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'Autistic' Or 'Person With Autism'? It Depends

Reprinted from DisAbility Scoop | December 2, 2022 by Michelle Diamant

New research dives into the heated debate surrounding the language of autism and finds that preferences about how to describe those on the spectrum vary substantially depending on who you ask.

In a study of 728 autism stakeholders, researchers sought to examine whether the term “autistic” or the phrase “person with autism” holds favor in the U.S.

Traditionally, there has been a push in the autism community toward person-first language, such as “person with autism,” in order to emphasize the strengths of the individual rather than their disability.

However, more recently, many self-advocates have started to favor so-called identity-first language — terms like “autistic” and “disabled” — as a means to embrace that the disability is an inherent part of who they are.

For the study, researchers surveyed 299 adults with autism, 81 parents of those on the spectrum, 44 family members or friends, 207 autism professionals and 97 people with no ties to the autism community.

The vast majority of adults with an autism diagnosis — 87% — preferred identity-first language such as “I am autistic” to describe themselves, according to findings published recently in the journal *Autism*.

Notably, however, the study authors point out that this leaves a “sizable minority” of individuals with autism who chose person-first language.

A majority of parents liked identity-first language best. But the trend flipped for the autism professionals and the friends and family members surveyed. People in these groups were more likely to prefer person-first terms while those with no affiliation to the autism community were pretty evenly split on whether to use person-first or identity-first language.

The takeaway, the researchers said, is how important it is for individuals to ask what members of the autism community prefer. “Although the majority of autistic adults preferred an (identity-first language) term, with a clear preference for ‘I am autistic,’ there are others who prefer person-first terms. As with the move toward the use of inclusive language regarding gender identity and respect for a person’s personal pronouns, so too should we be mindful of the ways that individuals in the autism community prefer to communicate about their identity,” wrote Amanda Taboas, Karla Doepke and Corinne Zimmerman at Illinois State University in their findings.

“Despite the absence of consensus, there exists a clear trend toward embracing autism as an identity along with identity-affirming descriptors,” the study authors concluded.

Trouble Staffing Special Education Services Leaves Students With Limited Options

By Savannah Tryens-Fernandes, AL.com/TNS | reprinted from DisAbility Scoop December 2, 2022

BIRMINGHAM, Ala. — Brooke Hilyer had few options left for her son Logan's education.

Last spring before Logan graduated elementary school, Hilyer was told by Elmore County Schools that her local middle school, Holtville, did not have a special education class available for children with multiple disabilities. "The short version of what we're experiencing is what we keep hearing from the county — there's a teacher shortage and they don't have the resources to provide a (class) for my son at our local school," Hilyer said.

According to the district, there weren't enough teachers and specialists for every school to have a class for students with more complex needs. And although there are other special education programs within most schools, the district is determined to keep class sizes manageable for teachers.

Due to staff shortages, students with multiple disabilities are instead bused to Millbrook Middle School. Millbrook is further away, requires a bus ride and is less convenient for Hilyer, who works at Holtville.

Hilyer couldn't get her son to ride a bus to Millbrook. He has autism, which makes it difficult for Logan to stay in place during the trip. He can't wear a harness on the bus, and because of her and her husband's work schedules, they couldn't drive him without being late to their jobs.

Beyond the difficulty in getting her son to the new middle school, she feared he wouldn't be prepared for more advanced instruction.

The pandemic was hard on Logan — and students with disabilities more widely. Research has shown that students with disabilities have scored lower on national assessments compared to their peers and have struggled increasingly with mental health and isolation. All the while, their special education programs are struggling to staff full-time teachers and related services personnel, making it difficult for their educational needs to be met.

Hilyer eventually decided to withdraw Logan from Elmore County. He now attends Bridgeway ABA, a program that provides intensive, one-on-one therapy to children diagnosed with autism.

The specialized program costs the family about \$400 a month out of pocket, with insurance covering the remaining costs. "You know, you do what you have to do for your child and it's not something I mind doing. I just shouldn't have to," Hilyer said.

What is hard for her is knowing her son won't get the socialization he's had with classmates he's gone to school with since kindergarten. "Just yesterday a little boy came up to me in the hallway and asked when is Logan coming back to school and I'm like, baby, I don't think he's gonna get to."

'The most complex needs'

Special education teacher shortages predate the pandemic and have long plagued schools both in Alabama and nationwide due to a combination of factors, namely the difficult conditions of the job. "The shortages we're seeing in special ed are not really due to a shortage of people going and getting trained," said Lauren Morando Rhim, executive director and co-founder of The Center for Learner Equity. "It's our attrition issue that is really the biggest and when you drill down on why special ed teachers are leaving, it is because special ed is siloed, teachers feel like their colleagues don't understand or value their work, they're asked to do too much and are spread so thin that they never feel any success."

According to the CEEDER Center at The University of Florida — which provides capacity building for teachers and school officials in an effort to help students with disabilities become more career and college ready — the number of fully-certified special education teachers has declined in the past decade.

Schools have seen larger student-teacher ratios in special education classrooms, declined enrollment in teacher preparation programs and a higher number of teachers being hired with emergency certifications, which are temporary teaching certificates granted to people who would not ordinarily meet criteria.

In Alabama, the state department of education began issuing temporary certifications for special education teachers in grades 6-12 this school year. The program allows someone with a bachelor's degree to be issued a one-year certificate if they are making progress toward completing required courses at one of three partner

According to officials at the state department of education, 76 people are enrolled in the program, but approximately 752 special education teachers were projected to be needed last school year. “There’s only one way to get teachers right now,” said Richard Dennis, superintendent of Elmore County Schools. “Steal them from your neighbors.”

Advocates like Morando Rhim are skeptical of these temporary measures and their impacts on students with disabilities. We’re really concerned about the mismatch of the children who have the most complicated, complex learning needs who are being taught by the teachers who are the least qualified,” Morando Rhim said.

A new report by The Center on Reinventing Public Education found that while virtually all students declined academically during the pandemic, students with disabilities were especially impacted.

According to the National Assessment of Education Progress (NAEP), students with disabilities’ math scores dropped by 8 points between 2020 and 2022, compared to 7 points for students without disabilities, and by 7 points in reading, compared to 5 points for students without disabilities.

Along with educational outcomes, evidence suggests that students with disabilities are experiencing increasing mental health concerns. Many families faced choices between health and in-person learning, oftentimes forgoing socialization with peers in order to keep children with medical conditions safe, according to the CRPE report.

‘Students are going to be at greater risk’

Paraprofessionals and related specialists such as occupational therapists, audiologists and speech-language pathologists also are in short supply.

“When we look at those related service providers, if they’re not there to support that student’s instruction, if those positions aren’t filled, then students are going to be at greater risk for not attaining educational standards, for not making progress within their (individualized education programs),” said Jeana Winter, executive director of the Alabama Parent Education Center, an organization that provides support to parents who have children with disabilities.

According to data provided by the Alabama State Department of Education, last school year districts across the state were projected to need 640 paraprofessionals, 1392 audiologists, 138 speech pathologists, 25 American Sign Language interpreters, 163 psychometric psychologists, 40 occupational therapists and 30 physical therapists.

The Alabama Disabilities Advocacy Program said clients without access to those specialists in classrooms can face profound impacts.

According to the organization, one of their clients can’t attend school because there is no nurse to administer their treatments. A few others that are homebound — meaning their disability makes it difficult to learn from school so instead they receive instruction at home — cannot get a homebound teacher and aren’t receiving instruction.

‘Communication is everything’

Students who are deaf or hard of hearing have been affected by large shortages of audiologists and ASL interpreters, roles that help students understand instruction.

“Communication is everything regardless of whether it’s oral language or sign language. If that language is not accessible to a student, it’s going to impede their ability to learn,” said John Mascia, president of Alabama Institute for the Deaf and Blind, which provides a number of residential schools and community-based programs for students who are deaf or blind.

“A kid could be super brilliant. But it would be like you speaking French to me if they don’t have an interpreter. The impact on these kids is that we can’t unlock their God-given talents if we don’t have a way to get complete and accessible communication to them.”

Kristen Wilburn requested her school, located in a rural district in the Black Belt, provide her kindergartner, who has cochlear implants, with an ASL interpreter.

The school district posted a job advertisement for a candidate to fill the position to help her child early in the summer, but as the school year approached, the role still had not been filled.

“Me and my family did have moments of panic for a couple of weeks,” said Wilburn. “I personally was trying to send out emails and post on social media trying to locate anyone that may be interested in the position.”

Local school districts in Alabama are responsible for filling their own job vacancies. Rural districts like Wilburn’s and Hilyer’s often experience the most difficulty because there is not a large pool of local candidates.

Certain specialists also often have to acquire licenses and certifications. Sign language interpreters must be licensed by the Alabama Licensure Board of Interpreters and Transliterators. Currently the state only has 293 people certified.

Frances Courson, professor of Deaf Studies & Deaf Education at the University of Montevallo, said the state does not have a standardized pay scale for interpreters and although there are teachers of the deaf and interpreters who are retired and willing to return to work, the state requires retirement benefits to be suspended. Many people are not willing to do that. "If the state would lift those requirements, these retired teachers and interpreters could help to fill some of the vacancies which would allow the schools to remain in compliance with Individuals with Disabilities Education Act," Courson said.

Wilburn's district couldn't find an ASL interpreter for her son and instead provided her with compensatory services, which are offered as an alternative remedy for students with disabilities when they are unable to receive the services they are entitled to in their IEPs

Wilburn's son received a teacher of the deaf and hard of hearing, who is specially trained to address his language development and academic needs and also provides ASL interpretation.

Wilburn said she gets nervous on days when the teacher of the deaf and hard of hearing is absent and no substitute is available — but otherwise the situation has "turned out pretty well."

But for other families across the country, compensatory services are often hard to attain.

According to the report by the Center on Reinventing Public Education, "an untold number of families are still waiting for compensatory services to make up for what students lost earlier in the pandemic. Many are not even aware they qualify."

As a result of the lack of available services and the pandemic, more families with children with disabilities are turning to alternative schooling options nationally, according to CRPE.

The Alabama Institute for Deaf and Blind's enrollment has remained steady, officials said, but programs there too have dealt with staff shortages "Lack of personnel and trained teachers is one of the biggest obstacles and barriers that we're dealing with currently," said Mascia of AIDB. "Many candidates just are not ready to really take on the stress and the complexity of many of our children. These kids can and do learn every single day, but they need well trained and motivated professionals that are willing to work really, really hard."

A better community

Alabama offers no incentives like bonuses to specifically hire more special education teachers and related services personnel. There are also no statewide programs in place beyond the temporary teacher certification.

Certain districts, like Birmingham City Schools, are offering bonuses up to \$10,000, but so far the state has only put forward budget proposals that will be voted on in 2023.

State Superintendent Eric Mackey, who has identified special education as a priority area, is pushing for nearly \$100 million in additional spending and will put forth a proposal to that effect to the state legislature when their session opens in January.

On top of increases in recent years designed to fill the gap between what federal funds pay for and the actual cost of educating children with disabilities, Mackey wants \$68 million to pay annual \$5,000 stipends to special education teachers.

The budget proposal also includes \$37.6 million for state-funded preschool programs for children with disabilities, up from \$17.6 million as well as an \$8.5 million program to fund grants for certified behavior analysts for students with autism that would pay for an analyst in nearly every school district.

But until the budget passes and more resources are put into special education programs, advocates remain concerned about the long-term impacts of the pandemic on students with disabilities and how they will be remedied. "Ultimately we're going to see our students with disabilities are going to be some of the most disadvantaged students because they may not be able to recover that lost progress if there's not qualified instruction," said Winter of the Alabama Parent Education Center, who previously was also the chair of Special Education Advisory Panel, which provides policy recommendations to the Alabama State Department of Education. "We're better as communities when students exit school and are qualified to live, learn and work independently," she said. "It's a lot for the school system to bear but they are the ones responsible to educate students which prepares them to contribute to their communities."

From Norman's Desk

Last month much of the nation east of the Mississippi River experienced a severe winter storm. Many states had widespread power outages, deep, snow, and severe icing. New York had at least 30 storm-related deaths with other states reporting other deaths. History shows that these deaths will probably be people with disabilities or seniors.

New Jersey lucked out with this storm as a “blocking high” over Greenland stopped the significant snow and ice from reaching our area. High winds did bring down powerlines, however, but compared to Kentucky and Tennessee, our area fared well with only scattered outages.

In the aftermath of this storms, the proverbial “20-20 hindsight” experts are questioning why people were not better prepared. Yet their pontificating never goes beyond the “should have” to talk about the realities of living on a fixed income, having a disability, or relying on other people for activities of daily living.

One person on Twitter pushed back on the “should have commentary” by tweeting “having a seven day supply of food is a luxury for many people.” True.

Yet being prepared as best as circumstances permit is everyone’s responsibility—especially if a disability is involved. Nobody understands the circumstances, needs, and solutions better than that person. So, how is this natural conflict between the need to prepare versus the capacity to prepare?

The Chicago-based Do One Thing, Inc., suggest just that. Do One Thing per month to prepare. For example, the next time you go to a party store pick up some party light sticks. Just because they are meant for parties and kids doesn’t mean they are can’t be used in power outages. A little creative thinking, a trait that most people with disabilities use to be independent, can solve many preparedness issues.

It is long past the time to think about extended power outages in winter and summer. Some suggestions:

- Have emergency supplies on hand before storms occur if possible.
- Flashlights, extra batteries, pre-charged power packs
- Portable, battery-operated radio and extra batteries.
- One-week supply of food to include items that do not require refrigeration or cooking in case the power is shut off.
- Store drinking water, first aid kit, canned/no-cook food, where you can get them easily, even in the dark.
- Non-electric can opener
- One-week supply of essential prescription medications.
- Extra blankets.

Information during weather emergencies can be obtained from the Emergency Broadcast System through these radio stations for Mercer County:

WPST - 97.5 FM
 WHWH - 1350 AM
 WKXW - 101.5 FM

In all of these situations, *prepare* for aides and personal assistants to be late, not show, or to be stuck in your home. All of these scenarios should be discussed and planned for by people who are dependent on aides or personal assistants.



‘Impending Intergenerational Crisis’: Americans With IDD Lack Long-Term Care Plans

By Sam Whitehead, Reprinted from Kaiser Health News | December 7, 2022

Thinking about the future makes Courtney Johnson nervous. The 25-year-old blogger and college student has autism and several chronic illnesses, and with the support of her grandparents and friends, who help her access a complex network of social services, she lives relatively independently in Johnson City, Tenn.

“If something happens to them, I’m not certain what would happen to me, especially because I have difficulty with navigating things that require more red tape,” she said.

Johnson said she hasn’t made plans that would ensure she receives the same level of support in the future. She especially worries about being taken advantage of or being physically harmed if her family and friends can’t help her — experiences she’s had in the past. “I like being able to know what to expect, and thinking about the future is a bit terrifying to me,” she said.

Johnson’s situation isn’t unique. Experts say many people with intellectual and developmental disabilities do not have long-term plans for when family members lose the ability to help them access government services or care for them directly.

Families, researchers, government officials and advocates worry that the lack of planning — combined with a social safety net that’s full of holes — has set the stage for a crisis in which people with disabilities can no longer live independently in their communities. If that happens, they could end up stuck in nursing homes or state-run institutions.

About one-quarter of adults in the U.S. live with a disability, according to the Centers for Disease Control and Prevention. Nearly three-quarters of Americans with disabilities live with a family caregiver, and about one-quarter of those caregivers are 60 or older, according to the Center on Developmental Disabilities at the University of Kansas.

But only about half of families that care for a loved one with disabilities have made plans for the future, and an even smaller portion have revisited those plans to ensure they’re up to date, said Meghan Burke, an associate professor of special education at the University of Illinois in Urbana-Champaign. “Engaging in it once is good, right? But you can’t only engage in it once,” she said. “It’s a living document, because things change, people change, circumstances change.”

Burke’s research has found several barriers to planning for the future: financial constraints, reluctance to have hard conversations, trouble understanding government services. Creating plans for people with disabilities also is a complex process, with many questions for families to answer: What are their relatives’ health needs? What activities do they enjoy? What are their wishes? Where will they live?

Burke has firsthand experience answering those questions. Her younger brother has Down syndrome, and she expects to become his primary caregiver in the future — a situation she said is common and spreads the work of caregiving. “This is an impending intergenerational crisis,” she said. “It’s a crisis for the aging parents, and it’s a crisis for their adult offspring with and without disabilities.”

Nicole Jorwic, chief of advocacy and campaigns for Caring Across Generations, a national caregiver advocacy organization, said the network of state and federal programs for people with disabilities can be “extremely complicated” and is full of holes. She has witnessed those gaps as she has helped her brother, who has autism, access services.

Medicaid pays for people to receive services in home and community settings through programs that vary state to state. But Jorwic said there are long waitlists. Data collected and analyzed by KFF shows that queue is made up of hundreds of thousands of people across the country. Even when people qualify, Jorwic added, hiring someone to help can be difficult because of persistent staff shortages.

Jeneva Stone’s family in Bethesda, Md., has been “flummoxed” by the long-term planning process for her 25-year-old son, Rob. He needs complex care because he has dystonia 16, a rare muscle condition that makes moving nearly impossible for him.

Stone said her family has done some planning, including setting up a special needs trust to help manage Rob’s assets and an ABLE account, a type of savings account for people with disabilities. They’re also working to give Rob’s brother medical and financial power of attorney and to create a supported decision-making arrangement for Rob to make sure he has the final say in his care.

Alison Barkoff is acting administrator for the Administration for Community Living, part of the U.S. Department of Health and Human Services. Her agency recently released what she called a “first ever” national plan, with hundreds of actions the public and private sectors can take to support family caregivers.

“If we don’t really think and plan, I’m concerned that we could have people ending up in institutions and other types of segregated settings that could and should be able to be supported in the community,” said Barkoff, who noted that those outcomes could violate the civil rights of people with disabilities.

She said her agency is working to address the shortages in the direct care workforce and in the supply of affordable, accessible housing for people with disabilities, as well as the lack of disability-focused training among medical professionals.

But ending up in a nursing home or other institution might not be the worst outcome for some people, said Berns, who pointed out that people with disabilities are overrepresented in jails and prisons.

Berns’ organization, The Arc of the United States, offers a planning guide and has compiled a directory of local advocates, lawyers and support organizations to help families. Berns said that making sure people with disabilities have access to services — and the means to pay for them — is only one part of a good plan.

“It’s about social connections,” Berns said. “It’s about employment. It’s about where you live. It’s about your health care and making decisions in your life.”

Philip Woody feels as though he has prepared pretty well for his son’s future. Evan, 23, lives with his parents in Dunwoody, Ga., and needs round-the-clock support after a fall as an infant resulted in a significant brain injury. His parents provide much of his care.

Woody said his family has been saving for years to provide for his son’s future, and Evan recently got off a Medicaid waitlist and is getting support to attend a day program for adults with disabilities. He also has an older sister in Tennessee who wants to be involved in his care.

But two big questions are plaguing Woody: Where will Evan live when he can no longer live at home? And will that setting be one where he can thrive?

“As a parent, you will take care of your child as well as you can for as long as you can,” Woody said. “But then nobody after you pass away will love them or care for them the way that you did.”



Community-Based Services Should Be Mandatory Medicaid Offering, Federal Agency Says

Reprinted from DisAbility Scoop by Michelle Diament | December 13, 2022

An independent federal agency is warning President Joe Biden and Congress that urgent action is needed to shore up the nation's home and community-based services system.

A report from the National Council on Disability finds that weaknesses in home and community-based services directly contributed to "needless deaths" among people with intellectual and developmental disabilities during the COVID-19 pandemic.

With limited investment in home and community-based services, the report notes that people often spend years on waiting lists and, during the worst days of the pandemic, those living in institutional settings typically had no alternative.

"For many people with disabilities during the pandemic, congregate settings had a devastating impact," said Andrés Gallegos, chairman of the National Council on Disability, which is charged with advising the president and Congress on disability issues. "In many instances, social distancing wasn't achievable and the inability to transition out of such a setting became a death trap."

Currently, there are 820,000 people with disabilities on waiting lists for home and community-based services across the nation, according to the report, but demand for such services may be much greater. NCD found that 14 million Americans need community-based services, 40% of whom are under age 65. As a result, the agency said that people under age 30 account for the fastest growing group of nursing home residents.

"Severe shortages of direct care workers and available affordable, accessible housing are just two examples are longstanding fragilities in the HCBS ecosystem," Gallegos said. "The neglect in addressing these matters led to the preventable deaths of scores of Americans with disabilities and will again if policymakers don't act."

The National Council on Disability is calling on Congress to enact legislation within the next year making home and community-based services a mandatory service under Medicaid and add significant funding to the program, among other changes.

