

## INTRODUCTION

**“Free appropriate public education.” This phrase first came into the lexicon of families and educators following the passage of Public Law 94-142 in 1975. It is the basic tenet of special education law, guaranteeing that children with disabilities have the right to be served in the public school system. Its sister phrase is “least restrictive environment.” In the decades since, there has been a great deal of debate about what least restrictive environment means. Parents with children with cognitive delays often fervently believe that their child must be included in full time regular education to be considered a real member of her school community. Parents of children with dyslexia often just as fervently believe their child must have small group reading and math instruction in order to develop the skill and “catch up”. Educators often believe a child with significant behaviors should be in a smaller class that focuses on behavior skill development. The educators and parents who believe one of these is particularly right for a student do so with passion—as they should. The framers of the law and the judges who have interpreted it since never meant for it to be a one-size-fits-all. The law refers to a continuum of services because the framers recognized that each student is different. However, I would pose that that the student is precisely the person who too often gets lost in these philosophical debates. As professionals, we have an idea of what is right for student with particular disabilities in general in our minds, or, as parents, what we want for our child, based on a broad idea of what we want our child’s school experience to be. This is not wrong, but we need to be asking, “What does this child need to learn X skill?” and, as age appropriate “What does this child want?” “How does this child see herself?” Those questions should be the crux of any discussion of least restrictive environment.**

**Before proceeding, full disclosure is in order. I am a former “child with a disability,” now an adult with a disability. I was fully mainstreamed at the dawn of the law allowing me to attend public school, thanks to the persistence of my mother, who does not remember herself as a force to be reckoned with, although I have no doubt she was. Her efforts in turn played a part in my choosing to attend college and graduate school, as well as work in non-disability related and disability related settings during my career. I will use illustrations from my life throughout this piece. For the parents in my audience who may feel underappreciated for your efforts as you read this further, I assure you this is not the case. Children with disabilities, past and present, owe a great debt to our parents, and the parents who came before, so that we could go to school, and lead the lives we do. My point to parents and educators both is simply that you must, whenever possible, put yourself in the student’s shoes, and/or ask the student’s**

**opinion when planning his education. It is true that not all choices should be left to the students, and not all students have the same level of skill at evaluating choices, but, if we say they have a lesser role in their own planning at the same time we are asking society to respect them as equals, we are being hypocritical.**

**If our goal is a society with fewer disability-related barriers, then we must not put them up ourselves. The phrase is often used that people with disabilities must learn, or we will have a hard time functioning in the “real world”, as if there were a difference between a supportive, accommodating environment and everywhere else. In the context, one of those worlds is real, and one of them, ostensibly the one with more disability supports or knowledge is a cocooned dry run, and as such, not real. However, the world we are all in, all the time, is the real world for each of us. How we make it a less restrictive environment for all, is the key. With that in mind, I would like to lay out some rules to keep in mind when trying to create an equitable environment.**

#### **RULE 1: ACKNOWLEDGE THE DISABILITY AND TEACH THE CHILD WHAT IT MEANS**

**Trust me, we who have the disability usually know we are different in how we learn, how we talk, how we think, how we move, or how we look. We do not need you to sugarcoat it for us. Disability does mean we have some area of function that is different than typical. We may want to improve that area, or we may be fine as is, choosing to emphasize our other strengths. From a reasonably young age, parents, educators, and professionals need to help us determine the pros and cons of anything we want to change or accept, and respect us when we make our choices. If you who support a child with a disability prefer not to say “disability” or don’t want us to “look disabled”, or “know we have a disability” or “be in a class with kids with disabilities” the unintentional message you are sending, while wanting us to feel good about ourselves, is that disability is not OK. The trick is not what word we use, or not telling a child about their disability, but being willing to say, “Yes, you may not be able to do something in the same way so and so does, but that does not make you a failure.” And, “Yes, you have a disability, but it is not an excuse not to try.” I do not remember my mother telling me I had a specific disability, but I do remember when I was three and announced that I wanted to be a gymnast, having seen one on *Sesame Street*, that she said that was not possible, but lots of other things were. Likewise, when I was in seventh grade geography and became intrigued with archaeology, she pointed out that wheelchairs did not likely handle the terrain of dig sites well, but I could still work for a museum. I applied for a museum job as an adult. I didn’t get it, but I**

knew it was not because I had a disability.

## **RULE 2: ONCE YOU HAVE ACKNOWLEDGED THE DISABILITY, BE HONEST ABOUT THE CHILD'S STRENGTHS AND WEAKNESSES WHEN PLANNING SERVICES**

Do not use the disability itself as a guiding rule for where the child should or should not be educated, as in, "Children with cognitive delays need to be in a separate class so that instruction can be paced for them" or "Children with cognitive delays need to be in typical classes so that they can benefit from typical models, learn social skills, get invited to birthdays, and meet future employers." Research can be found to support both of those viewpoints.

How, you may ask, if I favor an inclusionary society, can I say that both can be right? The key is in each child's needs and each family's priorities. Every child's school day should include opportunity for both academic and social skill development. If the primary goal for the child's placement in a given academic subject is social skill development, then that needs to be agreed upon and understood by the whole team, so that there is not an undercurrent of worry for

the teacher about academic benchmarks. If the goal is to learn the skill, then small group instruction for that skill might be better given the child's current level, attention span, etc. My point here is if the child has attention and cognitive challenges, it is one thing to say, "She needs to learn to pay attention in a large group," which is a good universal skill. It is entirely another to be able to expect that child to focus on individualized instruction for a skill while the large group around her is being audibly taught a skill which is at least a few steps above hers. Would we be able to do that very well without disabilities? Probably not. So, why are we asking it of her? It is because we fear that any time out of the classroom makes a child less a member of the community.

The problem is actually with how we grant community membership, not where the skill lesson is. Teachers can model that all students are equal members of their classes by:

- calling on them all for things they know
- putting them in small groups with each other regardless of ability
- giving them all classroom jobs
- teaching class volunteers and/or parents providing snacks about all needs and dietary restrictions, rather than depending only on the child with a disability's parent/paraprofessional/special educator to provide custom assistance

If such approaches are used, no one will appear to be excluded and the social invitations are more likely to come, even if the child is pulled out of the classroom for a brief time. This is not to say that all instruction that is below grade level or highly specialized in nature needs to be a pull out. It is just to say that any pull out should not be equated to the road to community exclusion.

Nor should we think having a 1:1 paraprofessional is a magic route to inclusion. Having an adult by your side, to make things easier for you or the teacher, or so that everyone worries less about your safety, is just not conducive to blending in. This would be one of those “Put yourself in the student’s shoes” areas for consideration. When you were in school, would you have wanted an adult next to you, no matter how nice they were? If you went to school with a child with a 40 year old shadow, would that be the child you wanted to sit with at lunch or invite for a sleepover? Be honest, now. If you are still saying, “OK, but a paraprofessional is the only way the child can succeed,” let me share a personal tale to make you reconsider the pros and cons. When I was in elementary school, I was pushed in my wheelchair by my typical peers, or, a friend of mine who also had a wheelchair and I had a neat little arm maneuver to help each other. Life was incident free for seven years, other than the occasional going down ramps too fast, and the occasional spill on the playground, from which I emerged no more bruised than any other child. My mother and my therapists encouraged me to ask peers for help when I went to junior high as a way of meeting new friends. My junior high principal informed my mother that this was a “liability” and that I had to be assisted by paraprofessionals. A few months later, I was at my locker with a bunch of girls, trying to be cool, when one of the paraprofessionals asked me, at regular volume, if I needed to go to the bathroom. I went home angry and humiliated that day and announced I would not return to school if I had to have their help. I did have to return, but shortly thereafter I got my first motorized chair so that I could be in the halls on my own. My mother cheerily pointed out to the assistant principal that a motorized chair might have greater odds of causing injury, but that we were honoring his wishes. In general, some children may need hand over hand assistance to complete any tasks, or true constant supervision. For them, a 1:1 can be an appropriate choice. However, looking at a 1:1 paraprofessional as the entry key to the general education world is too narrow a view. Many children can be supported through a mix of technology, classroom aides, peer buddies, and clear

**and consistent visual and verbal supports to guide them through classroom routines and work completion.**

**The possible negative social effects associated with pull out can be diminished by following the social inclusion modeling ideas above, but the challenge of giving students more time in the regular classroom can also be addressed by following:**

### **RULE 3: WHAT'S GOOD FOR ONE IS MOST LIKELY HELPFUL FOR MORE THAN ONE**

**Don't think of accommodations as extra work required to help one student, but alternative ways of presenting instruction and allowing students to demonstrate mastery that may benefit more than one student. This practice is called universal design for learning, an educational model that has its roots in some of the principles of architecture. In architecture, universal design means no one is prevented from access to a space when a door is widened or an elevator is put in, but more people can get to the space. In the educational sphere, this means that no student is going to be harmed if a text or a test is available in audio format as well as written, and some may benefit. This is only one example. All of us have different learning styles, visual, auditory, kinesthetic, etc.**

**If these different strengths are played to by making a variety of modalities for taking in knowledge and demonstrating skills available throughout the day, the whole class will benefit, not just the student who may have been identified as having a weakness significant enough to officially qualify for a support. The more classrooms can incorporate a variety of learning styles without calling attention to them, the more students with disabilities will feel part of the group.**

**Let's use the aforementioned student with dyslexia for example. As mentioned, his mother may have fought desperately hard for him to get specialized instruction, and the right to have things read to him, but he doesn't want to stand out, so he chooses not to avail himself of these services, and much to his mother's chagrin, still does poorly. Let's take, on the other hand, a student with Down syndrome whose mother has fought for her to be in general education most of the day, but who knows her social studies report is far different from that of the other students, even if the teacher runs a tight ship and no peer has called the child's work "baby work". This child announces to her mother that she would rather have social studies with "her" class, by which she means her small reading group of children with disabilities where the kids are doing things more on her level. Her mother feels like a failure because her child is self-selecting a special education group. Through universal classroom design, the student with dyslexia who needs to have his test**

read may do so without leaving the room, and the student with Down Syndrome may not feel different if she does a topical collage instead of an essay. They feel better because they were given choices which all the other students were as well, as opposed to having something special allowed for them.

Even with adaptations in place, it is important to take into account who the child regards as a preferred peer group. We as adults may want them to be with typical peers at all times, for the aforementioned modeling of social skills, etc. This is absolutely wonderful, but just as children with disabilities should not be told that they cannot be with children without disabilities, they should not be told that choosing to be with peers with disabilities is wrong either. We all like to be with people who get us, rather than feeling like a foreigner in a crowd. I would not trade having been mainstreamed for an instant and I was thrilled to have friends without disabilities. However, in retrospect, it was important to me to have friends with disabilities as well, whose mothers were not scared to have me over, whose homes had ramps, and who knew what I felt like. I would imagine it is similar to being the poorest reader in the classroom or having autism and not understanding social expectations. We may not want to be segregated, but it can get tiring being the different one. So, while all children with disabilities should be socially and academically challenged, we need to make sure they have access to peers with disabilities as well.

**RULE 4: (MODIFIED, WITH RESPECT, FROM RICK LAVOIE'S CREDO, "IF YOU WOULDN'T SAY IT TO AN ADULT, DON'T SAY IT TO A KID.") IF YOU WOULDN'T SAY IT TO/DO IT FOR/USE IT WITH A PERSON WITHOUT A DISABILITY, DON'T SAY IT TO/DO IT FOR/USE IT WITH A PERSON WITH A DISABILITY EITHER**

**Examples:**

- If you wouldn't have Barney in a typical classroom beyond preschool, do not have Barney in a special education classroom beyond preschool.
- If you are working with teenagers who are reading at a low level, find them low level reading books that still feature characters their age.
- If you wouldn't help a person without a disability without asking, do not help a person with a disability without asking, child or adult.
- If you wouldn't tell someone without a disability publicly that they have made a social mistake, afford a child with a disability the same courtesy of

private redirection and guidance, unless there really is a group social skills lesson going on at the time.

- **Within the family, if the siblings without disabilities have chores, give the siblings with disabilities chores as well if at all feasible.**
- **If siblings without disabilities go to some events without their parents, try to make those opportunities happen for the child with disabilities as well. This can be tricky, given specialized transportation and other needs, but a child who is fully included at school, but never apart from family after school hours, is not really living a fully inclusionary life. Some children, for various reasons, may need a parent when they attend a function. If this is the case, try to blend in.**
- **Regardless of functional level, dress and speak to your child in the same way you would a sibling without a disability of the same age, and provide them with age appropriate trappings. For example, most teenagers call their moms “Mom”, not “Mommy”.**
- **Family terms of endearment are fine, but should not be used in front of peers. Another illustration would be that your child may be interested in Barney well beyond typical age, and that is fine to an extent, but try to expose him to age appropriate media you find acceptable as well, so that he might have a frame of reference when socializing with other children. If there are no other siblings to give you guidance, check out the lunchboxes and backpacks of your child’s schoolmates.**

In general, it is wise to always consider whether you are expecting society to hold up a standard of equality that you do not in the home, however unintentionally. This is a double standard, and will not help the child in the long term.

A corollary of this rule is:

**RULE 5: IF AN ACTION OR POLICY WOULD BE CONSIDERED DISCRIMINATORY IF APPLIED TO A PERSON OF ANOTHER MINORITY GROUP, IT IS MOST LIKELY DISCRIMINATORY IF APPLIED TO PERSONS WITH DISABILITIES.**

Examples include:

- **Excluding a child with a disability from a class activity**
- **Requiring extra teacher pay for having students with disabilities in classes**

- **Making blanket statements about the abilities, habits, or preferences of people with disabilities, or making derogatory comments about a person's specific disability.**

If you are an educator with extra pay in your contract, and you are thinking, "There is a good reason for the pay--students with disabilities create extra work," I would argue that anything for any student may entitle teachers to extra pay if it occurs outside of work hours. However, teaching all students during the day is the job.. Extra pay implies that teachers are really only obligated to teach typical children, and everyone else is over and above. This is discriminatory in thought, even if not prohibited by law. In so saying, I do not mean that teachers are not entitled to appropriate training, classroom support, supplies, technology, and equipment to serve all children. Unquestionably, teachers are entitled to all such support. What I do mean is that the presence of a child with a disability should not entitle a teacher to more pay any more than the presence of a child of color would, and no one today would think to ask for extra pay for that. If appropriate service for the child requires overtime, then extra pay should be given for that, not because of who the child is.

#### **RULE 6: NOTHING ABOUT CHILDREN, WITHOUT THEM (WITHIN REASON)**

Federal law requires that all students attend their IEPs when in high school, but I would argue that it needs to be earlier. Children need to understand what their IEP entitles them to, and in turn what is expected of them. They need to hear about the supports they have, but also the progress they are making, and the strengths they show. They need to tell us what supports help them, and what incentives they would work for. They may not have the final say on something, but they need to know they have a voice at the table. When I was in ninth grade, I applied to be the yearbook editor. I was selected, but then told that my physical therapist and my mother had to give me permission to do it. I was very upset, because I did not understand that I was legally supposed to be receiving a minimum amount of physical therapy, which occurred at the same time as yearbook. I had never been to an IEP yet, and had no idea why my disability should make a difference in whether I could be yearbook editor. Happily, my IEP was amended.

"Within reason" comes into play because parents often hesitate to invite the student to a meeting if they are upset about something. This is appropriate. Students should never see adults arguing about them. However, the solution is to air concerns

**first, make sure the adults are on the same page, and then invite the student to participate in the rest of the meeting.**

**As always, not all children may grasp what's going on in a meeting. Every attempt should be made to make sure they get the basic idea and have an opportunity to express their views. If we expect our children to participate in a classroom, they can participate in a meeting.**

**A FINAL THOUGHT...**

**Inclusion is not easy, nor is it going to be perfect. There will always be bumps in the road that parents, teachers, and professionals cannot prevent, and times when everyone becomes discouraged. We just need to teach our children, and remember ourselves, that a bump in the road is never the end of the road.**