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## **Introduction**

As a parent of 17-year-old twins with profound intellectual and developmental disabilities (I/DD), I have concerns with Department of Education (DOE) regulation which limit opportunities for children with disabilities on the severe and profound end of the disability continuum. Programs that my children now access have been closed to younger entrants and I fear will be gone altogether when those who have been grandfathered in have aged out. Additionally, I see on the horizon a limiting of post-secondary options for children with severe and profound disabilities as disability-specific work and day programs are regulated out of existence, leaving some children with no path to meaningful post-secondary opportunities.

My children are not alone. There are thousands of children across the country who are born with severe and profound I/DD often accompanied by complex medical and behavioral conditions. There needs to be a place for these children in our educational system. The specialized nature of their conditions must not be trivialized and downplayed so as to fit into a neat, one-size-fits-all approach. Life is not that simple, especially for children with severe and profound challenges.

## **Misrepresentation of U.S. Supreme Court *Olmstead* Decision**

In my children's short life, I have seen burdensome regulation limit opportunities for children with I/DD. Their specialized school no longer accepts children under the age of 14 for fear of misguided lawsuits brought under the misrepresentation of the U.S. Supreme Court *Olmstead* decision. Post-secondary opportunities for individuals who cannot perform competitive work, such as sheltered workshops and facility-based day programs, are increasingly under attack by similar litigation.

The *Olmstead* decision was centered on ensuring appropriate residential accommodations for two adults with mental disabilities. It is now being misrepresented and applied to education and work settings with the goal of eliminating disability specific educational opportunities altogether.

The *Olmstead* decision did **not** eliminate disability specific settings that serve many individuals with I/DD in one facility, often referred to as institutional settings. Throughout their decision, the justices on the *Olmstead* Court emphasized the need for a range of settings for individuals with diverse mental disabilities and they spoke of the importance of institutional settings to protect health and safety for those individuals who cannot handle and benefit from community settings. *Olmstead* also made individual choice paramount in accessing services. *Olmstead* stated,

*"Unjustified isolation, we hold, is properly regarded as discrimination based on disability. **But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand.**" *Olmstead v LC* 527 US 581, 597 (Emphasis added.)*

*"For the reasons stated, we conclude that, under Title II of the ADA, States are required to provide community based treatment for persons with mental disabilities when,*

- (1) the State's treatment professionals determine that **such placement is appropriate;***
- (2) **the affected persons do not oppose such treatment;** and*
- (3) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." *Olmstead*, 607 (Emphasis added.)<sup>11</sup>*

***"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle and benefit from***

***community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” Olmstead, 601-602 (Emphasis added.)***

### **Least Restrictive Environment**

34 CFR 300.114(a)(2) *Each public agency must ensure that -*

- (i) *To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are non disabled are served in the least restrictive environment (LRE);*
- (ii) *Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.*

This regulation promotes integration for children with disabilities in order to expand opportunities, but when applied with too heavy of a hand, this regulation has removed opportunities for children with disabilities who benefit from specialized programming.

The elimination of disability specific education programs is occurring counter to IDEA. In my research of this issue, Jill Barker of the DD News Blog (<http://theddnewsblog.blogspot.com>), provided the following information,

IDEA does not rule out congregate or separate schools or classrooms if the child cannot be educated satisfactorily in a regular classroom and if the specialized placement is in accordance with the child's IEP. **In fact, IDEA and its regulations assure the appropriateness of services and placements for all children.**

An appropriate education is one that is in accordance with an IEP that has the important protection that it is written with the active participation of the child's parent(s). When school districts eliminate separate classes or schools, they take away the determination of what is appropriate from the parents and IEP team and leave it up to a general arbitrary policy that may or may not work for the individual child.

The assurance of an appropriate education is being overridden by the misinterpretation of LRE requirements, in much the same way that the misinterpretation of *Olmstead* is used to restrict services and placement options for people with I/DD.

Please see Exhibit A for a listing of the regulation supporting the assurance of an appropriate education.

Just as gifted children benefit from special classes and curriculum specifically geared to their abilities, children with severe and profound I/DD can benefit from programming designed around their disabilities. In a specialized environment, rather than being told to keep up with non disabled children, children with significant disabilities can thrive.

I question why gifted students are allowed special programming, but students with disabilities are finding their specialized programming under attack.

We also must remember, that there are children whose I/DD is accompanied by complex medical and behavioral conditions that make daily transport to school inappropriate due to health and safety concerns. For these children, application of LRE that stigmatizes the supports that allow for education in disability-specific educational settings or at one's residence (such as their family home or an Intermediate Care Facility for Individuals with Intellectual Disabilities) has harmful consequences and can lead to the lack of availability of appropriate supports for some of our country's most fragile children.

As a parent of children who attend a school for students with I/DD, I witness first-hand the benefits my children receive in an environment where all teachers and therapists have decades of experience teaching

and serving children with I/DD, and where my children can interact with other children with the same challenges. Professionals at their school are passionate about the field of disabilities and have chosen to devote their careers to it. Their passion and their loving and patient personalities directly benefit the children they serve. The collaboration of many teachers and therapists in one setting allows for creative problem-solving to address maladaptive behaviors or devise solutions to promote more functionality through adaptive techniques. This collaborative brainstorming happens daily in specialized school settings, settings that cannot be replicated in mainstream public schools.

Additionally, many public schools are not set up to handle conditions connected to children with disabilities such as safe transfers and lifts for quadriplegia, diapering, tube feedings, administration of medication, seizure disorders. Having appropriately trained and experienced nursing supports is essential to children with I/DD and so are teachers and assistants trained and willing to care for such concerns. Specialized schools are more able to have the staff on hand trained in these areas, and thus makes it more possible for children with complex conditions to leave their residences and interact with other children in a school setting.

Increasingly, however, disability-specific school-age programs are becoming van services rather than facility-based learning centers. The push for community inclusion at all costs has led to students being forced into the community at all times, visiting the YMCA, the library, museums, etc., rather than spending time at school developing skills and learning. While non-disabled students attend field trips, they are not perpetually shuffled from one community activity to another just to satisfy another's view of integration.

Finally, the educational experience should be outcome-oriented, meaning the least restrictive environment should be based on the individual and what affords the individual the greatest amount of independence and opportunities. My son can explore his school in his wheelchair and visit other classrooms independently. While my son is able to propel his chair, his intellectual disability does not enable him to understand hazards. As such, his independence in propelling his chair is greatly curtailed in a traditional public school with staircases, other hazards, and people who are not sensitive to his condition. Similarly, my son and daughter have access to therapeutic equipment at their school such as adaptive bicycles, gait trainers, and other equipment that allows them to develop physical and occupational skills. The special design of their school building enables them to use this equipment throughout the building giving them the maximum amount of freedom and opportunity. Such activity would be greatly impeded in a traditional school which is designed for non disabled children and may not have access to a wide variety of equipment and technical expertise. Additionally, my children participate in adaptive music concerts, track meets and swim meets. Such activities and competitions would not be available to them in a traditional public school where school events and teams are geared toward typically developing children. *For these reasons, my children's school is the least restrictive environment for them.* The U.S. Supreme Court *Olmstead* decision recognizes this outcome-based, individual approach to disability accommodation,

*Each disabled person is entitled to treatment in the most integrated setting possible for that person recognizing that, on a case-by-case basis, that setting may be in an institution. Olmstead at 605*

*Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times—perhaps in the short run, perhaps in the long run—for the risks and exposure of the less protective environment of community settings; for these persons, institutional settings are needed and must remain available. Olmstead, 605*

*For many mentally retarded people, the difference between the capacity to do things for themselves within an institution and total dependence on the institution for all of their needs is as much liberty as they ever will know. Olmstead, 605*

### **Transition Services (34 CFR 300.43)**

Transition services begin at age 14 and continue through age 22 and help the student plan for a productive life once they age out of school.

A January 2017 guide, "A Transitional Guide to Postsecondary Education and Employment for Students with Disabilities,"<sup>1</sup> produced by the Office of Special Education and Rehabilitative Services (OSERS) of the United States Department of Education discusses post-secondary education and training, regular and alternative high school diploma, dual or concurrent enrollment program, early college high school, and employment opportunities such as community-based work, internships, mentorships, and apprenticeships.

There are no sections of this guide which address the needs of children with severe or profound disabilities. One would think that the post-secondary education and training section would address opportunities for young adults with severe and profound disabilities. This section, however, states,

*"There are a number of opportunities and programs available for students preparing to exit secondary school. Many of these education and training opportunities involve formal or informal connections between educational, VR, employment, training, social services, and health services agencies. **Specifically, high schools, career centers, community colleges, four-year colleges and universities, and State technical colleges are key partners.**" OSERS Transition Guide, page 2. (Emphasis added.)*

What about supported community employment and sheltered work settings that provide a commensurate wage, and what about facility-based day programs for those with the most profound needs? Why are these opportunities not listed?

The section regarding alternative high school diploma states that this diploma pertains to children with "the most significant cognitive disabilities." But, the section goes on to say,

*"IEPs could include **transition services in the form of coursework at a community college or other postsecondary institution**, provided that the State recognizes the coursework as secondary school education under State law. Secondary school education does not include education that is beyond grade 12 and must meet State education standards." OSER Transition Guide, page 3. (Emphasis added.)*

Suggesting individuals with the most significant cognitive disabilities, functioning at the level of an infant or small child, could benefit from coursework at a community college is nonsensical.

Even the sections of the guide that address work opportunities say nothing about supported employment in a community setting, sheltered workshops or facility-based day programs.

Concurrently with the DOE limiting disability-specific programming and not offering appropriate transition services for individuals with severe and profound disabilities, other federal departments, namely the Department of Labor (DOL) and the Department of Health & Humans Services (HHS), are making it harder for young adults with severe and profound needs to access post-secondary opportunities. The DOL is making it more difficult for individuals to receive a commensurate wage by threatening the end of FLSA 14(c) wages certificates and increasing regulation under WIOA.<sup>2</sup> HHS has changed settings rules that make it harder for disability-specific work and day programs to receive HCBS waiver funding.<sup>3</sup> The DOE, the initial place an individual with disabilities receive services in life, should work with other federal agencies to maintain and promote opportunities so that children with severe and profound disabilities that are sent into the world from the education system have appropriate and meaningful opportunities in life.

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<sup>1</sup> This Transition Guide can be found at this link: <https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf>

<sup>2</sup> Information on DOL regulations on FLSA 14(c) certificates and WIOA can be found at this link: [https://www.dol.gov/whd/FieldBulletins/fab2016\\_2.htm](https://www.dol.gov/whd/FieldBulletins/fab2016_2.htm)

<sup>3</sup> Information on HHS regulation affecting HCBS disability-specific setting can be found at this link: <https://www.medicaid.gov/medicaid/hcbs/downloads/q-and-a-hcb-settings.pdf>

The preface to the Transition Guide referenced above indicates that OSERS “*provides oversight and guidance regarding the administration and provision of transition services by state education agencies (SEAs), local education agencies (LEAs) and state vocational rehabilitation (VR) agencies.*” As such, OSERS of the DOE, has a role to play in the provision of appropriate VR supports for children with severe and profound needs. These include commensurate wage opportunities through supported employment and sheltered work as well as facility-based day programs for those who cannot functionally perform work.

### **Conclusion**

While integration is a laudable goal, integration for its own sake is not. In practice, this means that a least restrictive environment for some may be a the most restrictive environment for others. As such, educational and transition programs must look at the individual needs and choices of each child.

It is for this reason that a basic tenet of the Americans with Disabilities Act as set forth by the Department of Justice recognizes the individual as having paramount importance in the administration of public services,

“...public entities are required to ensure that their actions are based on facts applicable to individuals and not on presumptions as to what a class of individuals with disabilities can or cannot do. 28 C.F.R § 35.130

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## Exhibit A: Regulation Supporting Assurance of an Appropriate Education

(NOTE: EMPHASIS HAS BEEN ADDED WITH BOLDED SECTIONS BELOW.)

### Least Restrictive Environment (LRE)

#### §300.114 LRE requirements.

(a) *General.* (1) Except as provided in §300.324(d)(2) (regarding children with disabilities in adult prisons), the State must have in effect policies and procedures to ensure that public agencies in the State meet the LRE requirements of this section and §§300.115 through 300.120.

(2) Each public agency must ensure that—

(i) To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and

(ii) **Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.**

(b) *Additional requirement—State funding mechanism—*(1) *General.* (i) A State funding mechanism must not result in placements that violate the requirements of paragraph (a) of this section; and

(ii) A State must not use a funding mechanism by which the State distributes funds on the basis of the type of setting in which a child is served that will result in the failure to provide a child with a disability FAPE according to the unique needs of the child, as described in the child's IEP.

(2) *Assurance.* If the State does not have policies and procedures to ensure compliance with paragraph (b) (1) of this section, the State must provide the Secretary an assurance that the State will revise the funding mechanism as soon as feasible to ensure that the mechanism does not result in placements that violate that paragraph.

(Approved by the Office of Management and Budget under control number 1820-0030)

(Authority: 20 U.S.C. 1412(a)(5))

#### §300.115 Continuum of alternative placements.

(a) **Each public agency must ensure that a continuum of alternative placements is available to meet the needs of children with disabilities for special education and related services.**

(b) **The continuum required in paragraph (a) of this section must—**

(1) **Include the alternative placements listed in the definition of special education under §300.39 (instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions); and**

(2) Make provision for supplementary services (such as resource room or itinerant instruction) to be provided in conjunction with regular class placement.

(Approved by the Office of Management and Budget under control number 1820-0030)

(Authority: 20 U.S.C. 1412(a)(5))

[71 FR 46753, Aug. 14, 2006, as amended at 82 FR 29759, June 30, 2017]

**§300.116 Placements.**

In determining the educational placement of a child with a disability, including a preschool child with a disability, each public agency must ensure that—

(a) The placement decision—

(1) Is made by a group of persons, including the parents, and other persons knowledgeable about the child, the meaning of the evaluation data, and the placement options; and

(2) Is made in conformity with the LRE provisions of this subpart, including §§300.114 through 300.118;

(b) **The child's placement—**

(1) Is determined at least annually;

(2) **Is based on the child's IEP; and**

(3) **Is as close as possible to the child's home;**

(c) **Unless the IEP of a child with a disability requires some other arrangement, the child is educated in the school that he or she would attend if nondisabled;**

(d) **In selecting the LRE, consideration is given to any potential harmful effect on the child or on the quality of services that he or she needs; and**

(e) **A child with a disability is not removed from education in age-appropriate regular classrooms solely because of needed modifications in the general education curriculum.**

(Approved by the Office of Management and Budget under control number 1820-0030)

(Authority: 20 U.S.C. 1412(a)(5))