



Reimagining Advocacy: Promoting an Authentic Transition to Adult Life

Laura Owens, Ann Deschamps, Sean Roy - TransCen, Inc.

The national network of nearly 100 Parent Training and Information Centers and Community Parent Resource Centers, funded by the U.S. Department of Education's Office of Special Education Programs, and the network of Parent Information Training projects funded by the Rehabilitation Services Administration, have traditionally been a trusted source of support for families and caregivers of individuals with disabilities. Providing families with information and referral services related to making the transition from school to community and work should be a core focus of all of the centers, but are they keeping up with the ever-changing transition landscape?

This resource is intended to encourage organizations and projects that provide families with information, advocacy, and referral services to reimagine how they approach "transition". It will examine the pitfalls of a compliance or systems-based mindset (which is a leadership model that recognizes that people, structures, and processes interact within organizational systems to foster or restrict organizational improvements), and suggest that integrating the notion of transition into all lifespan stages can help families embrace bright futures earlier. In short, the disability field is improving its understanding of how individuals with disabilities make a successful transition to adulthood. It is time our parent advocacy services reflect that same understanding.

Old Ways and New Thinking



Many parent training projects have roots in educational advocacy – originally established to help families understand their child’s rights under special education law. The focus of advocacy efforts under this model tends to be understanding systems and their compliance measures. And while school to community transition has associated service systems and requirements, it also brings in issues of expectations, decision making, and life and work skills preparation for families and caregivers. Transition is not about understanding and navigating systems, but about helping youth envision what a good life looks like and taking steps to get there.

The grid below offers suggestions to think differently about transition advocacy:

Old Idea	New Perspective
Transition is a specific service and there is no need to worry about it until their teenage years.	Families can create high expectations and encourage goal-setting beginning during the early childhood years. Starting early makes the transition process easier.
Educators know best and will take care of formal transition planning. All families have to do is attend IEP meetings.	Nobody knows the student better than the student and their families, and families play a valued and essential role in making sure transition plans reflect a student’s interests and future goals.
It is better to be realistic about what people with disabilities can do. That way nobody gets their hopes up.	Failure is an option and are opportunities to grow and learn. Students should not be restricted by what other people think they will be able to do. Allow the dignity of risk.
It is always best to get full guardianship over your student with a disability.	Families should be given information on alternatives to guardianship so a student’s individual rights can be maintained whenever possible.
Formal, eligibility-based services are the only source of supports for adults with disabilities.	There are not enough funds available for formal state services to support all who may need it. Families need to plan creative ways to support their loved one’s meaningful life.
Transitioning directly into a day program is the best option for students with significant disabilities.	All students should be given the opportunity to explore real employment and experience the benefits real employment brings people. Having a significant disability does not mean having a life void of new experiences and responsibilities.

Adjusting to a Lifespan Approach

Seasoned transition advocates have heard familiar refrains from families younger than transition age – “We are just trying to get through the day, and don’t have time to think about what adulthood will look like.” Or, “They are in elementary school. It’s too early to think about that.” Families have been conditioned to view transition as a thing that happens at a certain age, and are often left disappointed with the actual planning that takes place. Parent training projects can combat this rigid thinking by infusing the concept of planning for adulthood into each stage of a person’s lifespan. This requires coordination with other center staff who may focus on early childhood or elementary school, and necessitate branching out into information for those who are past school age.



Consider the strategies in the grid below:

Life Stage	Transition Message/Activities
Pre-School	<ul style="list-style-type: none"> • A great life is possible for people with all types of disabilities. • High expectations are key. • The path to adulthood is the same as with any child. There just may need to be some additional supports. • Start giving choices early on.
Elementary School	<ul style="list-style-type: none"> • Begin communicating high expectations to your child. Having a disability will not define what they can achieve. • Begin conversations about employment. “What type of job do you think looks interesting?” • Get in the habit of teaching real skills, such as understanding money and using technology. • Help your child participate in or lead their IEP meeting.
Middle School	<ul style="list-style-type: none"> • Begin making the connection to interests, jobs and skills/education needed to work in desired job field. • Understand and try to get on current wait list for services in your state. Not everyone needs formal services, but getting on the list does not hurt.
High School	<ul style="list-style-type: none"> • Help your loved one have a clear vision for what a good life looks like - including where they want to live, who they want to spend time with, and what they want to do for work. Communicate this vision to all educators and service providers. • Advocate for as many community-based work experiences as possible. This provides the opportunity to practice the jobs they are interested in. • Connect with other families who have gone through the transition years. They will be a wealth of information and support. • High school students should be participating and/or leading their IEP team meetings. This is a great place to practice letting others know what supports they need.

Life Stage	Transition Message/Activities
Post High School	<ul style="list-style-type: none"> • All placements or programs are flexible. Make sure your loved one has a voice and opportunities for growth. • Plan for what will happen once you are no longer able to support your loved one. • What makes a good life are the things that don't often get planned for, such as new experiences, hobbies, and relationships. Help your loved one do more of the things they want to do.

Competitive, Integrated Employment and Meaningful Day Services



The disability community is working hard to promote competitive, integrated employment as the preferred option for people, regardless of level of disability. Competitive, integrated employment refers to jobs that pay at least minimum wage and where people with and without

disabilities work alongside each other. Parent training projects are tasked with providing accurate information so families can help their loved one make an informed decision about jobs. However, it is crucial that these projects be well versed in the benefits of real jobs and have knowledge of customized employment so families can see that work is possible. This extends to the way parent projects conduct trainings (coaching on strategies to prepare for employment rather than simply giving out employment program contact information) and speak to families (promoting high expectations around employment).

Another emerging concept is that of “meaningful day services”. It suggests that day habilitation services do not need to be warehouses for people, but rather can be linked to employment preparation and should include a person-driven menu of meaningful activities. For example, a person’s day can include volunteering, auditing a college class, being part of a choir, or relaxing in a way they choose.



Summary

The idea of transition has changed a lot over the last 40 years. We have gone from a simple focus on employment, postsecondary education and independent living to a broader perspective that seeks to identify what a “good life” looks like for and with a person and how to get there. Our expectations around employment access have been raised and we are more aware of the impact of our advocacy and messaging on families. It is time to make sure that our parent training projects are aligned with current transition thinking and practice. To accomplish this, start by focusing on these key takeaways:

- **Transition should be focused on the individual, not the family.**
- **Transition should be woven into all aspects of your work with families.**
- **Beware of systems and compliance thinking – transition is about achieving a good quality of life.**
- **Families may require a more individualized approach to advocacy.**
- **Providing information on employment needs to go beyond providing standard program information. Promote competitive employment as the preferred option.**

Key Resources

[Open Doors for Multicultural Families’ series of multicultural/multilingual transition guides](#)

[Charting the LifeCourse Tools](#)

[Family Employment Awareness Training \(FEAT\)](#)

[Hire Me South Carolina Family Resources Page](#)

[I’m Determined](#)

[PACER’s National Parent Center on Transition and Employment](#)

About the Authors

Laura Owens, Ph.D., CESP

Laura, the President of TransCen, has over 30 years of experience, with a strong background as a national leader in the disability employment field. Laura also serves as a Professor at the University of Wisconsin-Milwaukee in the Exceptional Education Department where she teaches courses on high school inclusion and transition from school to work. She is an internationally known speaker having presented to businesses, organizations, schools, and at conferences in multiple countries.

Ann Deschamps, Ed.D.

Ann is Vice President of TransCen and the Director the Mid-Atlantic ADA Center. As Director of the Mid-Atlantic ADA Center, Ann oversees all activities of the Center, as well as implementation and coordination of the Center's ADA Trainer Leadership Network. Ann provides training and technical assistance and is involved in other TransCen projects focusing on school to work transition, promoting youth leadership, and teaching self-advocacy skills.

Sean Roy, M.S.

Sean is the Chief Innovation and Training Officer of TransCen. He previously worked on the Rehabilitation Research and Training Center (RRTC) on VR Practices and Youth and the Youth Employment Solutions (YES) Center as a Quality Control Manager. Sean is an experienced trainer and presenter and brings strong and varied experience in the areas of youth employment, access to post-secondary education, and family engagement.

About TransCen - transcen.org



TransCen, Inc., is a non-profit organization dedicated to improving education and employment success of youth and young adults with disabilities. TransCen provides employment services to youth and adults with disabilities by identifying their passions, skills, and talents, and developing them into career opportunities. They also provide training

and consultation around the country to families and professionals within state agencies, school districts, adult service organizations, and employers who work with or employ people with disabilities.

About RAISE - raisecenter.org



In 2014, SPAN Parent Advocacy Network (SPAN), a parent-led and family-centered non-profit parent training and information center (PTI), was funded by the Rehabilitation Services Administration (RSA) to provide support to individuals with disabilities through the transition from secondary school and into competitive employment and independent living.

RAISE was funded by a national grant from the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS) to provide technical assistance and support to eight (8) RSA PTIs.