



Supporting Families of Students with Disabilities in Postsecondary Education:

Learning from the Voices of Families

This Info Brief is intended to create increased understanding of the important role that families can play in the postsecondary success of students with disabilities. For the purposes of this brief, a postsecondary institution is defined as any accredited institution of higher learning offering 2-year, or 4-year degrees, or other institutions offering professional certificate programs. It is based in large part on findings from a national online dialogue titled *Connecting with Families: Supporting the Postsecondary Success of Young*

Adults with Disabilities, which was held January 22 through February 11, 2015. During the dialogue, families provided insights into areas in which they and their postsecondary students could benefit from support. Strategies and resources that postsecondary institutions can use to better engage families and address the support gaps identified during the dialogue are provided to enable institutions to partner more closely with families to promote the education and employment success of youth with disabilities.

This Information Brief is intended to assist administrators as well as faculty and staff in postsecondary education settings to better understand the value of engaging families of students with disabilities as partners in their students' success. In response to input received during a national online dialogue in 2015, ideas and resources are provided about actions postsecondary institutions can take to better assist these families in supporting their young adult children's education and career development efforts.

“Students don’t suddenly become able to communicate and plan well just because they turn 18, or just because they finish high school. Postsecondary schools need to find a path through the legal jungle to allow parents (or other advocates) to participate in planning courses; registering; planning and implementing accommodations; and asking questions. Banning the parent from the process is a dangerous idea and often places roadblocks in the student’s way that didn’t need to be there.” —Family comments on postsecondary academics

Introduction

Over the past 40 years, evidence has been steadily accumulating that family involvement is one of the strongest predictors of children’s school success, and that families play pivotal roles in their children’s cognitive, social, and emotional development from birth through adolescence and beyond (Harvard Family Research, 2011).

The evidence has been particularly strong as it relates to the post-school success of youth with disabilities. A literature review conducted by the National Secondary Transition Technical Assistance Center and the National Post-School Outcomes Center (Test, Fowler, & Kohler, 2013) found that for youth with disabilities:

- Parental expectations were an evidence-based predictor of post-school success in education and employment.
- Parental involvement was an evidence-based predictor of post-school success in employment.

Moreover, families play a key role in ensuring youth develop self-determined behavior, which is closely tied to successful education and career outcomes for young people with disabilities (Shogren, Villarreal, Dowsett, & Little, 2014). Further, when given personalized supports, families of youth with disabilities are

better able to identify educational and other services that are useful in assisting youth to meet goals for the future (Young, Morgan, Callow-Heusser & Lindstrom, 2014).

Although the long-lasting effects that parent involvement variables have on the academic achievement of adolescents and young adults suggest that parent involvement during high school and beyond still remains an important source of guidance and support, there is a tendency among both parents and school personnel to misinterpret the emerging adult’s desire for autonomy as a developmental barrier to continued family involvement. Studies have shown, however, that while the desire for autonomy serves as a moderator of preferences for certain types of involvement, it is not a barrier to any type of parent involvement (Xu, 2002).

The entry into postsecondary education and employment training programs can present particular challenges for families and youth with disabilities. In the K-12 setting, although the youth may have participated in or even led their individualized education programs (IEPs) or Section 504 planning meetings, their families had a clear role to play—that of advocate and services coordinator, tasked with making sure the youth’s education and support needs were being met. In the postsecondary setting, however, the youth typically performs these functions independently and also must self-advocate by disclosing his or her disability to the disability student services office to be able to access accommodations. While some youth may relish their newly found freedom to act as sole decision-maker, others may feel less confident or comfortable in doing so, particularly while they are also adjusting to the new demands associated with postsecondary education. Some youth may want to involve their families even though they may have mixed feelings about doing this, while others, sometimes with negative consequences, choose not to disclose or to ask for support of any kind.

Families continue to want to support their youth’s educational success, but are unsure what form this support should take given the youth’s need and desire

to exercise increased self-determination and assume new adult roles. Nonetheless, because the transition to adulthood takes longer today for both youth with and without disabilities than in previous generations, it is likely that the family will continue to provide some level of financial and emotional support both during and after the youth exits school (Furstenberg, 2010). Because of privacy concerns associated with the Family Educational Rights and Privacy Act (FERPA), however, many colleges and other postsecondary institutions exclude parents from all interactions involving the student thereby effectively precluding them from playing any meaningful role.

“It would be nice to get to a place where schools are actively seeking students with disabilities and promoting access as strongly as they promote academics.”—Family comments on access, equity, and accommodations

Opportunities for youth with disabilities, including those with intellectual and developmental disabilities, to access postsecondary education are growing (Grigal, et al., 2015), and enrollment rates for students with disabilities increased 20 percent between 2003 and 2009 (National Council on Disability, 2011). Despite this growth in opportunity, outcomes for postsecondary students with disabilities tend to lag behind those of students without disabilities. It is estimated that youth with disabilities pursue postsecondary education at a rate significantly lower than their peers without disabilities, and less than half who do enroll will complete a program of study (Wagner, Newman, Cameto, Garza, & Levine, 2005). Additionally, youth with disabilities encounter unique challenges in postsecondary institutions and they and their families note that these institutions need to work at “creating a climate of disability awareness and sensitivity” (Oertle & Bragg, 2014).

Given that research shows that youth with disabilities in postsecondary settings have better outcomes when they and their family members are engaged in ongoing planning, communication, and collaboration

to meet their needs, postsecondary institutions should include meaningful engagement of families in the arsenal of strategies they use to increase retention and persistence among this population of youth. Families of youth with disabilities who participated in the national online dialogue provided important information that postsecondary institutions can use to assist them in better supporting the educational and employment success of their youth.

Findings from the National Online Dialogue: What Families Are Saying

In early 2015, the U.S. Department of Labor’s Office of Disability Employment Policy (ODEP) and its youth-focused technical assistance center, the National Collaborative on Workforce and Disability for Youth (NCWD/Youth) conducted a national online dialogue titled *Connecting with Families: Supporting Postsecondary Success of Young Adults with Disabilities*. The purpose of the dialogue was to solicit feedback from families of youth with disabilities to inform the development of technical assistance to assist postsecondary institutions in better supporting these families. Content experts from the areas of family advocacy, postsecondary education, secondary transition, and employment facilitated a conversation based on two main questions:

1. How can postsecondary institutions better assist families like yours in supporting young adult children’s education and career development?
2. What type of information and supports would be most helpful to you, and other families, in assisting students with disabilities to make their own decisions and become self-determined adults?

Participants were also asked to provide comments on how postsecondary institutions and other providers could better assist families in supporting the educational and employment success of youth with disabilities. Families were asked to comment across a broad



range of topics including postsecondary academics, preparing for employment, physical and emotional well-being, access equity and accommodations, using technology, and building self-determination.

The online dialogue attracted 430 registrants, 104 of which were active participants. Of those registered, 63 percent identified themselves as parents. The majority of students attended community colleges (130), followed by vocational technical schools (68), universities (15) and military training programs (12). A large number of respondents (190) noted that their youth were engaged in other types of postsecondary educational programs. Ninety-four individual ideas were submitted, and 405 comments on those submitted ideas were offered.

The online dialogue generated a wide range of ideas across all topic areas and upon analysis of the ideas and related comments, eight broad themes emerged:

1. *Families play a critical role while their student with a disability is in postsecondary education.*

Participants felt strongly that postsecondary students with disabilities benefit from family involvement, from finding the best fit for their youth socially and academically to supporting their transition to work. Families also reported supporting skills building in independent living and social functioning, as well as providing assistance with course selection and health and mental health decisions.

2. *Supports in postsecondary education should not center only on academics.*

Families suggested that in addition to academic supports, postsecondary institutions should provide supports to address critical needs related to self-advocacy, independent living, employment, post-graduation planning, and inclusion into campus life.

3. **Families value peer mentoring as a strategy for student success.**

Some participants pointed to leveraging a student's peers as a strategy to help build social connections, combat the loneliness some students with disabilities feel in postsecondary programs, and to provide functional solutions to problems such as transportation/carpooling.

4. **Improved coordination is needed between postsecondary education, high schools, and workforce programs.**

Families pointed to the lack of coordination between secondary, postsecondary and career programs as a significant barrier to students' needs being met. They offered that flexible 18-21 transition programs, improved opportunities to earn credits during dual enrollment, and engagement of the business community (for internships and job placement) would result in new pathways to student success.

5. **Families benefit from ongoing information and support.**

Parents and other family members of college students tend to receive virtually no information or training from postsecondary institutions on how to assist their young adult with a disability toward college success. Contributors cited ongoing communication and family workshops as an effective way to keep families informed and involved.

6. **Postsecondary education should adopt Universal Design for Learning (UDL) strategies.**

Participants expressed a desire for postsecondary institutions to implement accommodation practices that could benefit students with or without disabilities. This would be in line with UDL strategies, which aim to give learners multiple ways to get information, demonstrate knowledge, and be engaged in learning.

7. **Assistive technology is an underutilized strategy.**

Dialogue participants advocated for broad and

consistent use of technology as a strategy to support students with disabilities in postsecondary education. Ideas submitted included early inclusion of assistive technology in transition planning and capacity building for postsecondary professionals.

8. **Self-determination and self-advocacy skills need to be built, not assumed.**

Some participants pointed out that the self-determination and self-advocacy skills postsecondary institutions expect students to be equipped with are difficult for some students with disabilities. It was suggested that postsecondary institutions support students in building these skills and provide opportunities to practice them.

What Can Postsecondary Institutions Do?

Through the *Connecting with Families: Supporting the Postsecondary Success of Young Adults with Disabilities* national online dialogue it was evident that families believe support in the following domains would greatly contribute to their feeling of connectedness and to the success of their youth in postsecondary education: 1) ensuring greater access to coursework, 2) focusing on student health, well-being, and social connections, 3) collaborating for work preparation and employment, 4) celebrating disability and diversity, and 5) planning for transitions at both ends of the postsecondary continuum.

Ensure Access to Coursework

Families shared concerns that students with disabilities do not always have access to coursework or the ability to participate in class and demonstrate knowledge in a way that is compatible with the disability. They identified UDL and leveraging assistive technology as possible strategies.

To provide students with equal access to coursework, postsecondary institutions can:

- Assist families to understand UDL so they may assist youth to identify strategies for process-

ing information, demonstrating knowledge, and participating in classroom activities.

- Collaborate with high school special educators to help inform youth and families about current assistive technology (AT) that can assist students in academics and organization, and provide on-campus support to students using AT.
- Encourage professors and instructors to keep online learning management systems accessible and up-to-date. This includes detailed information about changes in class times, rooms, assignments, and due dates.
- Expand the scope and capacity of the Disability Student Services (DSS) office to address academic access issues and to support students in finding solutions using assistive technology and UDL.
- Understand that some disabilities may impact a student's ability to request accommodations and advocate for themselves. Recognize that families can serve as crucial supports in assisting these youth in making solid academic coursework decisions.

“It would be extremely helpful to families if instructors would back up changes they make to their assignments or course calendar with a note to the class on the online learning management system.”—Family comments on postsecondary academics

“Computers are very helpful especially if you add apps like ZoomText or word prediction. However a number of teachers are not competent in some of these technologies. Some who are willing always learn from their students; but some who are resistant often become barriers, refusing students to take notes on their computers, for example.”—Family comments on using technology

Focus on Student Health, Well-Being, and Social Connections

Youth in transition to adulthood frequently rely upon their families for social and emotional support. Families used the online dialogue to express concerns that students with disabilities often feel isolated socially on campuses and may also need support in making health decisions. Postsecondary institutions should be aware of this concern and work in partnership with families to assist students in remaining healthy and socially connected.

To help maintain a focus on student health, well-being, and social connections, postsecondary institutions can:

- Inform families of health and mental health resources available, including local pharmacies and campus counseling options, so they ensure youth are aware of these resources to support their mental and physical well-being.
- Support the inclusion of students with disabilities in social, recreational, and intermural activities by disseminating information to the DSS office and ensuring that venues are accessible and transportation is available.
- Support the inclusion of students with disabilities in all aspects of campus life, including student government, advisory bodies, special interest clubs, and Greek organizations.
- Establish a network of peer mentors that can act as a resource for students with disabilities. Consider bringing together students, their peer mentors, and family members for special campus events.
- Conduct parent information workshops on supporting physical and mental health, and healthy decision making in all youth, including those with disabilities.

“We’ve been able to hire some wonderful peer mentors who take my son out once a week to do guy things. We’ve also been able to find good



tutors through the nearby university. (He's at the community college.)"

"It would be helpful if disability support services would include an inclusion specialist whose role would be to proactively plan and coordinate activities for all students with an emphasis on ensuring students with disabilities participate.

Include training on 'inclusive practices' for resident assistants and residential staff."—

Family comments on physical and emotional well-being

Collaborate Around Work Preparation and Employment

Families who participated in the online dialogue clearly saw preparation for competitive employment as the desired outcome of postsecondary education. They are seeking better coordination between postsecondary education and the systems that provide employment supports for people with disabilities and suggest stronger career readiness and employment search programs on college campuses.

To establish collaborations centered on work preparation and employment, postsecondary institutions can:

- Sponsor information sessions with students and families to discuss the youth's career goals and how they are related to current postsecondary education choices as well as resources available to secure internships and paid employment.
- Engage internship providers and potential employers to build awareness of effective strategies for providing job accommodations to students with disabilities. (See Job Accommodation Network in Resources section below).
- Partner with secondary education and transition programs to improve career-focused transition planning for students with disabilities. This may include strategies to strengthen individualized education programs and individualized learning plans to better prepare youth to choose high school coursework related to postsecondary goals.
- Collaborate with agencies and programs—including vocational rehabilitation—providing employment support for adults with disabilities to make sure their policies support postsec-



ondary education and student paid work experience while in college.

- Partner with your local Ticket to Work Employment Network or Workers Incentive and Planning Assistance (WIPA) provider to conduct parent training sessions so families can better understand Social Security benefits and work incentive programs. (See Resources section on Page 10). This will help dispel many long-held myths that youth who receive benefits cannot work competitively.

“Many students with disabilities live in fear that after they finish college they will lose critical benefits, such as Medicaid and Mediwaivers, but typically colleges don’t have the experience or systems in place to help the students and their families make informed decisions.”

“Postsecondary institutions and families can partner with centers (CILs) for independent living (found at www.ncil.org) to maximize independence. CILs help individuals reach their

personal best potential, even if they’ll never be completely independent, by teaching life and social skills.”—Family comments on preparing for employment

Celebrate Disability Diversity

Families noted that postsecondary institutions sometimes do not recognize disability as an aspect of diversity.

To celebrate disability diversity, postsecondary institutions can:

- Collaborate with Parent Training and Information centers and other disability-focused organizations to reach out to families of high school students with disabilities through open houses or information sessions that highlight opportunities in higher education.
- Celebrate the anniversary of the Americans with Disabilities Act (July 26th, 1990) and National Disability Employment Awareness Month (October) and work toward developing coursework in disabilities studies as part of the postsecondary program offerings.
- Provide families and students clear, concise, family-friendly information regarding accessing academic accommodations and disability-related supports on campus and train families, students, and staff on the appropriate application of the Family Educational Rights and Privacy Act (FERPA).
- Heighten staff appreciation of disability diversity through training sessions. Hold staff accountable for working with students with disabilities to identify appropriate accommodations and creative ways to demonstrate knowledge when needed.
- Create a phone or messaging resource so families can speak directly to a DSS staff or family liaison to get questions answered in real-time.
- Explore creating a postsecondary program

on campus for students with intellectual and developmental disabilities. Work to make sure such a program allows students to leave with credits or a credential that prepares them for competitive integrated employment.

“My son has found professors at the college level to be very much less considerate of the students in his class who may have disabilities. Any way to require professors to take a ‘Disability Diversity’ class much like the ‘Cultural Diversity’ class my son must take?”—Family comments on postsecondary academics

Help Plan for Transitions at Both Ends of the Postsecondary Continuum

Planning and support for students transitioning to postsecondary education is a high priority for families. There was also an identified need to support students as they prepare to leave postsecondary education for employment and life in their communities.

To help students and families plan for transition to and from postsecondary education, postsecondary institutions can:

- Encourage families and students to use their individualized education program (IEP) and other transition planning tools, such as individualized learning plans, to link student goals, interests, and accommodation needs with plans for postsecondary education.
- Create fact sheets with tips for parents to help youth in building decision-making and self-determination skills needed for campus life and academic success.
- Partner with Parent Training and Information centers and other disability-focused and led organizations to provide information workshops for families, special education teachers, and school transition and guidance counselors



on skills needed in emerging career fields and how secondary and postsecondary education can help build these skills.

- Provide pre-graduation orientation sessions for postsecondary students with disabilities and their families on what to expect after college. This may include information about searching for a job, interviewing skills, disclosure in employment setting, and internships, as well as an overview about how to access assistive technology and common community supports.
- Offer job placement assistance for college graduates with disabilities that includes help identifying job accommodations and transportation options.

“The years of work, starting in Pre-K, through elementary, middle, and high school, required much more time than today. The reason is after all those years my 23-year-old daughter has gained a great deal of independence and self-direction. My point is the technology may require years of effort but the outcomes can be wonderful. Thank goodness for all the assistive technology that helped create all these opportunities. Certainly the iPhone, iPad and apps have been true game changers.”—Family comments on using technology

Resources for Postsecondary Institutions and Families

National Collaborative on

Workforce and Disability for Youth

Funded by the U.S. Department of Labor's Office of Disability Employment Policy, NCWD/Youth (www.ncwd-youth.info) offers a wide variety of resources focused on improving transition-related outcomes for all youth, including those with disabilities. There is extensive information regarding career planning, employment skills, and the role of families, including:

- ***Understanding the New Vision for Career Development: The Role of Family:*** This Info Brief introduces families to career development. It highlights ILPs as a tool to promote career development and provides tips for how families can be involved.
- ***Helping Youth Develop Soft Skills for Job Success: Tips for Parents and Families:*** This Info Brief discusses the importance of soft skills and offers strategies parents and families can use to help their child develop skills for employment success.
- ***Individualized Learning Plans Across the U.S.:*** This interactive map highlights the status of ILPs in each state. Families can use this map to learn more about ILPs in their state and how students with disabilities are included in ILP activities.
- ***Kickstart Your ILP:*** This youth-focused guide provides a breakdown of ILP activities by grade level.
- ***Promoting Quality Individualized Learning Plans: A "How-to Guide" focused on the High School Years:*** This How-to Guide presents a wide range of curricula and strategies to assist schools in successfully implementing ILPs.
- ***"Shelly Saves the Future: A Story of Career Development" Informational Comic:*** This comic follows the high school senior, Shelly, as

she learns to take charge of her future through the use of an ILP.

- ***Graduation Options and Diploma Requirements: What Families Need to Know:*** This article from Our Children, the national PTA magazine, outlines the changing landscape of graduation requirements and diploma options to ensure students graduate prepared for college and careers.
- ***Youth and Disability Disclosure: The Role of Families and Advocates:*** This Info Brief highlights NCWD/Youth's The 411 on Disability Disclosure, and explores the role families and advocates play in helping youth understand the importance of appropriate disability disclosure.
- ***Using Universal Design for Learning: Successful Transition Models for Educators Working with Youth with Learning Disabilities:*** This Info Brief identifies and explains selected classroom-based strategies within the Universal Design for Learning (UDL) model.
- ***Making My Way Through College: A Guide for Students with Disabilities:*** This Guide provides information and resources on preparing for and succeeding in college and transitioning from college into the world of work that will be relevant to any student pursuing a degree or other type of credential (e.g., certification, license) at a two-year or four-year college or university.

Other Helpful Organizations and Materials

- ***Association on Higher Education and Disability (AHEAD):*** AHEAD is a professional membership organization for individuals involved in the development of policy and in the provision of quality services to meet the needs of persons with disabilities involved in all areas of higher education. www.ahead.org
- ***Association of Higher Education Parent/Family Program Professionals (AHEPPP):***

AHEPPP is a professional association of higher education professionals who are working to engage families to help ensure student well-being and success. www.aheppp.org

- **American Council of the Blind (ACB):** *Guide to a Successful College Experience.* www.acb.org/node/387
- **Autistic Self Advocacy Network:** *Navigating College.* www.autisticadvocacy.org/home/projects/books/navigating-college
- **Center for Parent Information and Resources:** Serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRCs), so that they can focus their efforts on serving families of children with disabilities. www.parentcenterhub.org
- **DO-IT:** The DO-IT (Disabilities, Opportunities, Internetworking, and Technology) Center is dedicated to empowering people with disabilities through technology and education. It promotes awareness and accessibility—in both the classroom and the workplace—to maximize the potential of individuals with disabilities and make our communities more vibrant, diverse, and inclusive. www.washington.edu/doiit
- **Job Accommodation Network (JAN):** JAN is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. Working toward practical solutions that benefit both employer and employee, JAN helps people with disabilities enhance their employability, and shows employers how to capitalize on the value and talent that people with disabilities add to the workplace. www.askjan.org
- **Landmark College:** *A Guide to Accessing College Readiness.* <https://aea8transition.files.wordpress.com/2013/04/guide-to-assessing-college-readiness-v5pgs1.pdf>
- **Minnesota State Colleges and Universities (MnSCU):** *Postsecondary Resource Guide:*

Successfully Preparing Students with Disabilities for the Postsecondary Environment. www.normandale.edu/Documents/osd/Resource_Guide-Reduced_Size.pdf

- **National Youth Transitions Center:** *Planning Ahead: Financial Aid for Students with Disabilities.* <https://heath.gwu.edu/2014-2015-heath-nytc-planning-ahead-financial-aid-students-disabilities>
- **PACER Center:** An extensive number of materials and resources relating to the role of families of youth with disabilities are available online. www.pacer.org/transition
- **Ticket to Work:** Provides access to employment services for social security beneficiaries. www.chooseworkttw.net/findhelp
- **Transition Year:** *Emotional Health & Your College Student: A Guide for Parents.* www.transitionyear.org/downloads/parent_pdf_guide.pdf
- **Work Incentives Planning and Assistance (WIPA):** The WIPA program enables beneficiaries with disabilities to make informed choices about work and supports working beneficiaries to make a successful transition to self-sufficiency. www.socialsecurity.gov/work/WIPA.html
- **WNY College Connection:** College Parents section of their website. www.wnycollegeconnection.com/parents-college-parents.100049.content

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local workforce development systems to integrate youth with disabilities into their service strategies. This

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