



In the Spotlight

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Parent Advocate: Full Time Job

staying on top of their child's special education programs by making sure the IEP reflects their child's needs and that it is being implemented appropriately can almost be a full-time job, minus the salary...

Back to school time can be stressful for all parents but parents of students receiving special education services have an added layer of anxiety to contend with. In addition to all of the basic activities that come along with getting back into the groove of school, they are also faced with another year of negotiating the "maze" known as special education in New York State. What many who are not familiar with the *process* of special education may not be aware of is that staying on top of their child's special education programs (known as Independent Education Plan or IEP) by making sure the IEP reflects their child's needs and that it is being implemented appropriately can almost be a full-time job, minus the salary, for some of these parents.

For those new to the process, reading through the pages and pages of rights, rules and regulations; deciphering the legal-ese in which every document is composed; and pouring over the numbers and corresponding comments in tests that comprise their children's evaluations can be daunting and frustrating. Others who have been involved in the "system" for several years and who have become savvy in their knowledge of the law and their rights as a result of their attendance at conferences, seminars and trainings targeted to parents of special education students are ready to do whatever it takes to make sure their children get what they need to succeed in school. But whether you are a new parent just finding your way or one that has acquired enough knowledge to hold an honorary law degree, the task of advocating for your child with special needs takes a significant amount of time and energy. Each year, parents of students with special needs have to re-introduce their children to their school district's Committee on Special Education or CSE (the team of professionals, including the parents, responsible for IEP development and implementation) and ensure that they have adequate time to meet with, discuss, process and fully understand all that is going on, as CSE's are barraged with meeting after meeting throughout the school year. The numerous meetings and processes can become so frequent and routine for the CSE that it is crucial for parents to remind them that when they meet to discuss their child, it is a very real and whole child they are dealing with and not just a bunch of test scores and papers. So why is it that negotiating special education in New York State has become so complex and the role of "parent advocate" has risen to the level of a second but equally time-consuming full time job for some parents?

For starters, under the federal Individuals with Disabilities Education Act (IDEA), the law that grants students with disabilities access to special education services and delineates the rights of their parents in the process, students are eligible for special education services when they are deemed to fit into one of the laws' identified thirteen disability categories and the CSE has determined that the disability impacts their ability to learn. Once a child is "classified" into one of these categories, the CSE then determines what the child's placement, services and annual goals should be, along with various other activities that will all (hopefully) prepare the child for living independently in the adult world.

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LDANYS

1190 Troy-Schenectady Rd.

Latham, NY 12110

Ph: 518-608-8992

Fax: 518-608-8993

E-Mail: statelda@ldanys.org

Website: www.ldanys.org



LDA Regional Affiliates

LDA of the Capital District
(a.k.a. Wildwood Programs)
2995 Curry Road Extension
Schenectady, NY 12303

LDA of Central New York
722 West Manlius Street
East Syracuse, NY 13057

LDA Life & Learning Services
339 East Avenue, 4th Floor
Rochester, NY 14604

LDA of Long Island
44 South Elmwood Avenue
Montauk, NY 11954

LDA of the Mohawk Valley
401 Columbia Street
Utica, NY 13502

LDA of New York City
27 West 20th St., Rm. 303
New York, NY 10011

LDA of the Southern Tier
112 Nanticoke Avenue
Endicott, NY 13760

LDA of Western New York
2555 Elmwood Avenue
Kenmore, NY 14217

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AT WWW.LDANYS.ORG**

The Learning Disabilities Association of New York State (LDANYS) was chartered by the New York State Board of Regents in 1958 and is a statewide 501c3 nonprofit, parent-driven organization that advocates on behalf of children and adults who have learning disabilities. LDANYS is the New York state affiliate of the Learning Disabilities Association of America. Our regional affiliates located throughout the state provide a variety of programs and services for children and adults with learning and other developmental disabilities and their families.

For more information about our organization or about the content contained here, please contact our state office at 518-608-8992.

Parent Advocate – continued

But while the IDEA provides a “framework” in which this whole process can occur, state regulations, local school district practice and individual CSE-member interpretation also come into play and murky the waters further. Dwindling state and local budgets to pay for services compounded by the fact that since IDEA was first passed in 1976, Congress has yet to fully fund it leaving states to bear the brunt of the costs may lead some decisions to unfortunately be influenced by money. Additionally, the law’s requirement that students with disabilities are entitled to receive a “free and appropriate public education” is not always in tune with the fact that most parents want, and rightly so, what is “best” for their children. However, IDEA is clear in its language, using “appropriate” instead of “best” and sometimes finding common ground between these two terms can lead to disagreements.

While many parents do spend countless hours on this process, it is vital that parents are fully aware of and informed of their rights under the IDEA. Congress intended the special education system it established under IDEA to be a system of “checks and

balances” by providing for the rights of parents to initiate due process in the event that disagreements cannot be resolved between the parents and the CSE if necessary. Congress also provided for several other mechanisms to resolve disagreements prior to due process including mediation and resolution sessions (in New York State). However, if parents are not familiar with these rights and do not utilize them when they can and should then the “check” on the system fails.

There are many organizations throughout New York State that can assist parents in understanding their rights under the IDEA and help them to negotiate the system. LDANYS is one of those organizations and has a myriad of resources on special education for parents on our website. One of LDANYS’ top priorities is advocating for and representing the interests of parents when regulatory and legislative policy changes that will impact their rights under the special education system are being considered. Parents need to know that while the special education system in New York State is can indeed be overwhelming, they are NOT alone and that there are organizations that exist to help them navigate the process.