

# Inclusion – What Does It Really Mean?

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## **There's inclusion, and then there's *inclusion*.**

Unfortunately, many parents end up in a politically-charged debate regarding inclusion of their own child, but may have little background on which to base their choices. It is important to advocate effectively in the interest of your child regardless of where you stand on inclusion philosophy. But do you *know* what your position is? What is the difference between 'inclusion' and 'mainstreaming'? What are the limits to how much modification is possible, or realistic, in the classroom, and how much is even advantageous? What are the best methods for successful inclusion of children on the autism spectrum? How do you know when it is working? Or when it's not and *why* it's not? Take some time to reflect on these questions before your next PPT. There truly are no right or wrong answers here, only what works, or doesn't work, for *your* child.

## **What is inclusion?**

IDEA, the Individuals with Disabilities Education Act, which is the federal law governing special education provision, does not even use the term 'inclusion', it speaks instead to the 'least restrictive environment'.

The IDEA law requires that a 'continuum of placement options' be made available by a school district to its students. That includes options such as: a typical classroom with a variety of supports, a resource room (which is a separate setting in which supports are given), a full time special education classroom with other kids with special needs, a special ed school outside of the district (either a regional program or a private one), residential placement outside of the school district, homebound instruction (usually a temporarily placement), and hospital (for severe health needs) or institution (prison) educational services. The district is required to look at the least-restrictive setting *first*, and more or less 'go down the list' until an appropriate placement is found. This does *not* mean the child has to *try* all the options on the list, only that the least restrictive are discussed first.

*The Parents' Complete Special Education Guide* (1996, Center for Applied Research in Education) lists what inclusion is, and what it is not.

## **Inclusion IS:**

- All children learning in the same school environment helped by supportive services so that they can be successful in their adjustment and performance.
- Having each student's specific needs addressed in the integrated environment of a regular school setting.
- All children participating equally in all aspects/functions available within the school.
- Educating and providing support for regular classroom teachers who will have special children in their classroom.
- Educating children to be tolerant of and to respect the differences in each other.
- Creating a comfortable environment within which students with and without disabilities can develop healthy social interactions and relationships.
- Educating and supporting parents in their concerns.
- Allowing parents to participate in the team process responsible for inclusion.
- Arranging for appropriate work and educational experiences for disabled children within the community environments.
- Using new delivery systems for special-education programs that emphasize collaboration between special-education staff and the classroom teachers.
- All children learning together in the same environment even though their educational needs and prescribed goals may differ.
- Making sure that each child has an appropriate individualized educational program.

### **Inclusion is NOT:**

- Dumping children with challenging needs into regular classes without proper supports and services necessary to be successful.
- Trading the quality of a child's education or the intensive support services the child needs for integration.
- Ignoring each child's unique needs.
- Sacrificing the education of typical children so that children with challenging needs can be integrated.
- All children having to learn the same thing, at the same time, in the same way.
- Doing away with or cutting back special-education services.
- Expecting regular education teachers to teach children who have challenging needs without the support they need to teach all children effectively.
- Locating special-education classes in separate wings at regular schools.
- Ignoring parents' needs.
- Maintaining separate schedules for students in special and regular education.
- Students with disabilities receiving their education and job training in facilities outside their communities.

### **Philosophy**

There is an underlying philosophy that all children deserve to learn and experience life with their peers. That the public school setting in general is one that is enriching in many ways, educationally as well as socially, and that this experience is fulfilling, fosters self-esteem and the acceptance of all regardless of differences. Surely we should aspire toward this goal for all kids. But good philosophy does not guarantee good reality. There are many factors involved in providing this experience to children. Before deciding whether inclusion is right for your child, you should weight whether or not these factors are in evidence in your school district, and in the particular classroom, and to what degree they are successful. We should be looking at both the environment as well as our child's individual profile realistically. We can then determine whether or not it is a good match, and what needs to be done to bridge the gap between the classroom as it is, and the needs and abilities of our child.

Therefore, one truly can be a supporter of inclusion as a philosophy, and still choose not to include our own child at the present time.

### **The reality**

The reality is that the lofty goals of inclusion do not always happen in the real world. This is not to say that there aren't some programs and some teachers that go to tremendous lengths to reach as high a level as possible. It is simply not always possible given the individual child's profile of strengths and weaknesses, or the availability of trained teachers who have experience in successful inclusion AND the autism spectrum. Successful inclusion requires that all of these are present to make for a good experience. We also need to factor in that the teachers involved have to want to include a child who has the most problematic of weaknesses in a regular classroom. Including a child with an autism spectrum disorder is a lot of work. Hard work, that involves not only teaching academics, but social skills as well, something our teachers are not receiving training in before getting their teaching degrees. They have time constraints, training constraints and sometimes a lack of support within the school administration. This is a larger hurdle than most people think, since administrators tend to adhere to the letter of the law which requires looking at the least-restrictive environment during a PPT, however, if they do not follow through with providing the supports that are the foundation of the philosophy, success is not likely to happen. **There should be no such thing as inclusion that is not a successful inclusion.** For our children, unsuccessful inclusion, the kind that involves untrained teachers without paraprofessional support and lack of time to plan and coordinate, can be extremely damaging. It is also important to remember that if we are thinking about 'successful inclusion' that that means long-term successful inclusion, not just this year with this year's staff and peers. That success needs to be carried forward throughout the school career across a number of different teachers, staff, and school buildings. It does not benefit the child if he is included one year, and then sent back to self-containment the next, the commitment must be long-term for as long as it is possible.

## **How do I decide?**

All kids are includable. According to the philosophy, at any rate. However, in reality, I have seen it fail far too often. Why? One reason is the necessary skills and resources are not always available to staff. That means, that while all kids might be 'includable', all classrooms are not able to support includable kids. How do you decide whether or not your school district can support including your child? In order to better answer that, let's look at the goals of inclusion. (Ed: *I ask many questions here, but do not answer them, that is for you to do. They are intended only to entice you to think, or better yet, to have a discussion with your spouse, so that you are making decisions for the reasons that are important to you, and not the reasons that other people with other agendas think are important.*) We are not addressing the question of whether or not inclusion is desirable, but rather, whether it is practical and realistic for your child, at this time and at this stage of development, within this school, under these circumstances. You can certainly revisit and rethink your answers as your child matures, because the needs change as they do.

**To foster acceptance.** Because our children generally have behavioral issues, sometimes disruptive or aggressive ones, they are among the most difficult to include successfully in terms of this goal. Will inclusion help his behavior? How? Will his own behavior interfere with the time he has in the class to learn? Will it interfere with others' time and ability to learn? Does it matter that his behavior may intrude on others' time and ability to learn? Should they, or the teacher, have a say in an inclusion decision? Will peers really accept him/her as he/she is? Will their impressions (good or bad) remain in their heads for years to come? If peers are aggravated or fearful, are they wrong? How much time is OK to be aggravated and fearful? If your child's behaviors are based upon anxiety, how much anxiety is OK? How much keeps him alert and making an effort, and how much interferes and is debilitating? How will you find out how much anxiety he is experiencing in the classroom? How much supervision is there so that peers don't tease and bully our child? How will you know if it is happening, and how much? Is your child able to tell you, or will you depend on others to be aware of it? How much teaching does the school do for peers, to help foster acceptance? It is, after all, THEM who need to accept HIM – so will he have their cooperation and good will? If not, how can he get it? Does he have the opportunity to gain it? In other words, if he is isolated at the table at the back of the room with an aide, can peers really accept him as a member of their class if they never get to know him? Would you call that a successful inclusion? Why or why not?

**To give the child equal opportunity to participate.** What does 'participate' mean to you? Parents should think about what exactly it is that they wish the child to participate in, and look at their motivations for their answer. Is it academics? Extra curricular activities? Social events? Is it because inclusion means the child has access to materials and subject matter that he might not encounter elsewhere? Or is it because you feel that among so many kids there is bound to be one who will be his friend? Does it matter to you if the child befriends a special needs kid or a typical kid and, if so, why does it matter? Does it matter if he participates all day, or only for things he will ENJOY or BENEFIT from participating in? How do you know the difference? How do you know if a child is enjoying, or simply tolerating? What would the child himself say if you asked him if he wanted to participate? Have you ever asked him (if you have an older child)? What things were important to him? Are they the same as what is important to you? What things are different?

**To provide a better learning experience.** How much modification is taking place now to his/her class work? Is he doing ½ the work of the others? ¼? The same amount and time frame, only different wording and added pictures? These are all different scenarios, and create different decisions. If the child is doing one simple problem while the other kids do 10 more complex ones, is holding up the pace of the class, and requires constant help even to do that much, would you still think it is the best placement? How anxious would YOU be if you could only do 1/10<sup>th</sup> of the work your co-workers were doing, and not nearly as well? What would it take to modify the work to a reasonable level that would enable the child to stay in the classroom and feel like he is a part of the group? Would he be able to improve his skills to a more reasonable level if given intense one-to-one instruction? '*Working at your own pace*' doesn't always mean a slower pace – for many it can increase the speed with which they learn – might the gap close to some degree this way? Are you afraid that if your child were in a more restrictive setting that he will fall below his grade level because demands or expectations would be lower? What events would make this occur, and how can they be prevented? If you could be assured he could maintain grade level (or for some of our kids, above grade level) work in a more restricted setting, would it then be more acceptable? How do you picture those restricted settings? Are they realistic? Have you visited any to see what is available? How can you compare different programs if you haven't seen any other than what he/she has? If they are not right for your child, what makes them not right, and are those things that can be changed? Are you being realistic about your child's abilities?

**To experience the 'real world'.** Is a room with 25 kids and one adult 'real world'? A gymnasium locker room? Are there settings in the community that reflect this, or are life settings totally different in nature? As an adult, are you ever in similar settings? If so, when and where, and do you benefit from them or simply tolerate them? If they are different in the community, does it still benefit the child to experience them in school? When your child is an adult and living in those situations, do you think he will call on his knowledge and experience as a child, or will it be so different as to be irrelevant? Would it be better to have his inclusion experiences happen within the community rather than, or in addition to, the school building? How can you or the school make that happen? Have you ever made a list of the benefits you believe your child is experiencing? Have you ever made that list and then checked it out to see if it is accurate?

## **Behavior**

There are many teachers who simply do not want to have a behavior problem in their classroom. **This is not a good reason to keep a child from being included.** However, there are many teachers who are quite adept at handling our children's behaviors, and they still remain problematic, not just for the teacher but for the other students as well. There are certain limits to acceptance that even the most caring child will not venture beyond. One of them is aggression. Let's be truthful – would you want to sit next to someone on a public bus every day whom you felt was a safety risk? I wouldn't. Remember that schools are liable for the safety of all students, and the lives of the children in their care should always be a priority. If children are truly afraid of your child because he hits them or pushes them on a REGULAR basis, they will not be willing or able to be his friends, and they will remember this behavior for years to come and not be his friend then either. Maybe not including him for the period of time it takes to get this under control and manageable, would be time well spent. On the other hand, if his outbursts are controllable, for the most part, and are not a danger to anyone, then there are many steps that can be tried in order to enable him to function in that class, and to have the peers accept his behavior at least to some degree. Be sure you have explored all of the options. Remember that inclusion is not perfect, even in the best of circumstances, and it does not guarantee your child acceptance or friendship, only the opportunity for it.

If your child is not aggressive but simply disruptive, imagine how tolerant you would be if the co-worker next to you were disturbing you and your work regularly. Let's face it, maybe other kids have to deal with this every day from your child. And they are trying to concentrate on things they will be tested and GRADED on. We really do need to address the question of fairness to the other 20-odd children in the classroom as part of the equation of inclusion, and look at ways that can be successful in preventing their losing out, because if you don't a lot of resentment among peers (and their families) is likely to develop, and that does not help your child either.

## **Social skills**

Now, here is a great case for inclusion. Kids who need to learn social skills need to practice them with other people. If you have a child who has few disruptive behaviors, but needs a lot of instruction in social skills, that is more easily managed in the typical classroom, at least at the elementary school level. It becomes more problematic as kids get older and their needs and the social demands change and become more complicated, and you may find yourself rethinking this as your child goes to middle or high school. The need for flexibility in scheduling is particularly difficult for many upper schools to manage. It begs the question, how much change can we expect schools to make in order to support our child, and how successful is that going to be?

Inclusion only works when it's done well. Unfortunately, it isn't done well often enough. For our kids, doing it well is harder than it is for some other diagnoses, because it is truly 'pervasive'; there is a lot of information that must be mastered not only by the teacher, but also by the psychologist, the language path, the OT, and whomever is going to be doing social skills training, social groups, parent training, etc. This is a tall order. We may already know from past experiences that there are 3 categories people, professionals as well as family members, friends, etc, can fit into. They are: 1) people who 'get it' naturally, who gather a lot of information as well, and who are excited about the prospect of 'thinking outside of the box' and implementing new things, 2) People who get some information but don't really master it, and therefore make a lot of well-intentioned mistakes, and 3) People who will simply never be able to "get it" no matter how much they learn, because it isn't in their inherent nature. **People who work directly with our children cannot be in this category – ever.** While their intentions should be appreciated and rewarded, they will not be capable of furthering the education or the social

capabilities that these kids need to have. What category does your team fit into? If it's the first one, congratulations!!! If it's the second, you might want to ask for some changes, but if it's the third, you may need to rethink the whole plan.

### **An exercise in inclusion**

Below are some situations to consider. Decide for each - if this were YOUR child, would you continue to include him or not? What other decision might you make for him, and would that be a better situation given his profile?

*A pre-adolescent has a teacher who thinks she's doing what is needed, but at every PPT she gives examples of things she's done that you know to be wrong. He struggles in there socially and academically, though he is not failing. He has a GREAT special ed teacher in a resource room, though he's only with her one hour a day. However, the psychologist who does social skills is one who has had all the training one could expect but he just isn't getting it. He is not a good personality match on top of it, and your child HATES going to his class. He has the wrong matches for social group participants, and your child learns nothing there because their needs are more substantial than his. The language person is new, and seems motivated but is not trained enough to take over the social skills group or individual teaching. The school refuses to have the great special ed teacher take over because she has the responsibility of a class of her own, which is not a good match for him as a full-time placement. **Would you continue to include him? What would you do instead? Why?***

*A parent has several PPT's in which topics of discussion range from: giving significantly longer periods of homework than the other kids (because he works so slowly), time outs, allowing breaks but only when THEY say he can have them (and then they are in the hallway because there is nowhere else to go), that he needs to pay attention more to lectures in class (even though he has auditory processing problems), that he needs to have the same homework amount as the other kids because he would 'look different' if it were modified, and that he needs to prepare himself for middle school next year when the demands will be even higher. This parent has tried in vain to explain her child, but they all think they are doing the right things, and do not listen. **Would you continue to include him? What would you do instead? Why?***

*A kindergartener is mainstreamed into a typical kindergarten in the morning, but does receive special education services in the afternoon. He is extremely active and crashes into people, knocks things over without realizing it and also on purpose, hits children, screams in their faces, and has one child whom he is fascinated by that he follows around at VERY close range. He says inappropriate things, and disturbs the class CONSTANTLY. The kids obviously are frightened of him, back away when he comes near (even giving up their toys), cry when he yells at them, and are angry and upset when he interrupts fun activities like songs and movies. The teacher and the para spend a great deal of energy 'putting out fires', and often neglect other children's needs because at least their needs are not dangerous, but it doesn't seem to be enough. They are becoming frustrated because they cannot continue teaching the class, and they have a curriculum they need to be getting through. **Would you continue to include him? What would do instead? Why?***

Regardless of a child's disability label, there are many decisions to be made in placement that you probably won't hear in a PPT meeting. Parents need to make the choices that are right for their child, but they first need to know what that is. Gathering information beyond what is offered in a one-hour formal meeting is essential, and if you have the opportunity to observe the class (even if it is in the library as you are volunteering there) that would be tremendously helpful, or find someone else who is knowledgeable who could do it for you. I have often found that when I visit a classroom after having spoken to the parent, what I see happening is not what they described. Sometimes, it is because they have too optimistic a view of their child, of inclusion in general, or the individual teacher's abilities. Sometimes they have received misleading information from staff, with motivations ranging from protecting their own reputation as an 'autism expert', to misunderstanding the disability and the child's needs, to not wanting to disagree with their boss in front of a group of peers at a formal meeting. There is a lot of pressure put upon teachers to 'show progress', and sometimes that colors the information enough that parents misinterpret what they are hearing, sometimes because they really WANT to believe he is making progress.

Answering the questions presented here may be one way of making decisions on the implications and assumptions that we have about inclusion. 'Inclusion' is a word that has many meanings and many faces. **What does it mean to you?**