

A Field in Transition: The Journey from Here to There

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Good morning! It is an honor to be in the midst of so many researchers, leaders, advocates, and others from around the country who are so deeply invested in ensuring young people on the autism spectrum can truly thrive in all aspects of their lives. Changing the landscape of opportunities and outcomes for youth in transition certainly requires our *collective* efforts. Our concentrated, coordinated, and creative efforts.

My own entry into this field and into the lives of youth with disabilities was certainly unexpected. It came when I was in college, just two years after the transition mandates were added into IDEA. Working in a group home in Chicagoland, then as a high school transition teacher in San Antonio, and now as a professor of special education in Nashville, I've been part of a field that is anything but static.

Indeed, the field of transition *itself* has always been in transition. Our understandings of its purpose, its scope, its starting point, its destination, its participants, its partners, and even its very definition (which I think still eludes us). In many ways, this particular gathering is intended to bend this field even further (and perhaps even faster). To identify new directions that might lead to a future of flourishing for individuals with autism and other disabilities. And so I thank you for being here.

So, what is this thing we call “transition”? From the field's perspective, it is this collective investment we make in raising the aspirations young people with disabilities have for adulthood and then ensuring they have the very best chance of experiencing the life they now envision for themselves. We do this by equipping youth with the skills, knowledge, experiences, supports, and relationships that we think matter most. And we do so while holding the highest of expectations—both of these young people and also of our communities.

But from the perspective of young people (as you just heard on the panel), though, the answer is a much more personal one. Transition is about catching a glimpse of who you are and want to be, of coming into your own and shedding the roles of childhood, of steering your life in the ways and directions that *you* choose, and, perhaps most simply, about pursuing a “good life” as you see it. Or, as they Ann and Rud Turnbull so often emphasize, of experiencing an “enviable life.”

And so you see very quickly that the boundaries of transition—both temporally (i.e., when it starts and stops) and topographically (i.e., the landscape of experiences that comprise this transition)—are not so easy to delineate. In policy and practice, we can certainly attach ages to our services and supports—14 or 16, 18 or 21. But we also know that the trajectories of young people are often set long before they reach middle school, and those trajectories can shift and shake so very quickly in the early years after graduation. Let me punctuate this point by sharing findings from an ongoing study.

My own very careful analyses of numerous national data sets arrives at a very definitive conclusion: children with ASD grow up. As I have plotted on this gorgeous graph, they tend to get one year older with each passing year. Indeed, a nearly perfect linear relationship emerges. And while I should emphasize that this study has not actually been peer-reviewed, I do believe this finding will be replicated in your own state. *As a field*, we must adopt a **long view**. What are the policies, practices, and partnerships that best prepare children, that best launch youth, and that best support young adults? Transition is not a culminating event but rather an accumulating process.

Likewise, schools, agencies, and organizations all place parameters on the services and supports they will offer. *But as a field*, we must adopt a **broad view**. One that approaches young people more holistically (not in separate slices), that fuses together the constellation of services and supports they will need, and that recognizes that the pathway to adulthood cannot only be lined only with formal systems. We have to draw deeply upon the untapped capacity of local communities to support their citizens with disabilities in this transition.

This is long-haul work that requires our broad-range investments.

So, let me now turn to the topic I was given. The question of outcomes.

Some of you know that I recently spent a year in an RV with our family of five crisscrossing the country on my sabbatical. We logged 40 states and 35 national parks in our motorhome, which we affectionately named *Cousin Eddie*. And so the metaphor of a journey really resonates with me. I can't tell you how many times I heard the same two question shouted from the back of the motorhome as we trekked the country: ***Where are we going?*** And repeated refrain, ***Are we there yet?***

These are the same questions we raise here: As we think about the movements we trying to make in this field of transition, do we know where we are trying to go? And how will we know when we've arrived? For the 300,000 transition-age students with autism in the United States (ages 14-21), what does it mean to go from *here* to *there*?

Student outcomes have always dominated conversations about transition education. Remember that it was follow-along research illustrating the poor postschool outcomes of early special education graduates that helped spur the introduction of federal transition mandates. It was the persistence of those disappointing outcomes that catalyzed research on evidence-based predictors and practices. And presently, we have measures like Indicator 1 (graduation), Indicator 2 (dropping out), and Indicator 14 (postschool outcomes) that touch upon some of what students experience during and after high school. But there is more to do here:

1. We need a more expansive view of relevant outcomes.

The portrait of transition first proposed by Madeline Will emphasized those bridges to *employment*. Andy Halpern's model of community adjustment encouraged us to also think about *residential environments* and *interpersonal networks*. Preparation for *further education* was added to the purpose of special education in the IDEA of 2004. But is there more to our

flourishing than where one learns, lives, or works? What outcomes might comprise a “good life” for youth and young adults with ASD? We are the potential marks of a successful transition?

It isn't actually a very hard question to answer. You need only think about your own lives and the things that contribute to your thriving as an adult; about the things that make your own life rich and enjoyable. Is it the relationships you enjoy, the places you go, the groups you are part of, the activities you experience, the contributions you make, or something else altogether? What are those “universal aspirations” that young people hold?

To drive home this this point, let me simply ask you to transport yourself back in time to when you were in high school. And think about how you would have answered the question you were asked a million times: What are you looking forward to most after graduation?

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. Moving out. Making money. Being free. Hanging out with friends. Making your own decisions.

And even now, your descriptions of what matter most are likely to extend beyond your work and where you live (hopefully). Ask people what brings them “life” and helps them flourish; and you likely hear some common themes:

- having a network of friends
- being part of a family
- loving someone who loves you back
- being part of a caring community
- having opportunities to make a difference in the lives of others
- feeling (and being) needed
- being able to steer your life in directions you choose
- living out your faith
- belonging
- staying healthy
- being safe
- having freedom

And so it is important to know if young people are experiencing *good outcomes*. But it better to **also** know whether people are experiencing a *good life*. Both are quite important and they are in many ways yoked together. A good job, presence in a neighborhood, lifelong learning opportunities, and involvement in the community—these provide the contexts in which people develop friendships, live out their vocation, contribute in valued roles, grow in their faith, and find a place of belonging.

As a field, are we thinking this broadly? Do our policies, programs, and practices collectively aim toward this broad range of destinations? What does our research tell us about the pathways to all of these places? Or about the extent to which each is experienced by the students we serve?

2. We must be guided by individual aspirations.

Individualization is a hallmark of special education. And it should be should be acknowledged throughout our discussions of transition outcomes. Among the constellation of possible outcomes we have already discussed, it is those that matter most to a particular individual that should drive his or her transition education.

What is it that young people with disabilities say they want?

According to the NLTS2012, a striking 95% of high school students with autism expect to have had a job by age 30. They do not have dreams of underemployment or unemployment, they do not aspire to piece-rate wages and sheltered workplaces, and they do not say they envision for themselves a lifetime of exclusion from the workforce. They have gifts to bring to the world of work and they want to “bring it.”

More than 80% of youth with autism hold the aspiration to live on their own in early adulthood. They do not have dreams of living in large congregate settings (unless it is a college dorm) and they envision much more than a life on the couch. They want to “have a life” and to live life well.

More than four fifths of (84%) of adults with disabilities consider involvement in a community of faith important aspect of their lives. We don’t have data that breaks this down by disability category. But it is clear from our own studies that people with disabilities do not want to always be the focus of ministry or on the peripheries of congregational life, they want to be in the heart of their faith community, to be among the ones serving and leading, to be seen as indispensable to the body of believers.

Three quarters (75%) of youth with autism expect to obtain some type of postsecondary education after high school. They do not want to miss out on lifelong learning opportunities, tailgate parties, new experiences, and a real career pathway.

The presence of a disability label is not a reliable predictor of a person’s aspirations for their lives. Young people with ASD overwhelmingly tell us they want what anyone might want—to be at the center of their communities, not on the peripheries or in the margins.

As a field, how are hearing these aspirations, elevating these aspirations, and responding to these aspirations? Do our policies, practices, and partnerships aim toward what young people say they want for their lives? Do we even know what that is?

3. Success means bridging the gaps.

So, this is where our collective work focuses as a field—bridging the gap between the aspirations young people hold and the outcomes they experience. Between their vision of what it means to flourish and the actual experiences they are having. One person at a time.

Individual definitions of a good life can be influenced by so many personal and external factors, including one’s culture and community, their family and their faith, their strengths and needs,

and even the point in history in which one lives. Different students will hold a variety of priorities for whether, where, or how they work, learn, live, recreate, and socialize after high school. Although I do believe our benchmarks for transition success should reference the outcomes typical of similar-age peers without disabilities, it is also critical to examine the extent to which each person's outcomes reflect her or his own personal goals for life after high school. The gap we are trying to bridge between what Maya desires and experiences, what Liam desires and experiences, and what Benjamin desires and experiences. Not merely between what people with and without autism experience.

If you agree, that it means that one barometer of the quality and effectiveness of our services and supports is the extent to which individuals with disabilities actually attain their personal goals. Success is not judged by what we write down on a personal planning document or the boxes we check off on a report, not merely by the services and supports we plan to deliver or actually deliver (as important as these all are). But rather by the degree to which the goals people have for their lives actually materialize.

Why do I emphasize this point? A 30,000 foot look upon the national landscape suggests that while some young adults with ASD are flourishing, many others are not. Despite the incredible progress we have made in our field over the last 29 years, the gap between aspirations (on the left of each screen) and outcomes (on the right of each screen) still remains far too wide for too many people.

- Up to 8 years after leaving high school: only 37% of individuals with autism were employed at the time of the interview; 63% had been employed at any point since leaving high school. They have held an average of 3 different jobs.
- Up to four years after leaving high school, only 57% of young adults with autism had enrolled in any type of postsecondary program. Up to eight years after leaving high school, just 23% of young adults with autism had completed any type of program with any type of degree or certificate.
- Only 39% of adults with IDD who had autism attended a religious service at any point within the past month. Relatedly, nearly one in three families (32%) have left their faith community because their son or daughter was not welcomed or included.
- And finally, up to eight years after leaving high school, only 27% of young people with autism live independently or semi-independently in the community. And more than one third (38%) indicated they were not satisfied with their current living situation.

The distance between aspirations and outcomes is the gap the field must narrow.

I would add here that most of us do not see our own lives in these very fragmented ways, where outcomes in one domain have little to do with the others. As so we may need to consider how multiple outcomes (e.g., work, college, relationships, community) are examined in combination and tandem with others rather than separately.

As a field, are we focused on the correspondence between people want and what they experience? Which policies, practices, and partnerships lead most in this direction?

4. We need much better measures.

It strikes me that some of the most important things in life are among the hardest to measure. And so, not surprisingly, the field of transition is replete with measurement challenges. Some valued outcomes are hard to measure because they are subjective or multifaceted—things like belonging, quality of life, self-determination, spirituality, or freedom. Others are especially hard to capture for individuals have communication challenges or cognitive impairments. A proxy is just not the same as the personal.

And so we are prone to only examine the veneer of a good life. For example, we almost always treat postschool outcomes dichotomously in our studies and reports—whether someone is either working or not working, accessing postsecondary education or not, living in a particular place or not. Although such measurement approaches can certainly ease analyses, they just don't adequately capture the relevant dimensions and quality of these experiences. For example, a variety of job features can influence whether a young person considers their job to constitute a "successful" employment outcome—sufficient pay, adequate benefits, opportunities for advancement, alignment with one's interests, degree of inclusivity, and the availability of supports. We often struggle (or neglect) to speak to quality.

Sometimes it is the intersection of outcomes that matters. For example, I would argue that an emphasis on **relationships** must be among the defining features of transition. We cannot call something inclusive higher education if friendships never form. We cannot call something integrated employment if no one really knows her name. We cannot call something community living if there is no community.

Likewise, consideration of choice is critical. Did he or she really choose this outcome? Was it an informed choice? Was it a limited choice? Was it a well-supported choice? Or is it just the illusion of choice? Whose aspirations do these really reflect?

I'm also reminded of a review we did of 35 years of research published in the CDTEI journal. This was back in 2013. We were intrigued by the breadth of data collection approaches used to answer research questions. The use of research-created surveys and questionnaires was the dominant approach to data collection. This may reflect in part the complexity and diversity of constructs researchers have tried to measure. But so few of the measures used had been validated or had adequate psychometric evidence. We still need compelling, reliable measures to assess the outcomes of high interest to the field of transition. The value of research findings are inherently tied to the quality of the measurement.

As a field, are we pushing deeper in our efforts to capture the breadth and depth of these outcomes? Are we able to measure what matters most? Does the portrait we are sharing about transition outcomes reflect the whole story, or an incomplete snapshot?

5. We need to examine outcomes over time.

Because transition addresses such a wide span of time, temporal considerations matter. The outcomes considered most relevant or important to individuals with disabilities may look quite different at various points in the transition process. *Middle school versus high school. In-school versus post-school. Early versus later adulthood.* Students' achievements during high school (e.g., skill and knowledge acquisition, grades, early work experiences) provide the most proximal measures of the impact of the transition programs and practices. But the longer-term impacts of transition services are much less clear.

As researchers, we actually know very little about the specific pathways students take as they exit school services and navigate early adulthood. The months and early years after graduation can be marked by considerable fluidity and can change substantially over time as young adults find their footing. Transition is not a discrete event that takes place the day the school bus stops coming, but rather a process with fits and starts, one that is more sinuous than direct.

Although scores of studies have focused on the outcomes of students at some point during the very early years after high school exit, most of this scholarship has addressed a single point in time (i.e., 1, 2, or 4 years out). For example, postsecondary education research primarily has focused on enrollment rather than completion; and employment research focuses on job acquisition rather than maintenance and advancement over time. Focusing on both attainment *and* maintenance pushes us to address the types of supports, services, and settings necessary at key junctures in this transition.

Longer-term outcomes also need attention. The achievements of adults with disabilities in later adulthood more than five years out reflect a period of time when career and community pathways have typically stabilized and the overall success of the transition to adulthood can best be evaluated. Yet few studies have adopted such a long-term perspective. And few funding mechanisms are available to support this much-needed longitudinal work.

As a field: What can we say about the evolution and attainment of relevant transition outcomes over time? Do we know how one outcome cascades into the others that follow? How are our practices aligned to this recognition?

6. We need multiple units of analysis.

So far, I have largely emphasized the outcomes that youth experience. But we also should reflect on the outcomes that matter most for families, for schools, and for communities. Individuals with disabilities are embedded within these and other systems. What will we point to that tell us that families are flourishing? That schools are different because of the investments we are making?

Or that communities are stronger because they are receiving the gifts and presence of people with disabilities? I am convinced that the outcomes of students with disabilities are intricately linked to these other areas. And I also suspect that our efforts to foster the inclusion of young people with disabilities depends on the degree to which we can make the case that inclusion is better for everyone.

Do we know what outcomes matter for families, for educators, for schools, for employers, for congregations, for college campuses, and for communities as a whole?

Moving Forward

And so the conversation now shifts back to each of you: What combination of experiences over time are most likely to lead to particular postschool outcomes? Our field needs a much deeper understanding of how the *combination* of services and supports students receive during secondary school, postsecondary school, and young adulthood lead to the various outcomes students are pursuing. We have a good start here. Numerous studies have examined a constellation of factors that might be associated with the postschool outcomes of students with disabilities—we call these predictors or correlates. But so much of this research has focused on the extent to which a small number of discrete skill domains (e.g., social, communication, travel, self-care skills), isolated experiences (e.g., occupational course taking, paid work experience, general education inclusion), and/or other discrete factors (e.g., interagency involvement, parent expectations) predict specific post-school outcomes. What remains unclear is (a) which *combinations* of educational and other transition experiences *over time* best position students with disabilities to attain their goals for life after high school, (b) how the quality of those experiences impact students' trajectories, and (c) the ways in which the programming schools, agencies, and others provide should be tailored to align with the individual needs and goals of students.

This is challenging work, isn't it? But it is work that matters immensely for the hundreds of thousands of transition-age students with autism who are striving toward their "good life."

Let me close with a quick call to be both reflective and humble as we move forward here. I feel fairly young in this field. The striking thing about our history as a field is that we have so often been wrong about all that individuals with disabilities could accomplish and contribute. We can see that easily looking backward.

We wonder how our predecessors could have been so shortsighted—institutions, sheltered workshops, segregated programs, etc.. But we also run this same risk, don't we? One day down the road, people may like back at us...and they might see what we have proposed and pursued...and wonder why we did not see a different, better way. We will be their "barbarous ancestors." And so as we push for more progress, we should not assume certainty, we must always be reflective about where we are and we are going, we must seek good advice along the way, and we must be willing to let go of what doesn't work.

Have we made incredible progress so far? Certainly so. Are we there yet? Certainly not. What is our next best step on this journey? This will be the conversations that follows today. Thank you—Arun and Autism Speaks—for inviting us all to be together this week. I look forward to the conversations that follow.