



GUIDING SPECIAL-NEEDS STUDENTS AND FAMILIES FROM SCHOOL INTO ADULT LIFE

BY ROSA CIRIANNI

Ryan D. at Turtle Back Zoo with New Concepts for Living. The nonprofit, headquartered in Paramus, has two day program centers and offers community and medically-supportive residences for individuals 21 and older with intellectual and developmental disabilities.

For families with special-needs children, the reliability of a public school system's programs and professional support can be a vital resource. However, when their children grow up and no longer qualify for those services, many families say they feel lost and overwhelmed.

That is when school districts can help bridge the gap, by offering information and encouraging families to plan early — years in advance — so guardians caring for individuals with intellectual and developmental disabilities (ID/D) who are 21 and older can access support when they need it.

"Parents call me all the time and say, 'I feel like, all of a sudden, I'm on an island by myself.' It's a lot different than what they're used to. They've lost the support of the school district that they've been in for a very long time," said Lisa Marshall, member of the Warren Board of Education and the Sussex County Special Educational Services Commission Board of Directors.

"They trust the teachers, they trust their case managers, and now they're all gone, and they're

not helping them anymore. So, the transition is very, very difficult, and then you enter a program where you have to navigate it yourself," Marshall added.

That transition takes many special needs students from their school district or contracted services to adult systems, which may include residential or day programs, or funds given to their legal guardians for direct care. While federal and state guidelines require transition planning to begin early, some experts say that they find many families are not prepared when the time comes.

SCHOOLS PLAY A CRITICAL ROLE Districts help by setting transition goals through Individualized Education Programs (IEPs). In New Jersey, public schools are legally required to help stu-

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dents with disabilities prepare for life up to age 21. This is part of special education law under the Individuals with Disabilities Education Act, which ensures “all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.” If a student is born with autism or a congenital disability, they can be registered by a hospital, a doctor or a medical professional, which may allow them to be eligible for Special Child Health Services Case Management.

As a case manager for the Warren County Case Management Registry System, Marshall said she talks to caregivers about devising a feasible roadmap for their ID/D loved one’s future. Transition planning is required in a student’s IEP by age 14. But advocates say the quality of those plans can vary. An important caveat: Once a student with special needs accepts a high school diploma, they are no longer eligible for support. However, they may still participate in a graduation ceremony.

“By law, they have to have a transition plan, but it needs to be a plan,” said Marshall, who sits on the New Jersey School Boards Association’s Special Education Committee. “Not ‘my child likes video games.’ What are we actually working toward?”

Too often, she said, plans are vague or unrealistic and fail to match a student’s abilities with meaningful post-school opportunities. Although school districts are not responsible for managing a student’s adult life, they are responsible for preparing them for it.

“The school’s job is to educate them and get them on that path,” she said. “The parents’ job is to make sure supports are in place.”

That distinction can leave families navigating complex systems on their own, including Medicaid eligibility, vocational programs, power of attorney, guardianship and long-term financial planning, including establishing special needs trusts and an NJ ABLE account, which is a N.J. Division of Disability Services tax-advantaged savings program so people with disabilities can save and invest money without jeopardizing their eligibility for public benefits.

TRANSITIONS INTO ADULT CARE In the Garden State, many agencies offer community housing,

Key questions board members can ask regularly:

- Do we have a designated transition coordinator or accountable staff? Who?
- What transition programs exist for 14–21, and how do they link to adult services?
- How do IEPs include measurable, realistic post-school goals tied to community supports?
- What are the age 18 to 21 options (in-district, regional partnerships, county services, etc.) available?
- What data do we collect on post-school outcomes (employment, day programs, residential) and improvement plans?
- How is funding for transition allocated? Have we pursued extraordinary aid or cost-effective in-district solutions?
- How do we ensure family engagement and accessible outreach (language/culture)?
- How often does the district director of special services report on transition program effectiveness?

Possible board requests/actions:

- Annual “Transition Audit” presentation (program inventory, budget, staffing, outcomes).
- Require Director/Special Services to present a plan for students likely to need adult services.
- Require documentation that IEPs for ages 14+ include transition goals and assigned transition contact.
- Approve periodic parent-focused transition workshops and networking events.

sometimes referred to as group homes, and day programs for adults with intellectual and developmental disabilities (ID/D). Some are willing to help families navigate the transitions from the public school system to adult care.

“We are just an example of what’s available out there. We’re certainly the exception,” said Steve Setteducati, CEO of New Concepts of Living in Paramus, N.J. “Unfortunately, I think what they find, is a lot of these day programs are not so welcoming. They’re not so open. They don’t have time. They don’t return phone calls, which I don’t understand. Whether we’re going to take someone or not, we always welcome them in, and we always try to give them as much information as we possibly can—whether it’s good news or bad news,

but it seems that there's not a lot of that out there."

NCFL is a nonprofit that runs an 81,500-square-foot Achievement Center day program in Paramus, a smaller center in Rochelle Park and 23 community residences, some of which are designed for medically-fragile individuals. Two more homes and 15 apartments are planned for later this year. All of them are located in Bergen County, which will accept people from throughout the state.

"I recommend seeing as many programs as you like. We're certainly happy to sit with most anyone and talk to them about our program and other resources out there. But really, just getting familiar with your options is probably the best advice you can give any guardian," said Deena King, NCFL intake manager.

NCFL has had school transition teams and ID/DD adults aged 18-21 with their guardians visit their centers. The agency also is considering hosting seminars for transition teams to provide education about the process. The NCFL Achievement Center offers physical therapy, speech therapy and occupational therapy all under one roof in a

state-of-the-art building. Plus, it has multiple sensory rooms, a Town Square center for classes like karate and events such as its annual Halloween party and prom. It also offers life-skills areas for teaching cooking, ingredient and grocery shopping, and laundry; a robust community outing calendar; and plans to build a specialized indoor aquatic therapy center.

QUESTIONS BOARDS SHOULD BE ASKING Local boards of education play a key oversight role, even if they do not run day-to-day programming. According to advocates, board members should focus on one central question: "What is our district doing to prepare students for life after age 21?"

"That's the number one question every board should ask," said Marshall, who shared that she also has personal experience with IEPs. "That's the transition period. If the answer is, 'We have one program for everyone,' I would question that."

School officials seeking more direction can call their county special education specialist or contact New Jersey School Boards Association.

"The school doesn't have to know everything," Marshall added. "But they need to know where to send people."

Marshall recommends districts avoid a one-size-fits-all approach and instead tailor programs to each student. She suggested boards request a presentation from their special services department to learn more about what is being offered.

INDIVIDUALIZED PLANS ARE CRITICAL Marshall gave an example of one student who struggled with traditional academics, but enjoyed baking.

"They were trying to teach him fractions," she said. "But, he wasn't going to learn that way."

Instead, educators incorporated measurements into baking activities. The student now participates in a daily program centered on that skill. Families can ask for measurable, realistic vocational and life-skills goals tied to community experiences for their students who may visit work sites, attend college classes and build social skills by being out in the community.

"You find what excites them," she said. "And you build around that. Just like any other student, you want to make them a productive member of society. Whatever that looks like for them."

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Family Transition Toolkit: From School to Adult Life

School districts can offer special-needs families guidance on resources for their loved ones as they transition out of school services at age 21. For eligibility into the state system of care for IDD adults, families are advised to start the process by age 14.

- Apply for care under the New Jersey Division of Developmental Disabilities
- Confirm Medicaid eligibility requirements
- Apply for Social Security
- Choose a support coordinator
- Connect with your county case management unit for local program lists, benefits counseling, etc.
- Tour day programs
- Get on community housing lists
- Build independent living skills, if appropriate

For more information, visit the N.J. Department of Education's The New Jersey Transition Toolkit at www.nj.gov/education/specialed/programs/njtransition/