

# Reflections of the ESE Policeman

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Looking back over a span of time, approaching two decades of involvement in the parent-disability movement, I felt the need to try and capture some of my thoughts and experiences to share with others. I cannot begin to count the number of meetings, emails, and hours of telephone calls over the years, helping others tread the path that each parent of a child with a disability must walk. With information and perseverance I have lived the dream of IDEA in the true intent of which it was written. I was able to procure a free appropriate education in the least restrictive environment based on the unique needs of my son following the process set forth in procedural federal law - and it worked! It is the same repetitive procedural process you will use from your child's third birthday until they age out of IDEA at 22 or exit with a standard diploma. Learn to do the drill. There is no educational guarantee that children will learn, but there is a guarantee that they will have an equal opportunity to learn. Parents have a right to participate in this process, but no right to dictate it. This is a team effort with a focus on one child - your child.

The journey begins without notice, and without any time for preparation. It continues on for a lifetime, once started. How exactly does one walk this path successfully? This is what I will attempt to share with you based on my own personal experiences, and those shared with me by countless other parents. Fortunately, others have gone before us and in their efforts, created opportunities for all of us who follow behind. I benefited from those efforts just as many will benefit from mine and yours.

My involvement with families came when things were not going well, and usually had escalated to the point of being confrontational and adversarial. Consequently, my appearance in a school meant there was a conflict and my acquired knowledge meant the rules must be followed or procedural safeguards were brought to bear... This created an association that my appearance meant non-compliance and my insistence that you become compliant. This led to the birth of the ESE policeman. I had zero tolerance for non-compliance with mandated, non-optional federal law, but instead of citations I wrote procedural complaints. My desired outcome was first compliance, and secondly to be able to work with the schools to become compliant. When all is said and done it still comes back to a classroom and a teacher. Somewhere along the line this stopped being a job and became my life. It touched my heart. It is who I am and what defines me. I can clearly remember being immersed in unanswered questions and floundering in frustration. What an overwhelming relief it was to finally talk to someone who understood what I was going through and that could answer my questions. I vividly remember my first parent conference and the realization that I was not alone and help was there. I still think of that daily as I guide others seeking information and support.

1) The first step of the journey requires dealing with a myriad of emotions one experiences when becoming the parent of a child with a disability.

These strong emotions never go away. They lie just beneath the skin and can emerge at any given moment. Finding a way to cope with and control them is critical in achieving a successful outcome. When you understand that you are not alone, and there are so many others that have already experienced what you are going through, and can share with you, then the first steps on a very long road have been taken. Generally emotions manifest themselves in two ways, sorrow or anger. Emotions are a necessary part of coping with a disability, but emotional outbursts that create adversarial climates are counterproductive to acquiring needed services. The process must become business. Non-emotional, clearly documented, collaborative business is what produces the desired child-focused outcome.

2) Acquire the knowledge needed to be able to participate meaningfully in the business process.

In knowledge there is power, and in unity, strength. You cannot play the game if you do not know the rules, and regardless of the type of disability, we all play by the same rules. These rules are foremost, federal laws, and secondly, state laws with district policies, and lastly, all must be consistent with federal law. You must know the rules, but learning when and how to practically apply them produces the desired outcome. Which laws do you use and what procedural safeguards do you use? Do you apply individually, or to policy?

3) Find the path of least resistance using procedural process to gain the sought-after outcome for one child.

(Individually, I always looked at the path of least resistance, using procedural process to gain the sought-after outcome for one child.) Applying the law to policies and practices brings system changes for all children...written or unwritten, spoken or unspoken. If it is something that it is routinely practiced, it is policy and must be consistent with federal law. When reauthorizations of the laws occur parental rights slowly get chipped away, making it harder and harder to force system change.

4) Build long-lasting effective change by being proactive and working collaboratively.

Being collaborative and proactive, rather than adversarial and reactive, produces long-lasting effective change. Parents and professionals working together provide the best outcomes for children. Your actions open or close doors for all those who come behind you.

5) Information is the change-agent, and dissemination of information to any and all is the key.

Collaboration does not mean compromising the integrity of federal laws. It does mean working together toward a common goal, resulting in the maximum usage of pooled resources. (Information is the change agent and dissemination of information to any and all is the key.) Developing networks to sustain information dissemination will assure the continuation of future system changes. Change is unsettling, but necessary for growth. To make lasting changes, it requires changing the way people think.

6) Engage people in disability advocacy by showing them that the only thing separating anyone from disability is time.

(The only thing separating anyone from disability is time.) It is inevitable. If you are lucky it will be by aging, if not it could be in the next instant. Unfortunately, until disability impacts you or your family, civil rights for people with disabilities is not a high priority in society or on bureaucratic lists. It has always been, and still remains, the role of parents of children with disabilities, or individuals with disabilities themselves, to pursue equality and access to basic civil rights others take for granted. The single largest barrier for persons with disabilities is persons without disabilities.

7) For clear perspective, focus on three things: that your child be gainfully employed, live independently, and pursue a quality of life of his own determination.

(Focusing on three things from the beginning brings things into a clearer perspective for a parent. I wanted my son to be gainfully employed, live independently, and pursue a quality of life of his own determination.)

This simple premise was the catalyst for how I determined my course of action on behalf of my son, and my focus when advocating for systemic change. I achieved this for my son and continue teaching others with those three things foremost in mind. I began seeking an inclusive classroom, then inclusive schools, and now, an inclusive community. I have seen the first two become reality. The last still remains elusive, but hope continues that some day even it may be accomplished. Inclusion in all things from the beginning is the precursor to being accepted as a part of the whole community. Segregation and isolation will become a life sentence.

8) You are a stakeholder and need to be at the table.

Public schools are what we make them. Our involvement as parents from supporting the classroom teacher to becoming part of school advisories is necessary so that we remain a consideration and our children have a voice when policies and practices are developed. Without your involvement that voice is lost. That voice must be heard not only in the schools, but on state and federal levels.

Public schools represent the diversity of the community in which you live. The schools are where we acquire the fundamental building blocks for participation in society. It is where we learn to socially interact and coexist with tolerances. Purposeful segregation denies any opportunity to foster tolerances and acceptance in a class room, in a school, or in a community.

#### 9) Define yourself as a child advocate.

Webster defines an advocate as one who speaks for others. I cringe when I hear someone introduce themselves as a parent advocate. I would agree to the term “civil rights activist” or “child advocate”. Parents are advocates for their own children and need to embrace that responsibility. Creating dependencies on others to make decisions for you will not achieve the outcome necessary for success. Learning the process and applying it individually will. Only you know what is best for your child because only you know your child best.

#### 10) Remember that you are role modeling for your child how to be a self advocate.

Self- advocacy will not only accomplish what is needed, but establishes something your child will role model and use when they seek independence as adults, leaving the entitlements of public schools and into the eligibility of community living. Opportunities for participation often must be created if they do not exist. Equal access is not a privilege – it is a right, and the need is not to create separate, special access, but rather create equal access to all existing opportunities community wide.

This is a grassroots, disability, civil rights movement, and for change to happen it cannot be disability specific, and must include disability groups combined, working toward civil rights for all.

I have always looked at what is sustainable for others coming behind when focusing my efforts. I understand the difference one individual can make. I have seen much change in my community over the years as a result of my willingness to step forward and get involved. My goal is that when the time comes for others to step forward to become parent leaders they will have all the information needed to make a difference in their own lives and in the lives of others. I will not see equality for persons with disabilities in my lifetime. With vigilance it may happen in yours. When I am gone, it is my wish for my legacy to be *“a father who stood up for children with disabilities and made a difference”*. Until that day, I will continue to share information, encourage others to become involved, and remain watching *“like a Hawke”*