

# Inclusion – in whose best interest? How pediatricians can effectively advocate for children with neurodevelopmental disabilities

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One of the long-term consequences of many genetic and acquired disorders in early brain development is the need for special education support in elementary school and beyond. In the United States, federal law ‘requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs’ (Individuals with Disabilities Education Act [IDEA]).<sup>1</sup> This is implemented in the form of an Individualized Education Program (IEP) which is established and updated yearly for each student in one of 14 federal disability categories. The National Education Association [NEA] (which represents teachers and other educational professionals) supports the IDEA, recognizing that a ‘full continuum of placement options and services’ should be considered for each student.<sup>2</sup>

One of the important components of the IDEA is the determination as to whether or not students with special needs should spend most or all of their time in educational classrooms with non-disabled students. The IDEA mandates placement in the least restrictive environment in which the child’s needs can be met. The term ‘inclusion’ (a word which does not actually appear in the law itself) is what the IDEA is designed to accomplish, that is the provision of support and resources that enable children with disabilities to belong to and be recognized as members of their educational communities.

It is important to keep in mind that the IDEA states a preference for placement in general education and for attendance at the neighborhood school. The IEP team must justify any time the child spends outside of general education, and a child can be removed from general education only if he or she cannot be educated satisfactorily there, even with the provision of supplementary aids/services and programmatic modifications/support.

Currently in the United States 75% of children with disabilities spend part or all of their school day in a general education classroom. While this is a remarkable achievement in the drive to optimize opportunities for all children, it may create a number of challenges in the individual classroom. Laws and initiatives are formulated at the national and state levels, while policy decisions are implemented in local school districts and schools, often

by superintendents and principals who may differ on interpretation and focus. Therefore, the specifics of inclusion (‘inclusive classroom’) may vary across school districts and schools.

More than 6 million children in the United States receive educational services based on the IDEA.<sup>2</sup> In an era of diminished financial resources, funding is a reality which cannot be ignored.<sup>3</sup> Available funding affects the quality and quantity of educational services for typically developing children as well as those with special needs. Providing services in an inclusive classroom may require less funding than in a special education environment, and with the variability in state and local resources, any opportunity to save money may be embraced. However, inclusive education should not be based on financial considerations.

For many teachers who serve as the regular education component of the inclusive classroom there is a no more controversial topic than what the inclusive classroom should look like: who should be included and for what extent of the academic day.<sup>4</sup> Parents, teachers, and administrators who ardently support full inclusion believe that it is the best educational model to prepare all children for the real world. On the other side are those who believe that inclusion of children with special needs in a regular education classroom should be made on a student-by-student basis. As both positions are held passionately, at times final decisions in regard to educational placement may not easily be reached. These decisions have important implications for the individual child, his or her classmates, teachers and other school professionals, and those interested in the broader implications for a well-educated society and adult workplace.

Current research supports the concept that peer interaction between students with special needs and regular education students is an advantage of inclusion for both populations, and that best teaching practices of differentiation and modification of instruction meet all students’ needs more effectively.<sup>5</sup> Those who express concerns about inclusion often argue that the extra time required to meet the needs of the disabled students impedes the learning progress of the non-disabled students. Decision-making in regard to inclusion is confounded by the requirements of federal laws such as No Child Left Behind<sup>6</sup> and initiatives such as Common Core State Standards,<sup>7</sup> a set of national educational benchmarks in language arts and mathematics from kindergarten through 12th grade which most states have adopted. For example, providing the least restrictive environment for children and meeting the achievement requirements of No Child Left Behind can be at odds with each other.<sup>8</sup>

For example, a child with autism might be placed in a grade school inclusive classroom, with both academic and social goals on the IEP, given recognized abilities at a higher level than students in a classroom solely for children with autism. An autism specialist assigns an instructional assistant to give this student a chip every 3 to 5 minutes for appropriate behavior. As a reward when five chips have been earned, the autism specialist requests that the student be allowed to play with Play-Doh during classroom teaching time. This might be unacceptable to the general education teacher and the special education co-teacher because of the impact on other students and the demands of a stringent academic curriculum dictated by the required standards of learning. In this situation, time given to this playtime is an important social development goal for the child with autism, but can mean time extracted from academic learning. This example highlights the importance of establishing an appropriate reward system in these situations.

What I (DWW) have learned, as a regular education teacher who also teaches children with varying and sometimes multiple disabilities, is that the recommendations for inclusion made by the NEA, the American Federation of Teachers (AFT), and the Association for Supervision and Curriculum Development (ASCD) are not always taken into consideration in school models. In conversations with numerous regular education teachers in a well regarded school district, I discovered that few had received any formal professional development training before being assigned to the inclusive classroom; most had the same number of students as the general education classrooms at their grade levels; and very few received extra planning time to coordinate with specialists.

Here is an example of an inclusive first grade classroom in a suburban Northern Virginia school district. Of the 21 students in the classroom, three students have an autism spectrum disorder (one of whom also has severe language and emotional delays); one student has emotional disabilities; one has cerebral palsy; one has visual motor integration problems; one student has identified attention-deficit-hyperactivity disorder (ADHD) without medication; and 14 regular education students. All seven of the students with IEPs require speech and language support as well as intervention from special education specialists. Three receive occupational therapy support; and one physical therapy and adaptive physical education support. (By the end of the school year, of the 14 without IEPs, two students were diagnosed on the autism spectrum scale and one student with severe ADHD, bringing the total of special needs students to 10.) While the ideal for the inclusive classroom would be a natural balance of students with and without disabilities, as in this 'real-world' situation, this was not the case.

In this classroom the students variably read from beginning first grade to ready-for-third-grade levels. There were children adept at working with numbers in the thousands and students who could not count beyond the number 10.

Some could work independently or in small groups at learning stations, while others fell on the floor in tantrums or wandered aimlessly without adult guidance. The daunting challenge for the teacher(s) in this classroom was to successfully meet the educational, social, emotional, and physical needs of such a varied group of students while maintaining the intrinsic motivations and rewards of teaching which are the joy and satisfaction of seeing students succeed.

From a teacher's perspective, this is when it is imperative to follow the recommendations of educational researchers to 'remember, with responsible inclusion the responsibility is first and foremost to the student.'<sup>9</sup> That means to each student in the classroom – special education and regular education students. All should be making appropriate academic progress for an inclusive classroom to be considered a successful learning environment. Socialization should not be the only consideration for placement. A special education teacher and/or instructional assistants are usually present in the inclusive classroom in order to fulfill the IEP goals of the special needs students. Ideally, the special education teacher and regular education teacher share the responsibility for planning, instruction, and assessment.

In order for the inclusive classroom to be successful the class size should be smaller than a regular education class; extra time for planning between all the professionals servicing students should be provided; and regular education teachers in inclusive classrooms should be given extra training. Students with severe disabilities may not be best served in the inclusive classroom because of their high level of need and the impact of this on other students' learning. Guidelines for responsible inclusion programs should examine the following components: students, human and material resources, continuum of services and most effective models, program evaluation, professional development, school philosophy, curriculum, and role definition for general and special education teachers.

In the first grade classroom described above, the teacher was not given extra training, was not provided with extra planning time, did not have a smaller class load, and was not consulted when the students were assigned to her class. Several months into the school year and 2 days before this first grade teacher was to receive her student with cerebral palsy, she was told that the child was in a wheelchair and would have a fulltime assistant (nursing-trained but not instructionally trained). The plan was that the physical therapist, occupational therapist, and adaptive Physical Education teacher would meet with the teacher and make recommendations after they had time to work with the child and determine her levels of ability.

The teacher immediately began searching the internet for information about cerebral palsy and the consequences it has on children. That was the extent of the teacher training provided to a teacher who would be responsible for her first student with cerebral palsy. The entire classroom

had to be rearranged to accommodate a wheelchair and to give this new student access to every learning station, the morning meeting corner, and the classroom library.

For this teacher, involving the students in adapting the environment was a very effective way of preparing them for the child's needs. The students followed the lead of the teacher and welcomed the new student with enthusiasm and warmth. As this teacher recognized, 'It is not what a kid is, but what a kid needs'<sup>10</sup> that is most critical to the education process – acknowledging the needs of all children in an inclusive classroom.

Every child, with or without an IEP, requires special attention at some point in a school day. In this regard what is learned is more important than where it is learned. As advocates for children, pediatricians are in an excellent position to provide advice and recommendations in regard to inclusion, given their understanding of child/family dynamics as well as biological factors in brain development. Parents often ask whether an inclusive classroom is the right choice for their children. To provide guidance and recommendations, pediatricians need to understand the varied perspectives of students, families, teachers, school personnel, and the local community as well as the specific requirements of underlying legislative and administrative mandates as implemented in individual schools.<sup>11</sup>

From the pediatric perspective, establishing a family-centered medical home is an important component of care. 'In a family-centered medical home, the pediatric care team works in partnership with a child and a child's family to ensure that all of the medical and non-medical needs of the patient are met. Through this partnership the pediatric care team can help the family/patient access, coordinate, and understand specialty care, educational services, out-of-home care, family support, and other public and private community services that are important for the overall health of the child and family.'<sup>12</sup> Providing advice and recommendations in regard to possible inclusion should be an integral part of the medical home as it is envisioned.

When all these factors are considered, pediatricians can play an important role in the placement of their patients in classrooms. They can discuss with parents the importance of the NEA,<sup>13</sup> AFT,<sup>14</sup> and ASCD<sup>15</sup> recommendations for smaller class size, specific teacher training, additional planning time, and the continuum of services that should be available. They can recommend that parents visit schools (specifically the inclusive classroom at their child's grade level) and provide information that can be shared with teachers to further their understanding of the underlying causes of motor, cognitive, and behavioral impairments.

Well-informed parents make effective advocates for their children.<sup>16</sup> Parents are informed when an IEP is written with mutually defined goals and the child's attainment of each goal is reevaluated at the end of 1 year. Pediatricians can assure parents that any portion of the IEP can be addressed at any time within that year. Parents may share their child's IEP goals with their pediatrician to determine if they are realistic goals.

For example, the above mentioned first grade student with cerebral palsy had an IEP goal, added by the parent, that she learn to write her name using a pencil. The classroom teachers were uncertain that this was a realistic goal. Consultation with the child's pediatrician would have been helpful to provide an opinion in this regard. Pediatricians can also serve both as advocates for children as well as bridges when conflicts arise between school recommendations and parental wishes.

Pediatricians can ensure that the parents are well informed about best practices in effective classrooms with inclusion. They can prepare parents to ask such questions as, 'How will my child be safely removed from the school during fire drills and in case of emergencies?' 'How will my child be provided the special bathroom and hygiene requirements dictated by the needs of a child with cerebral palsy?' 'Is there playground equipment provided that adapts to the physical needs of my child and allows him to participate with peers at recess?'

For some children the inclusive classroom may not meet their needs effectively. Special education needs classrooms offer a reduced pupil to teacher ratio and teachers with specific training for special needs students. In these situations after all the facts are known, pediatricians should not be afraid to speak up and recommend alternative placement.

Finally, there may be differences between the legal mandates of IDEA and the reality 'on the ground' in individual schools and classrooms. It should be remembered that it is illegal under the IDEA to make decisions based on the nature or severity of the child's disability, on administrative convenience, or on the configuration of the service delivery system. Parents need to be aware that they have legal recourse if they are not satisfied with their child's educational placement.

In conclusion, this opinion is meant to highlight the complexity of this issue, and not to provide a 'solution'. All stakeholders – parents, teachers, and administrators – should be included in the decision-making of the educational placement of a child with special needs. What all children learn from exposure together must be balanced carefully with the needs of each individual student, to promote long-term success in school in the workplace and more broadly in society. Well-informed pediatricians can have an active voice in promoting educational goals for their patients.

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## REFERENCES

1. U.S. Department of Education. Building the Legacy: IDEA 2004. <http://idea.ed.gov/> (accessed 5 June 2013).
2. National Education Association. NEA Policy Statement on Appropriate Inclusion. <http://www.nea.org/home/18673.htm> (accessed 5 June 2013).
3. National Education Association. Fact Sheet for Congressional Offices: Kids Not Cuts! <http://www.nea.org/assets/docs/Leave-Behind-Kidsnotcuts0213.pdf> (accessed 5 June 2013).
4. Cassidy JM. Teachers' attitudes toward inclusion of students with autism and emotional behavioral disorder. *Electr J Inclusive Educ* 2011; 2: Article 5.
5. Katz J, Mirenda P. Including students with developmental disabilities in general education classrooms: educational benefits. *Int J Spec Educ* 2002; 17: 14–24.
6. U.S. Department of Education. No Child Left Behind. Elementary and Secondary Education Act (ESEA). <http://www2.ed.gov/nclb/landing.jhtml> (accessed 5 June 2013).
7. Common Core State Standards Initiative. Implementing the Common Core State Standards. <http://www.corestandards.org/> (accessed 5 June 2013).
8. Moores DF. Waist deep in the big muddy: the Individuals with Disabilities Education Act (IDEA) and No Child Left Behind (NCLB). *Am Ann Deaf* 2011; 155: 523–5.
9. Vaughn S, Shay Schumm J, Forgan JW. Instructing students with high-incidence disabilities in the general education classroom. Association for Supervision and Curriculum Development, Special Topics, 1998.
10. Sailor W. Serving all kids, no exceptions. *Education Week* 8/3/2011.
11. Hurwitz KA. A review of special education law. *Pediatr Neurol* 2008; 39: 147–54.
12. American Academy of Pediatrics. National Center for Medical Home Implementation. Frequently asked questions. <http://www.medicalhomeinfo.org/about/faq.aspx> (accessed 5 June 2013).
13. National Education Association. <http://www.nea.org/> (accessed 5 June 2013).
14. American Federation of Teachers. AFT resolutions: inclusion of students with disabilities. 994. <http://www.aft.org/> (accessed 5 June 2013).
15. ASCD. <http://www.ascd.org/Default.aspx> (accessed 5 June 2013).
16. U.S. Department of Education. The Power of the Parent Voice: Secretary Arne Duncan's remarks at the Office of Special Education Programs (OSEP) Leadership Mega Conference. <https://www.ed.gov> (accessed 5 June 2013).