



Mission First. Every Individual, Every Day.

November 8, 2021

Technical Assistance Collaborative  
c/o Jenn Ingle  
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Dear Ms. Ingle,

Thank you for the opportunity to comment on the draft of the North Carolina Olmstead Plan. As described in the introduction and stated by the late Justice Ginsburg, we agree that people with disabilities have been, and continue to be unjustly segregated from their communities due to the overuse of institutionalized settings. Placement in such settings deprives individuals of their rights to access competitive and integrated employment, access the full array of resources and supports, develop social relationships, and more. This is why the vision of the Olmstead Plan to champion “the right of all people with disabilities to choose to live life fully included in the community” is so important. These values set the framework from which the state will operate to increase people with disabilities’ access to their communities.

As an organization, Melmark has spent decades serving individuals with disabilities who exhibit severe challenging behaviors. The people we serve are the exact population this Olmstead Plan was designed to assist in accessing the community, as their profile often leads to hospitalization and institutionalization. We offer a variety of community based service models that have the clinical sophistication to prevent these individuals from requiring institutionalization and/or provide them with an effective step-down placement when transitioning out of institutions. Thus, our mission aligns well with the mission of the Olmstead Plan to “assist people with disabilities to reside in and experience the full benefit of inclusive communities” (p. 7).

Because of this alignment of mission, we are very interested and invested in the work of Olmstead Planning. Along those lines, we do have recommendations to improve the state of North Carolina’s ability to successfully support children and youth with disabilities in community based settings, and keep them out of institutionalized settings.

### **Importance of Addressing Special Education in Olmstead Planning**

Repeatedly throughout the description of the purpose and development of the Olmstead Plan, there are references to other state agencies that serve individuals with disabilities. These include mention of the need to work with and plan across various agencies in order to achieve the stated goals of the Olmstead Plan. We applaud this strategy. It shows an awareness of the fact that any individual with a disability likely receives a number of different services to support them. In order for individuals at-risk of institutionalization to be successful in community-based settings, it is therefore necessary for the strategies laid

out in the Olmstead Plan to be applied across these various services. However, when planning for children and youth with disabilities, there is a glaring omission in focus. Specifically, the Olmstead Plan fails to address the special education services, or lack thereof, provided to high acuity students with disabilities (i.e., students with disabilities whose profile and support needs places them at-risk of institutionalization).

There is general consensus that education is one of, if not *the* most important support children can access. It is at school where children and youth learn the skills deemed essential for success in life. This is especially true for those students who have disabilities, as they are not only taught academics at school, but also critical skills in the areas of adaptive behavior, communication, self-management, and other functional skills they need to succeed in all areas of their life. Additionally, schools are the primary arena for social interaction for children and youth. Socialization at school is also of increased importance for students with disabilities, as they may not be eligible for many other typical social opportunities such as sports teams or more informal social groups. Third, school is where many children access therapies that are essential for their development. Again, this is even more relevant for students with disabilities who get services such as speech, occupational, and physical therapy through school when they may not be able to find providers outside of school.

It is because of this unique importance that state and federal policy guarantees access to a free appropriate public education (FAPE) for all students with disabilities via the North Carolina Policies Governing Services for Children with Disabilities and the Individuals with Disabilities Education Improvement Act (IDEA, 2004). Furthermore, it is why the Supreme Court of the United States decided that simple access to educational opportunity is not enough. In their decision on *Endrew F. v. Douglas Co. School District* (2017) the court unanimously decided that students with disabilities deserve to make meaningful progress on their special education goals.

Unfortunately, these standards are often not upheld in North Carolina. Too often, children and youth with disabilities who have complex needs are not adequately served in the available school settings. As a result, these students often fail to make educational progress and are subject to severe disciplinary responses such as regular suspension and involvement with law enforcement. In the most extreme of responses, students with disabilities are actually prohibited from attending school full time via a process of placing them on homebound or modified-day placements.

Homebound is the practice of changing a child's placement in their individualized education program (IEP) so they are not able to attend school at all. Instead, a teacher is sent to the individual for a set number of hours per week. Similarly, a modified day placement is when the IEP is altered so a student can attend school every day, but for a reduced number of hours. It is important to note these arrangements are intended for use for individuals with complex *medical* needs, such as those with severely compromised immune systems or those who are receiving intensive medical treatments that prevent them from attending school (e.g., chemotherapy). However, in North Carolina the use of

homebound and modified-day placements has been broadly used for high acuity students with disabilities when schools find it difficult to accommodate their needs (e.g., a student with autism who exhibits aggressive and/or self-injurious behavior).

To illustrate the prevalence of this issue, Disability Rights North Carolina, in collaboration Department of Public Instruction, conducted a survey on homebound and modified-day placements during the 2016-2017 school year. The survey was completed by approximately two-thirds of school districts. Those school districts reported 1,163 students had been placed on homebound during that year and another 295 were placed on a modified day. Almost two-thirds of students on homebound were only provided with *0-3 hours of educational services per week*. Most of these students are those most at-risk of institutionalization, and they are denied what should be the foundation of their supports due to these restrictive placements. They are unable to access the instruction they need to learn important life skills, they do not receive therapies needed to learn critical skills such as how to communicate, and they are denied some of their only opportunities for social interaction. The inability of schools to support these students places additional stresses on the families of those children as they are required to support their child all day, every day. Many parents are forced to quit jobs, which places the entire family in greater economic and housing instability.

The effects of this lack of educational access leads directly to an increased risk of institutionalization. For further context, in conversations with representatives from state run developmental centers regarding the educational status of children and youth referred to them, those representatives report that virtually all of them are placed on homebound. As such, to achieve the goals set forth in the Olmstead Plan for children and youth with disabilities, it is essential the Olmstead Plan address education. As outlined below, it is clear the priorities in the Olmstead Plan would be strengthened by improving access to effective education for students with disabilities.

**Priority Area 1: Strengthen Individuals' and Families' Choice for Community Inclusion through Increased Access to Home and Community Based Services and Supports**

In order to address this, the Olmstead Plan made suggestions to increase the employment and day services available for individuals with disabilities. However, the corollary to employment and day services for children and youth is school. Many children and youth with disabilities who experience institutionalization are unable to access the most important community available to them, the community of a school. It is clear from the Olmstead Plan and working groups that this a concern for students in institutions. However, the data indicate this is an issue even when those children and youth are *not* institutionalized. In order to address this priority for *all* individuals with disabilities, the Olmstead Plan should address the lack of capacity to serve high acuity children and youth with disabilities in schools.

**Priority Area 2: Address the Direct Support Professional Crisis**

The Olmstead Plan recognizes the importance of high quality direct support professionals (DSPs) to the success of individuals with disabilities succeeding in community based settings. It smartly mentions the need to hire and retain qualified individuals. To address this, the plan proposes to increase the pay for DSPs and also the need to require competency-based training. This is important as, high acuity individuals who are at-risk of institutionalization need highly skilled professionals to work with them across settings to ensure they can succeed in the community.

All of the points about DSPs are also relevant to educational professionals. Paraprofessionals in schools often serve the role a DSP does in the community. Currently the starting pay for a paraprofessional, or instructional support staff, is \$2,101.72 per month. Most paraprofessionals work for 10 months out of the year, which equates to an average of \$21,017.20 per year. This is comparable to the data in the Olmstead Plan stating that DSPs average wage is \$11.95 per hour, which would equate to an annual salary of \$24,856 for DSPs who work full-time. Per federal and NC DHHS poverty guidelines, a single adult earning less than \$25,520 per year qualifies as impoverished (<https://files.nc.gov/ncdhhs/HHS-Poverty-Guidelines.pdf>).

If the Olmstead Plan recognizes, accurately we might add, that a DSP serving a high acuity individual with disabilities after-school and on weekends deserves to receive a wage that places them above the poverty line, then it also follows that a professional working with that same child during the school day should also earn a wage placing them above the poverty line. This is not the case currently, as paraprofessionals working full time often qualify as living in poverty.

Additionally, the Olmstead Plan recognizes that highly skilled professionals are required to support high acuity individuals with disabilities. However, paraprofessionals often receive little to no training on evidence-based interventions to support students with disabilities, especially those at-risk of institutionalization. It is unfair to expect paraprofessionals to support these students without sustained training in evidence-based practices that are the most effective for this population.

Failing to address these issues in the school setting leaves children with disabilities without the highly skilled professionals they need to be successful in school. Without those professionals, these children and youth with disabilities are at greater risk of institutionalization.

### **Priority Area 3: Divert and Transition Individuals from Unnecessary Institutional and Segregated Settings**

As stated repeatedly, effective educational services should be the foundation of children's and youth's supports. If children are unable to access their education, their chances of avoiding or successfully transitioning from institutionalized settings decrease dramatically. Without access to school, they do not receive the instruction,

therapies, and social supports they need to remain in community based settings. Additional stress is placed on families, thereby increasing the likelihood of institutionalization. Proper educational placements is a critical piece in avoiding and transitioning from institutionalized placements. This is why in many other states there are specialized educational placements, some that offer community based residential services as part of their special education offerings in accordance with IDEA and the North Carolina Policies Governing Services for Children with Disabilities, that serve as effective diversionary or step-down placements for individuals who require more sophisticated supports than are generally available.

**Priority Area 4: Increase Opportunities for Supported Education and Pre-employment Transition Services for Youth with Disabilities, and Competitive Integrated Employment for Adults with Disabilities**

This priority is important to increase the number of youth with disabilities who are able obtain competitive integrated employment as adults. If an individual is able to obtain such competitive integrated employment, their likelihood of avoiding institutionalized placement increases drastically. However, if a student is unable to access school due to a homebound or modified-day placement, they will be unable to access any of the proposed increases in supported education and pre-employment transition services. Therefore, to achieve this goal for those children and youth with disabilities at-risk of institutionalization, the lack of effective educational supports must be addressed.

**Priority Area 5: Increase Access to Safe, Decent, and Affordable Housing**

As stated previously, if students are placed on homebound or modified-day placements, families become responsible for their care throughout the day. This means many parents are forced to quit their jobs. The accompanying loss of income causes increased housing instability. Ensuring access to a full school day for children and youth with disabilities would help ensure access to safe, decent, and affordable housing.

**Priority Area 6: Address Gaps in Services**

School also plays a critical role here. If students are able to get effective supports and access school for a full school day, there is a greater chance they could stabilize in community-based settings. The fact there are so many children and youth on homebound and modified-day illustrates that one of the biggest gaps in services is in education.

With that being said, the Olmstead Plan does mentions several gaps in services that would be beneficial to high acuity children and youth with disabilities. However, those recommendations will be limited if the educational issue is not addressed. For instance, it mentions increasing mental health access in schools. This could be helpful for students who are able to attend school, but those on homebound or modified-day would not be able to access these services. Further, mental health services overlooks the

services required for individuals with intellectual and developmental disabilities who are often unable to participate in traditional mental health interventions as they may lack the communication and social skills necessary to participate.

Similarly, the plan mentions a need to increase the outpatient therapists trained to treat children with co-occurring mental health and intellectual/developmental disabilities. Unfortunately, outpatient therapists are often ill equipped to help these individuals progress due to the nature of outpatient services. These individuals require access to evidence-based special education curricula with intensive, daily intervention from highly skilled professionals to make progress and learn critical skills. The most natural place for children and youth to learn skills is in school. As stated previously, it is a federal and state requirement that every child have a FAPE. We need to eliminate the barriers that allow this gap in services to persist.

### **Priority Area 7: Explore Alternatives to Overly Restrictive Guardianship**

Individuals receiving a quality special education are less likely to require guardianship because they have the skills necessary to be independent, obtain competitive integrated employment, and live independently. If children are unable to access effective education, and are placed on homebound for years, they are unable to develop these skills. As a result, the practice of using overly restrictive guardianship is likely to persist.

### **Priority Area 8: Address Disparities in Access to Service**

In this section, the Olmstead Plan mentions the measureable differences in access to services between white people with disabilities and people of color with disabilities. This is also true of the education system. Disproportionality is well documented in schools, where children of color receive an increased number of and harsher punishments for the same behaviors exhibited by white children. This means children of color are more likely to be placed in homebound placements for behavioral reasons. They are also more likely to enter the juvenile justice system due to behavioral challenges at school, beginning the process of the school to prison pipeline. To address disparities in outcomes for individuals of color with disabilities, the Olmstead Plan must ensure these individuals receive equitable educational opportunities as well. This is particularly true in special education services

### **Priority Area 11: Use Data for Quality Improvement**

Data on the educational services for children and youth with disabilities, especially data on the use of homebound and modified-day, are poor. Some data have been taken due to advocacy by Disability Rights North Carolina, but it has not been consistent or sufficient. Additionally, it is not disaggregated by important variables such as race, the infractions leading to restrictive placement, and more. Improved data collection on educational services is critical in understanding the true opportunities for community inclusion for children and youth with disabilities.

### **Recommendations to Remove the Barriers to Special Education to Prevent Institutionalization for Children and Youth with Disabilities**

As can be seen with the above examples, the Olmstead Plan could be improved by addressing the many barriers students with disabilities and their families face in accessing effective special education. Below are a number of recommendations for how to address these issues. Recommended strategies are organized according to the categories of policy changes, capacity building, improved funding, and data collection and analysis.

#### **Recommended Policy Changes**

As stated repeatedly, a full day of effective education in a school is essential to all children and youth's success, and even more essential for children and youth with disabilities. Schools offer critical supports to students and their families, especially for high acuity children and youth with disabilities who have needs that exceed the capacity of most school settings. State and federal policy recognizes the importance of a stable school experience for these individuals. However, due to a variety of reasons addressed below, schools overly rely on inappropriate and unproductive responses to these students such as homebound and modified-day placements, seclusion, mechanical and chemical restraint, and involving law enforcement. Not only are these responses unproductive, they often exacerbate the issues by preventing these children from the progress and full school day to which they are entitled. Without the supports a full day of effective education affords, these children and youth become further isolated, lose essential skill instruction, have an increase in mental health challenges, and enter institutionalized placements at higher rates. In order to decrease the use of institutionalized placements, it is recommended that North Carolina work to implement policies that accomplish the following:

- End the use of homebound and modified-day for students with disabilities
- Discontinue the use of mechanical restraint, chemical restraint, and seclusion in response to challenging behaviors exhibited by students with disabilities
- Decrease the number of students in the legal system by reserving the use of law enforcement, including school resource officers, to situations that present a significant likelihood of imminent harm to others or significant criminal activity (e.g., selling drugs on school property)
- Work with advocacy organizations such as Disability Rights North Carolina to develop and implement district wide guidelines on alternatives to the use of seclusion and restraint to manage challenging behavior for students with disabilities and/or mental health challenges
- Include educational experts on Olmstead Planning. This should include experts in special education and representatives from relevant organizations (e.g., the

Department of Public Instruction, the education team from Disability Rights North Carolina, Exceptional Children Assistance Center).

### **Recommended Strategies to Build Educational Capacity**

Schools often struggle to support children with the most complex needs. These children often have needs exceeding the training of public school employees. To support them and provide them the effective education they are entitled to, professionals require highly specialized training that goes beyond what is available for special education teachers and other school support personnel such as counselors, social workers, and school psychologists. To improve the capacity of educational professions to serve high acuity children and youth with disabilities, the state of North Carolina should enact the following:

- Require registered behavior technician training for special education teachers and paraprofessionals who work with students with disabilities and challenging behaviors
- Require training and education about disabilities, common manifestations of disabilities in school settings, and crisis de-escalation and intervention for professionals who are responsible for interacting with students with disabilities who exhibit challenging behaviors. This includes law enforcement and school resource officers.
- Require training for school administrators and general education teachers on special education law, evidence-based instruction for students with disabilities, and what “meaningful progress” (Endrew, 2017) looks like as depicted through the progression of annual individualized education programs
- Require training for administrators, general education teachers, and special education teachers on inclusion practices
- Require training for administrators and special education teachers on the need to include in individualized education programs both annual goals and behavior intervention plans stemming from an evidence-based functional behavior assessment (IDEA, 2004; North Carolina Policies Governing Services for Children with Disabilities) that directly targets challenging behaviors exhibited by students that interfere with their progress
- Require training for administrators and teachers to document it as a suspension any time they have a student leave the school early due to challenging behaviors
- Require training for administrators and educators of students with disabilities on the least restrictive environment to ensure the continuum of placements is adhered to. This includes considering specialized placements (e.g., specialized private schools) as an alternative to students being educated in homebound and modified-day

placements, hospitalized and therapeutic settings (e.g., day treatment), and institutionalized settings (e.g., psychiatric residential treatment facilities, residential settings with schools overseen by the Department of Health and Human Services)

- Require linkages between behavioral health settings and schools so that children have appropriate discharge planning to the educational setting

### **Recommendations for Improved Funding**

High acuity children and youth with disabilities often require supports that are unavailable in most school settings, including those supports that are available in specialized classrooms and public separate schools. Due to the level of specialization required, these supports can carry considerable costs that present a barrier to public schools investing in them. In order for these children to fully access the free appropriate public education they are entitled to by state and federal policy, and thereby access greater stability and success within the community, additional funds should be allocated towards these critical placements and supports.

- Create a fund to reimburse public schools districts for students whose individualized education programs require extraordinary costs to implement
- Fund positions to hire board certified behavior analysts to work within school districts to support students with disabilities who exhibit challenging behaviors
- Develop and fund the full continuum of placements as identified in the North Carolina's Policies Governing Services for Children with Disabilities and the Individuals with Disabilities Education Improvement Act (2004). This includes placement in specialized private special education schools (IDEA sec 300.325, NC 1503-5.2) and extended school day programming (NC 1506-1.5(a)(2)(C))
- Increase the pay of paraprofessionals to the equivalent of \$15 per hour, which is commensurate with the planned pay increase for direct support professionals providing community based services

### **Recommendations for Improving Data Collection and Analysis**

Access to effective educational settings is a critical element of a child or youth's success, both for long-term success and short-term stability. It can be difficult to track the educational placement of high acuity children and youth with disabilities due to their inability to find a stable educational placement. Their profile and accompanying challenging behaviors often result in restrictive educational placements (e.g., homebound and modified-day, isolated in a classroom with no access to peers, psychiatric residential treatment facilities, day treatment, prolonged in-patient stays in the emergency department) that prevent them from accessing a full day of school and/or educational services that

produce substantial progress. Additionally, these individuals can often transition quickly between restrictive educational placements, making tracking those educational settings difficult. To better understand how many and which children and youth are unable to access their full educational entitlement, a data collection and reporting system is needed. As such, North Carolina should:

- Track and analyze on a regular basis the number of new and continued homebound placements, modified day placements, hospitalized and/or therapeutic placements including day treatment settings, and institutionalized placements including psychiatric residential treatment facilities and residential settings with schools overseen by the Department of Health and Human Services .
- Disaggregate data by gender, race, ethnicity, disability, grade level, school within a local school administrative unit, and whether the student has an IEP or a section 504 (29 U.S.C. § 794) plan
- Change reporting practices to record students in therapeutic and institutionalized settings as hospitalized placement. These include day treatment, in-patient hospitals, psychiatric residential treatment facilities, and residential settings with schools overseen by Department of Health and Human Services.
- Keep students in hospitalized and institutionalized settings enrolled in their home district to ensure their district remains involved in their case and prepares for transition upon discharge from those settings.
- Develop robust monitoring and reporting systems to ensure data is being collected, analyzed, and reported on the use of: (a) seclusion; (b) restraint of any kind including physical, mechanical, and chemical restraint; and (c) suspension, including calling parents to pick up children early.

### **Summary Comments**

In closing, we at Melmark Carolinas commend the Olmstead Plan in its mission and vision to improve the services for individuals with disabilities so they can avoid unnecessary institutionalization and enjoy access to inclusive communities. This is the precise work that we at Melmark have been engaged in for decades, as our various service models work to both divert high acuity individuals with disabilities from requiring institutionalized care and transition those who are placed in institutions back into the community.

With that being said, when it comes to supporting children and youth with disabilities in their communities, we believe the Olmstead Plan has a serious omission in that it does not address the barriers these individuals face in accessing their education. The centerpiece of supports for children and youth in general is their education. In North Carolina, high acuity children and youth with disabilities, those who are at the greatest risk of institutionalized placement, are often excluded from accessing effective special education and from even

entering their public school. This is due to a number of reasons including inadequate policies, lack of capacity, lack of funding, and poor data collection and analysis.

Focusing on improving the educational access and quality for these individuals would dramatically strengthen the Olmstead Plan and improve the chances that high acuity children and youth with disabilities avoid institutionalization. This is because they would be able to learn the skills necessary for them to be successful in community settings, receive essential therapies, and access peer and social groups that are otherwise unavailable. Additionally, their families would be able to depend on them receiving appropriate support throughout the day, thereby allowing them to get a needed reprieve so that many could enter the labor force and enjoy greater economic and housing stability.

Due to these reasons, we urge those responsible to reconsider this oversight and include recommendations that address the educational system in the Olmstead Plan. In order for children and youth with disabilities to truly achieve success in inclusive communities, there is no more important area to focus on than the education system.

Sincerely,



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