of “disability,” the world of “can’t and won’t” and enter the world of possibilities and beyond for their family.

*Lena Winslow*

