What Matters Most: Toward a Future of Flourishing

The following is a keynote speech given by Erik W. Carter, Vanderbilt University.

Good morning! It is an honor to be at this gathering, especially at this time—among advocates and allies from all across the country who are so deeply invested in ensuring people with severe disabilities and their families can truly thrive in all aspects of life. Professionally, I have been raised in TASH—always enamored with its vision that communities are incomplete without the presence of people with disabilities, captivated by its pursuit of pathways no one thought possible, and compelled by its commitment to weaving values, research, and advocacy in powerful ways.

TASH has long been a home for both innovators and instigators; for both preachers and practitioners; and for people who see yesterday's progress as the prelude to today's change. We are all working in tandem to change the landscape alongside people with severe disabilities. So I am humbled to be part of this 40th birthday celebration.

As Barb Trader shared, my own research and teaching focuses primarily on equipping young people with severe disabilities with the skills, supports, opportunities, and relationships that enable them to transition well to all that lies ahead after graduation—to a good life, to an enviable life. And so in my brief time with you today, I want to focus on how we might create a future of flourishing during throughout this period of transition. A future of flourishing for the more than 1 million students with intellectual and developmental disabilities attending schools across the country. And a future of flourishing for TASH, an organization that remains committed to seeing (and spurring) this journey to completion.

Adulthood—with all of its opportunities and challenges—is coming. Children with disabilities grow up. Our collective efforts as a field must much more closely reflect and better support

this recognition. Because it is the expectations we hold, the opportunities we provide, the services we deliver, the supports we arrange, and the relationships we forge that will make the difference between those young people who find a future of flourishing and those whose aspirations go unfulfilled. Our investment—individually and collectively—is an important part of what matters most to the young people we serve.

As we help young people with disabilities navigate these transitions, what commitments should characterize our efforts? What investments should we make to enable young people with severe disabilities to truly flourish through high school and beyond? Let me highlight ten modest ideas.

1. Universal Aspirations

The first may be most important: We must be led by the aspirations of young people. Our starting assumption must be that there is no separate set of dreams for young people with severe disabilities. Put yourself back in high school. And think about how you might have answered that perennial question: What are you looking forward to most about life after high school? As young people on the brink of adulthood, we all had great excitement about the future. And probably some nervousness about what comes next. But I bet you had hopes of living the "good life," however you defined that for yourself. You envisioned a future of flourishing.

The very same is true for young people with severe disabilities. Here is my very simple point: *The presence of a disability is not a reliable predictor of people's aspirations for their lives.* Young people with labels of severe disability want the very same things—a satisfying job, close relationships, a comfortable and safe place to live, a college degree, involvement in their community, friends they can count on, a reliable way to get around, a chance to give something back, and an opportunity to be part of a caring community. The presence of a disability simply is not a reliable predictor of what young people with disabilities want for their lives.

I suspect your own conversations with adolescents affirm what research confirms:

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◆ More than three-fourths (78%) of all high school students with intellectual disability have a goal aimed toward work in the community[1]. Young people do not have dreams of underemployment or unemployment, they do not aspire to piece-rate wages, and they do not say they envision for themselves a lifetime of exclusion from the workforce.

◆ More than half (51%) have a transition goal to live independently in the community[2]. They do not have dreams of living in congregate settings (unless it is a college dorm) and they envision much more than a life on the couch.

◆ More than four-fifths of (84%) of adults with disabilities consider involvement in a community of faith important aspect of their lives[3]. They do not want to be the focus of ministry or on the peripheries of congregational life, they want to be the ones serving and leading.

◆ More than one-third (35%) of all high school students with an intellectual disability have a transition goal to attend some type of post-secondary educational institution[4]. They do not want to miss out on lifelong learning opportunities, tailgate parties, and a real career pathway.

We must be driven by the aspirations of young people.

2. Expectations Matter

Second, *our* expectations must match *their* aspirations (and perhaps exceed them). The most powerful force in changing transition outcomes may just be the *expectations* parents, professionals, and others hold. Our history has shown this. TASH and its members have long held expectations others thought impossible.

◆ When people wondered whether *certain* children could learn, TASH was certain they could. And proved it.

◆ When people wondered whether *certain* children should spend much time learning alongside their peers, TASH was certain they should…and could. And proved it.

◆ When people wondered whether *certain* adults would have anything meaningful to contribute in the workplace, TASH was certain they would. And proved it.

◆ When people wondered whether certain young adults could be trusted to be the leading influence in their own lives, TASH was certain they should…and could. And they proved it.

1 www.nlts2.org
2 www.nlts2.org
[3] National Organization on Disability. (2004). 2004 *NOD/Harris survey of Americans with disabilities*. Washington, DC: Author.
4 www.nlts2.org

Through a coordinated combination of research, advocacy, and innovative practices, members of this organization have consistently challenged prevailing views of what was possible.

Our expectations still matter now. In fact, they too are among the things that matter most. More than almost any other factor, *expectations predict outcomes*. Let me illustrate with a few findings from my own research. Let's take parent expectations. We found that young adults with severe disabilities whose parents expected them to obtain post-graduation work way back in high school were more than five times as likely to have paid, community employment within two years after exiting[5]. How about teacher expectations? We found that high school students with severe disabilities who had teachers who expected them to hold down a job were 15 times more likely to obtain that paid job in the community[6]. In the literature on evidence-based predictors, expectations consistently emerge as of foremost importance.

Why? Because expectations shape experiences. And helping families and professionals grasp a vision of a "the good life" early on changes the trajectories of young people, what they are taught, where they are taught, and with whom they are taught. But experiences also shape expectations. And so we find ways to support students to have success in areas even when others might think it impossible or implausible: general education courses, hands-on work experiences, and other inclusive activities may help parents (along with others in the community) catch a first glimpse of what might be possible when their son or daughter is provided the right opportunities, supports, and encouragement.

I would argue, though, that expectations are not just for individuals. They are also for communities. As a professional community, we must help hold those expectations high, especially for families who are exhausted from holding them on their own and for educators who stand all alone in their vision.

Our own expectations must exceed the aspirations of young people.

3. Elevating Outcomes is Our Goal

Third, we must see equipping young people to achieve these

[5] Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies, 23,* 50-63.
[6] Carter, E. W., Ditchman, N., Sun, Y., Trainor, A. A., Swedeen, B., & Owens, L. (2010). Summer employment and community experiences of transition-age youth with severe disabilities. *Exceptional Children, 76,* 194-212.

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aspirations as our central charge. As the purpose we pursue. In fact, this is the primary goal of special education services. Elevating outcomes is among the chief reasons we send students to school until age 18 or 22. The Individuals with Disabilities Education Improvement Act explains one of the purposes of special education just a few pages in: "...to prepare [students] for further education, employment, and independent living...." Elsewhere, our work as educators is anchored to a broader national commitment "...equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities." In my view, both are just jargon-filled ways of saying that our primary charge is to help young people with disabilities to flourish.

This means that one important barometer of the quality and effectiveness of special education and transition services is the extent to which young people with disabilities actually attain the outcomes they aim toward. In other words, the success of our work is judged not simply by what we write down on an IEP or transition plan, not merely by the services and supports we plan to deliver; but rather by the degree to which the goals students with disabilities have for life after high school actually materialize.
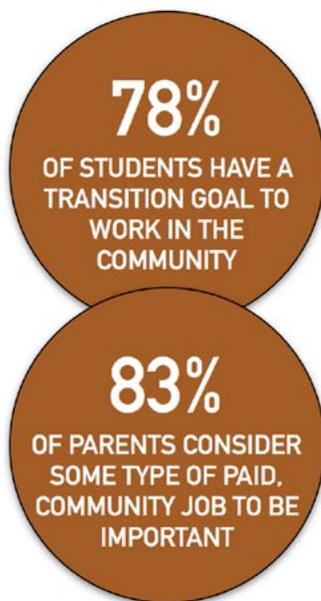
If this argument holds for you, we have much work to do. Despite 40 years of IDEA and 25 years of transition mandates, the gap between aspirations and outcomes remains far too wide.

◆ Up to two years after leaving high school, only one-quarter (26%) of young adults were working and almost half (43%) of those jobs are in segregated settings[7].

◆ Regardless of the source you reference, national employment rates for adults with ID tend to hover around 15-20%[8].
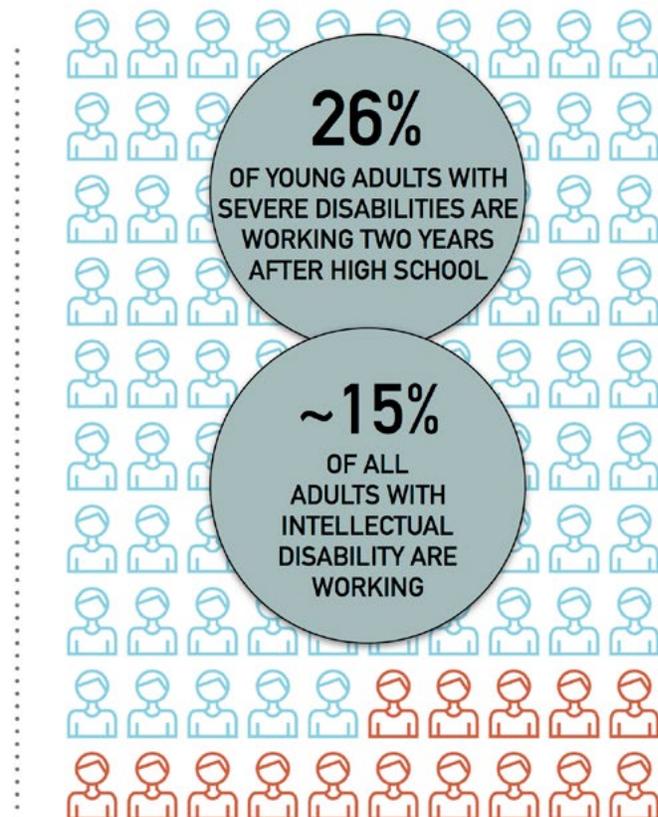
◆ Just 15% of students have enrolled in a postsecondary school

[7] Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies, 23,* 50-63.
[8] http://www.thinkwork.org

78%
OF STUDENTS HAVE A TRANSITION GOAL TO WORK IN THE COMMUNITY

83%
OF PARENTS CONSIDER SOME TYPE OF PAID, COMMUNITY JOB TO BE IMPORTANT

ASPIRATIONS

26%
OF YOUNG ADULTS WITH SEVERE DISABILITIES ARE WORKING TWO YEARS AFTER HIGH SCHOOL

~15%
OF ALL ADULTS WITH INTELLECTUAL DISABILITY ARE WORKING

EXPERIENCES

Sources: Butterworth et al. (2014); Blustein, Carter, & McMillan (in press); Carter, Austin, & Trainor (2012); www.nlts2.org

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within two years of leaving high school[9].

◆ Up to four years after leaving high school, only 14% of graduates with intellectual disability live independently or semi-independently in the community[10].

◆ Almost 130,000 adults with intellectual and developmental disabilities live in residential contexts with 7 or more people with disabilities[11].

◆ Less than one-half (48%) of adults with disabilities within the service system attended a religious service at any point within the past month[12].

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[9] www.nlts2.org
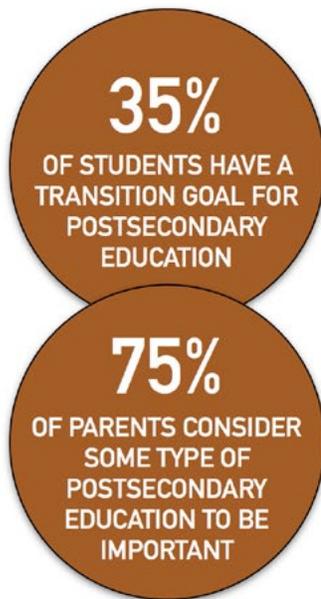[10] www.nlts2.org
[11] www.stateofthestates.org
[12] Carter, E. W., Kleinert, H. L., LoBianco, T. F., Sheppard-Jones, K. A., Butler, L. N., & Tyree, M. S. (2015). Congregational participation of a national sample of adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 53,* 381-393.

◆ Nearly one in three families (32%) have left their faith community because their son or daughter was not welcomed or included[13].

◆ The distance between aspirations and outcomes is the primary gap we must narrow.
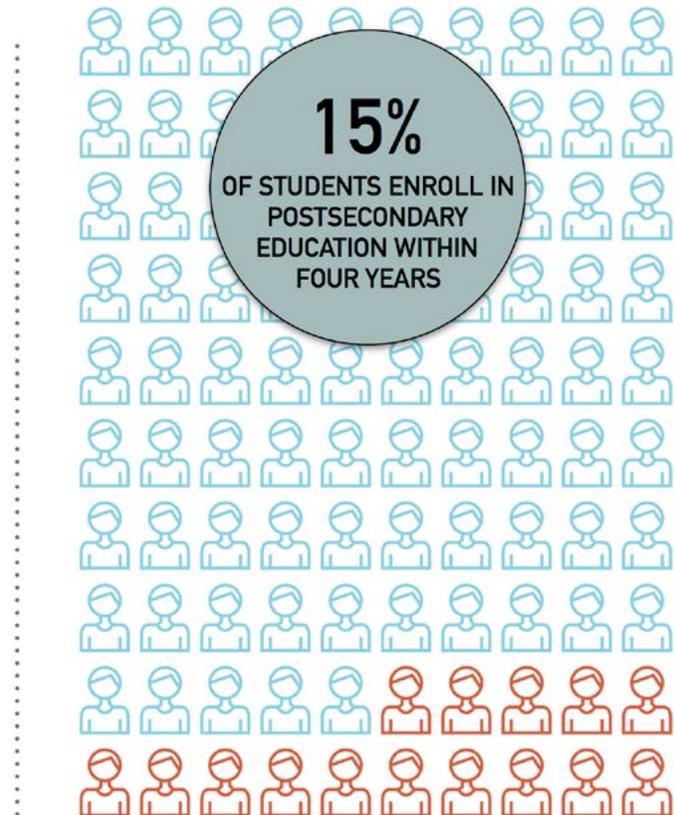
4. Changing our Introductions

Fourth, I am convinced part of changing outcomes has to involve changing our introductions. Think about how we so often talk and write about people labels of intellectual disability or autism within professional circles. It is often in terms of what someone cannot or struggles to do. We define by deficit. We diagnose based on difference. We rush to remediate. We publish primarily about problems. Such a message has inadvertent consequences.

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[13] Ault, M. J., Collins, B. C., & Carter, E. W. (2013). Congregational participation and supports for children and adults with disabilities: Parent perceptions. *Intellectual and Developmental Disabilities, 51,* 48-61.

35% OF STUDENTS HAVE A TRANSITION GOAL FOR POSTSECONDARY EDUCATION

75% OF PARENTS CONSIDER SOME TYPE OF POSTSECONDARY EDUCATION TO BE IMPORTANT

15% OF STUDENTS ENROLL IN POSTSECONDARY EDUCATION WITHIN FOUR YEARS

ASPIRATIONS

EXPERIENCES

Sources: Blustein, Carter, & McMillan (in press); Newman, Wagner, Cameto, & Knokey (2009); www.nlts2.org;

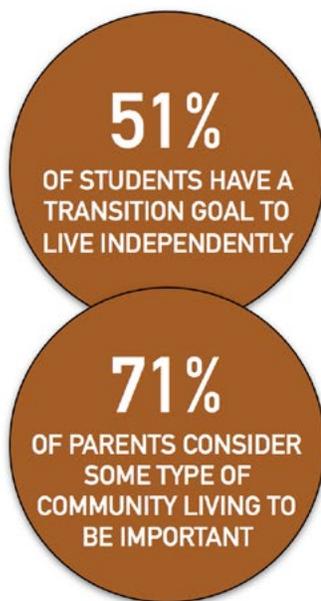*What Matters Most: Toward a Future of Flourishing*

For example, when an employer considers the question, "What would a person with Down syndrome have to contribute to this business?" or a youth ministry leader wonders, "How do we include a teenager with autism in our youth programs?", all they might have to work from is an image of what a person with that particular label cannot do. Frankly, that makes for a challenging introduction. It is hard to envision a place in a community for someone only on the basis of what people cannot or struggle to do. How we introduce people surely matters during the transition period. And how come to we know young people also matters.

The transition mandates within Individuals with Disabilities Education Improvement Act (IDEA) specifically state that services must be "based on the individual child's needs, taking into account the child's strengths, preferences, and interests" (34 CFR 300.43(a), italics added). Yet how little attention we give to identifying and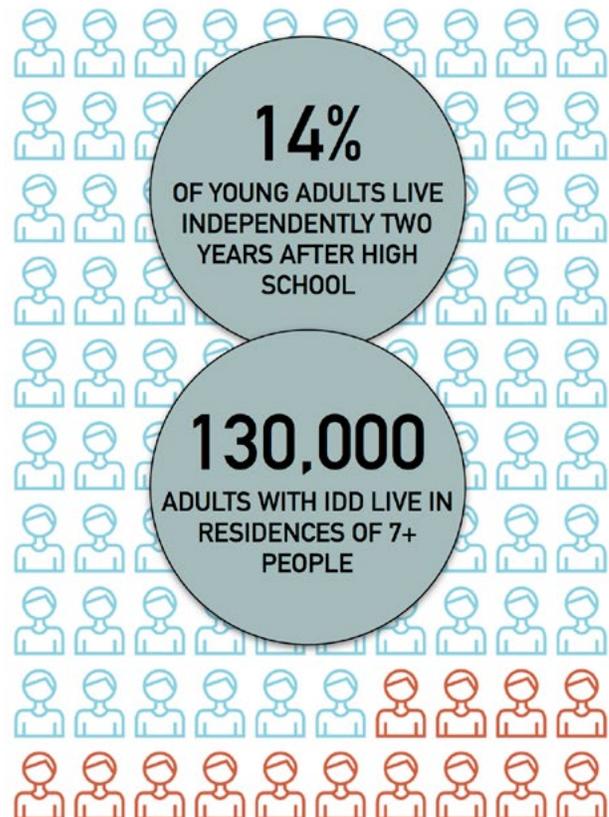 communicating the wonderful strengths and positive traits young people with IDD might have to share with others—both in research and practice. And yet it is on the basis of these strengths and gifts that connections to workplaces, relationships, and communities are made. Can young people with severe disabilities be known first and foremost for their strengths and contributions?

Absolutely. We recently published a study in TASH's Research and Practice for Persons with Severe Disabilities journal in which we asked more than 400 parents to complete the Assessment Scale for Positive Character Traits[14]. It includes 26 statements, each addressing the extent to which their transition-age son or daughter shows characteristics like kindness, humor, gratitude, empathy, optimism, forgiveness and courage. Gathering this type

[14] Carter, E. W., Boehm, T. L., Biggs, E. E., Annandale, N. H., Taylor, C., Logeman, A. K., & Liu, R. Y. (2015). Known for my strengths: Positive traits of transition-age youth with intellectual disability or autism. *Research and Practice for Persons with Severe Disabilities, 40,* 101-119.

51% OF STUDENTS HAVE A TRANSITION GOAL TO LIVE INDEPENDENTLY

71% OF PARENTS CONSIDER SOME TYPE OF COMMUNITY LIVING TO BE IMPORTANT

ASPIRATIONS

14% OF YOUNG ADULTS LIVE INDEPENDENTLY TWO YEARS AFTER HIGH SCHOOL

130,000 ADULTS WITH IDD LIVE IN RESIDENCES OF 7+ PEOPLE

EXPERIENCES

Sources: Blustein, Carter, & McMillan (in press); www.nlts2.org; www.stateofthestates.org

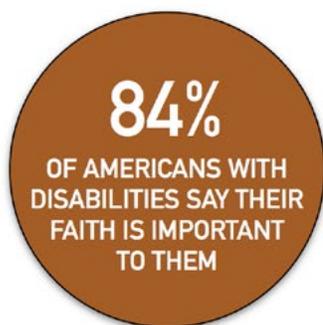*What Matters Most: Toward a Future of Flourishing*

of "strengths-focused" data has some interesting implications for fostering inclusion and community participation.

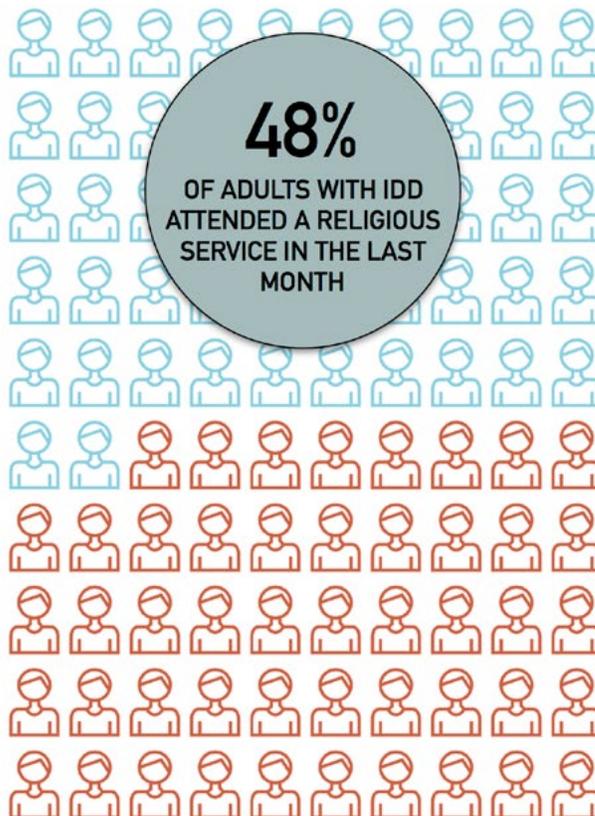Consider just a few snapshots from this study:

◆ 93% of parents described their son or daughter as happy

◆ 86% said they enjoyed life and was thankful for life's simple pleasures

◆ 86% said they had a great sense of humor

◆ 86% of these young people were described as thoughtful and helpful to others

◆ 82% said their son or daughter demonstrated care for others

◆ 78% said their son or daughter was bothered, concerned, or upset when someone else was uncomfortable or distressed

◆ 74% said they were courageous

◆ 68% said they bounced back easily

◆ 63% said their son or daughter did not try to retaliate or get back at others who had her them; and

◆ 52% said they did not lose their temper (come on now, these are adolescents we are talking about)

◆ More than 97% of youth were described as possessing at least five of the strengths reflected on the ASPeCT-DD measure and the median number of strengths was 20. No one had none.

Can we find a place for these strengths in our workplaces, our schools, our congregations, and our communities? How many businesses would benefit from hiring someone with qualities like honesty, persistence, and optimism? How many faith communities could find a place for someone known for her gratitude, empathy, and kindness? How many neighbors would be eager to develop a friendship with someone who is funny,

84% OF AMERICANS WITH DISABILITIES SAY THEIR FAITH IS IMPORTANT TO THEM

48% OF ADULTS WITH IDD ATTENDED A RELIGIOUS SERVICE IN THE LAST MONTH

ASPIRATIONS **EXPERIENCES**

Sources: Carter, Kleinert, et al. (2015); National Organization on Disability (2004); www.faithanddisability.org

thoughtful, and joyful? My point is that our introductions matter. Such findings offer an important reminder that transition professionals should be careful not to perseverate on the deficits and challenges young people experience to the omission of the strengths they might bring to relationship and activities. Instead, our understandings and introductions of young people should incorporate a clear message that they bring strengths and the gifts to the community that make them indispensable.

The best transition planning pinpoints strengths and then figures out who in the community needs exactly that contribution.

5. Location Matters

Fifth, when it comes to transition education—like all of education—location matters. Go back to your memories of school. Think about the breadth of classes, clubs, extracurricular activities, service-learning opportunities, and other programs you took part in throughout middle and high school. And the skills, relationships, and goals you developed along the way that prepared you for adulthood. Access to these same learning opportunities still remains elusive—despite 40 years of IDEA and 25 years of transition mandates. Only 17% of students with ID spend almost all of their day in general education classes alongside their peers without disabilities[15]. For students with the most significant disabilities (on the alternate assessment), less than 3% spend most of their day in these same classrooms[16]. And the majority—nearly 57%—spends almost all of their day in segregated classrooms or entirely different schools altogether. Preparation for the world of work so often takes place in separate and simulated contexts. Access to extracurriculars is elusive.

Even when students with and without disabilities are enrolled in the same high school classrooms, our own research finds they may not actually be present (which is true about 15-20% of class time for students with severe disabilities) or most of their participation happens when sitting alongside a paraprofessional rather than alongside peers (which is true about 50-60% of the time)[17].

Why does this matter? Longitudinal studies confirm that early

inclusion predicts later inclusion—in college and beyond. And having integrated work experiences during high school predicts integrated employment in adulthood[18]. I would phrase the corollary even more strongly. Early segregation does not merely predict later segregation; it almost ensures it. Movement is too often only in one direction as people with severe disabilities get older—toward the peripheries of a community. The trajectory we establish in school is quite likely to continue after graduation. We must establish a trajectory of full and meaningful participation.

When it comes to transition preparation, location matters.

6. Relationships Matter More

Sixth, relationships matter more. We focus quite a bit of time addressing where students should spend their time, much less fuss is made about with whom they spend that time. The physical dimensions of segregation matter, but it is the absence of relationships that matters most. People need relationships more than programs. Having somewhere we belong, a place where we are missed, someone who remembers our birthday (and makes sure it is celebrated well), people to love, people who love us back—we flourish most when we are in a relationship. Yet, friendships and relationships with people not paid to be there receive such scant attention in our service systems. We surround young people with professionals and paraprofessionals—in the classroom, in the community, on the job site—and inadvertently crowd out peers. Why does this matter? Because peer relationships change how young people with disabilities view themselves and their own futures. As they have conversations with peers about extracurricular activities, community involvement, future jobs, and going to college, their aspirations change. Their aspirations change because their spheres of influence change. But the perspectives of peers also change. Young people become known not by their labels, but by their names; not for their deficits, but for their strengths and their friendship. Attitudes and expectations of others are rarely changed when people remain at arm's length or from an informational campaign. And our schools are filled with future corporate, congregational, community, and civic leaders. The relationships they do or do not have will have a long-term ripple effect on future attitudes and opportunities.

According to their parents, just one-fifth (22%) of youth with

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[15] www.ideadata.org

[16] Kleinert, H., Towles-Reeves, E., Quenemoen, R., Thurlow, M., Fluegge, L., Weserman, L., & Kerbel, A. (2015). Where students with the most significant cognitive disabilities are taught: Implications for general curriculum access. *Exceptional Children, 81,* 312-328.

[17] Feldman, R., Carter, E. W., Asmus, J., & Brock, M. E. (2016). Presence, proximity, and peer interactions of adolescents with severe disabilities in general education classrooms. *Exceptional Children, 82,* 192-208.

[18] Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of post-school employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies, 23,* 50-63.

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labels of intellectual disability frequently see friends outside of middle or high school. Two-fifths (42%) never or rarely receive telephone calls from friends. And one-quarter (25%) have not been invited to another youth's social activities even once during the past year[19]. For adults, this isolation only seems to grow after the structure of schooling ends.

I would emphasize that absence of such relationships is not inherent to having a severe disability. Our research—and research of others in TASH—repeatedly affirms that that paucity of relationships is not a core characteristic of people's disability labels[20]. Instead, it is the natural consequence of how we choose to support students. It has much more to do with the opportunities we provide, the invitations we extend, and the supports we offer. In the research we are doing around peer-mediated supports in high schools, we see over and over that friendships readily form when students and without severe disabilities are part of shared activities, connected on the basis of common interests, given valued roles, and provided "just enough" support[21].

Relationships must be among the central markers of "inclusion" during transition. We cannot call something inclusive education if peer relationships are absent. We cannot call an experience integrated employment if no one knows her name. We cannot call it community living if there is no community.

Relationships matter.

7. Evidence-Based Interventions

Seventh, we have to invest more heavily in ensuring the best of what we know works permeates our transition practices. There was a time when most of our moves had to happen in the absence of strong research. But much is now known about how to design transition services and supports in ways that change the trajectories of students. Members of this organization have been active in developing a strong and growing set of evidence-based and recommended practices that hold the best potential for improving youth outcomes. Indeed, the knowledge base on systematic instruction, data-based decision making, tiered

systems of support, work-based learning, self-determination, and other areas of intervention is both deep and strong. Groups like the National Technical Assistance Center on Transition, the Center on Secondary Education for Students with Autism Spectrum Disorders, the Center on Transition Innovations, and IRIS all make this information freely available to educators and families on their websites and through their technical assistance work. And the sessions permeating this conference all equip you with practices for supporting transition and inclusion well. The pressing question for our field is less: "Which intervention strategies promote desired outcomes for students with disabilities?" Rather, it is "How do we ensure the best of what we know works actual penetrates the practices of everyday schools across our state and country?" "How do we equip practitioners and leaders with both the vision and tools to serve a different way."

Students deserve access to the very best instruction and the most effective supports.

8. Beyond Professional Borders

Eighth, we have to think beyond the "usual suspects" to have a real chance at transforming the post-school landscape. We have to think beyond the service system. Our current efforts in the field of transition focus far too narrowly on using the formal system of services and supports designed exclusively for people with disabilities. While our educational and service systems can (and ought to) play a key role in strengthening pathways to college and career, it is unlikely that sweeping changes can be accomplished by relying entirely on any service system. It is—and likely will continue to be—stretched beyond its capacity (and far too limited in its vision). But there is good news. Our communities are filled with ordinary people who have incredible ideas, assets, and connections that could be drawn upon to help young people with severe disabilities to flourish. Yet we so rarely invite them into this work. And they may not initially see what they have to offer. Engaging civic groups, employers, community leaders, congregations, generic community networks, families, and others residing in a community may be the real key to unlocking opportunities.

Let me share just two brief examples.

Across several states, a series of "community conversation" events are being hosted as a way to engage a broader cross-section of people in generating creative solutions for improving employment outcomes for young people with severe disabilities[22]. Solutions

[19] www.nlts2.org

[20] Carter, E. W., Bottema-Beutel, K., & Brock, M. E. (2014). Social interactions and friendships. In M. Agran, F. Brown, C. Hughes, C. Quirk, & D. Ryndak (Eds.), *Equity and full participation for individuals with severe disabilities: A vision for the future* (pp. 197-216). Baltimore, MD: Paul H. Brookes.

[21] Carter, E. W., Asmus, J., Moss, C. K., Amirault, K. A., Biggs, E. E., ... & Wier, K. (2016). Randomized evaluation of peer supports arrangements to support the inclusion of high school students with severe disabilities. *Exceptional Children, 82,* 209-233.

[22] Carter, E. W., Blustein, C. L., Bumble, J. L., Harvey, S., Henderson, L., &

that reflect local priorities and doable possibilities. A local planning team invites a cross-section of the community (e.g., perhaps 50-80 members) to a two-hour event held over chocolate and coffee (this is the critical component), aiming for at least half of the people to be persons who think they have no connection to disability issues. Through a series of small-group conversations at round tables, and a whole-group discussion, hundreds of ideas are generated that might be carried out as part of local change efforts. In essence, new voices are being invited to help answer the question: What could we do as a community to expand meaningful opportunities for people with disabilities here in this place? We have already held 17 "community conversations" in Tennessee focused on the transition to employment. And we are struck by the ideas and opportunities (and jobs) that emerge when people can think outside of eligibility requirements, funding mechanisms, and program constraints.

A second example. Four states have been part of the Putting Faith to Work project (www.puttingfaithtowork.org), which involves inviting local faith communities to play a role in supporting their members with disabilities to connect their gifts and talents within the workplace[23]. Congregations are networks of people who are connected to places of employment throughout the community (as employers or employees), they are invested in helping their members to thrive, and they can get to know people in ways that a service system never could. But they are rarely asked to use their commitment and connections to address a pressing need for people with disabilities. To date, more than 40 people with disabilities have been supported by congregations to obtain jobs that match their passions and sense of calling—largely outside of the formal service system, all from a simple invitation to a community to use its assets in new ways.

While we must work to strengthen our service systems, we must simultaneously move as if there is no service system. And to ensure we are engaging the "unusual suspects."

9. Rethinking Our Outcomes

Ninth, we may need much better metrics to gauge our success. We have become captivated in this field by documenting post-school outcomes and the factors that predict them. For example, Indicator 14 appropriately calls our attention to the percentage

McMillan, E. (in press). Engaging communities in identifying local strate-gies for expanding integrated employment during and after high school. *American Journal on Intellectual and Developmental Disabilities.*
23 www.puttingfaithtowork.org

of students with disabilities who are working or in postsecondary education one year after high school. While we must move the number up on these types of outcomes, I am not sure they fully capture what we know matters most went it comes to flourishing. For example, we almost always treat post-school employment as a dichotomous outcome in research and policy—someone is either working or not working. But a good job is defined by so much more: the right hours, sufficient pay, adequate benefits, opportunities for advancement, alignment with one's interests, availability of supports, and interactions with great co-workers. So few of our transition outcomes are considered in terms of alignment with the aspirations of young people or the quality of the experiences young people access. And there are other aspects of life that we neglect to consider altogether. I already mentioned relationships and sense of belonging. But there are others: Do young people have a real say in their own lives? Are they connected to and contributing to their communities in ways that reflect their sense of calling, purpose, or vocation? Do they feel safe?

We tend to move toward what we measure. And so we need to measure better.

10. A Bigger Story

Finally, I am convinced we have to tell a much bigger story about why all of this matters. Documenting the impact of well-supported inclusion and transition on students with severe disabilities has been a longstanding focus of research. And the data are quite compelling. Young people have much to gain from their inclusion in the workplaces, colleges, congregations, neighborhoods, and social networks that make up community life. But this individual storyline alone is not changing the landscape. The full story has to address how everyone in a community benefits when inclusion becomes widespread. The community is the proper unit of analysis in research on inclusion. In other words, the shift must be toward understanding how an entire community might be strengthened by the presence and participation of young people with disabilities. We are seeing this theme in new work focused on the "business case" for integrated employment. Yes, integrated employment is good for people with disabilities. But the plot that seems to be moving the needle is that integrated employment is good for businesses. A better bottom line, improved workplace culture, reduced absenteeism, and new innovations are all themes of this work. For society, this is accompanied by lower costs. We are seeing this in work

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on inclusive faith communities, where congregations that have traveled from segregated to integrated have come to see people with disabilities as indispensable to their thriving as a community. They do not only talk about why inclusion is good for people with disabilities. They speak powerfully about why it is good for the entire community. And we have seen this in research on the impact of well-supported inclusion on peers and classmates.

We have to tell a much bigger story.

Flourishing as an Organization

In each of these ten areas, there are opportunities for TASH and for you as its members. Let me close by highlighting some of those opportunities. A few avenues through which we might thrive as an organization.

First, we must be relentless in our push for better opportunities and outcomes. This organization ought to be proud of the progress we have pushed. But I am afraid we are now in a prolonged period of drift and stagnation that needs to be broken. The move away from segregated settings has slowed or reversed in the past decade:
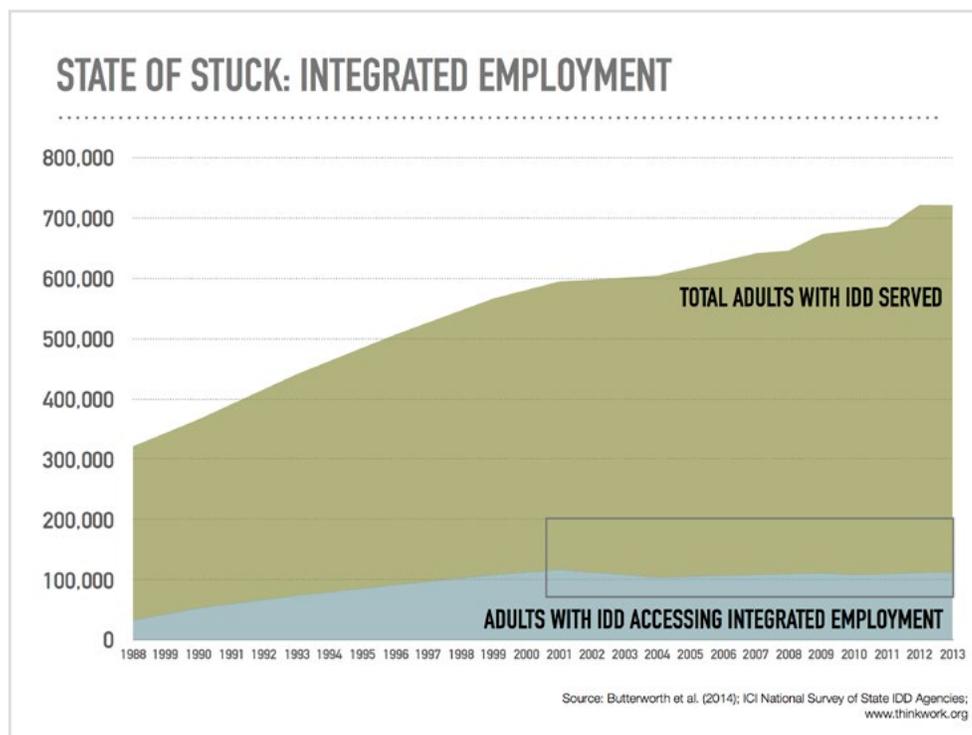
◆ Consider trends in the number of people with intellectual disability accessing integrated employment over the last 25 years (see Figure 5). It has not changed. And by percentage, it may even have retreated.

◆ Consider trends in inclusive education over the same period. The percentage of students with ID spending almost all of their day in general education classrooms has not changed in the last decade (see Figure 6).

◆ Our culture needs a fresh call; our professionals need a new push. TASH must provide it.

Second, we must stay strong on our values. Inclusion, full

participation, presumption of competence, dignity of risk, human rights, self-determination—these are just some of the values TASH and its members have gifted to the field. They are what makes this organization so distinctive and so deliberate. They keep us steady and unify us.

Third, we must be leaders in research. On the forefront of carrying out the highest quality and most cutting edge scholarship. Indeed, this organization already counts among its members the most well-regarded researchers in the field of education and transition. We cannot not see our values and our research as competing priorities. Each is insufficient without the other; neither ought to be elevated over the other. When done well, the best research helps lead us toward the realization of our values in policy and practice.

Fourth, we must remain in the company of people whose vision exceeds our own. Among people whose expectations will challenge ours. This certainly includes young people and their families who keep calling us to see beyond our current vision of what is possible. But it also means investing in partnerships and coalitions with other organizations who are striving toward similar changes in the landscape, but see possibilities we cannot. We should not go it alone.

STATE OF STUCK: INTEGRATED EMPLOYMENT

TOTAL ADULTS WITH IDD SERVED

ADULTS WITH IDD ACCESSING INTEGRATED EMPLOYMENT

Source: Butterworth et al. (2014); ICI National Survey of State IDD Agencies; www.thinkwork.org

What Matters Most: Toward a Future of Flourishing

Finally, we must complete the work. We must finish the call. From that smoke-filled room where TASH was born in the mid-1970s to this smoke-free gathering today in Portland 40 years later, we still carry that charge. We have to see this work through to the end. TASH is incredibly well equipped to lead this work. It is equipped with all of you—allies and advocates, innovators and instigators, preachers and practitioners. People whose passion and persistence hold the best possibilities for changing the transition landscape.

Thank you for your presence at this gathering. For your investment in this organization. And for your deep commitment to supporting people with disabilities, their families, and this organization to flourish.

STATE OF STUCK: INVOLVEMENT IN GENERAL EDUCATION

STUDENTS WITH INTELLECTUAL DISABILITY IN GENERAL EDUCATION (80% OR MORE OF THE SCHOOL DAY)

Source: www.ideadata.org

Author Bio

Erik W. Carter, Ph.D., is Professor of Special Education at Vanderbilt University. His research and teaching have focused on evidence-based strategies for supporting inclusion and valued roles in school, work, and community settings for adolescents and young adults with intellectual disability, autism, and multiple disabilities. He has published and presented widely in this areas in an effort to equip practitioners and policy makers with clear guidance on the most effective approaches for enhancing the relationships and outcomes of students with severe disabilities.