



Engaging Families and Raising Expectations around Employment

Perspectives from and Strategies for the Administration on Disabilities Grantee Network

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Introduction

Families play a critical role in supporting preparation and successful employment for their family member with a disability. This is especially true for families of persons with higher support needs. While the larger disability community continues to work towards increasing access to competitive employment for all, some families may take a more cautious approach to real jobs in the community. The reasons for this tend to be rooted in fears over vulnerability, misunderstandings around the role of Social Security benefits, lack of examples of how people can be supported on the job, and lack of trust that the existing service system can provide needed supports. These misgivings also represent an opportunity for various disability stakeholders to engage families and provide them with the information needed to become partners in the employment process.



The [Disability Employment Technical Assistance Center \(DETAC\)](#) provides training and technical assistance (TA) to the network of [Administration on Disability \(AoD\)](#) grantees. These grantees include [Centers of Independent Living \(CIL\)](#), [State Councils on Developmental Disabilities \(Council\)](#), [University Centers for Excellence in Developmental Disabilities \(UCEDD\)](#), [State Protection and Advocacy entities \(P&A\)](#), and [Traumatic Brain Injury \(TBI\) State Partnership Programs](#).

All these entities provide services directly to people with disabilities, which include advocacy and training around accessing competitive employment. All of them have the potential to provide information and support to families that raise expectations that a real job in the community is possible for their loved one. The main challenge is to do so within the parameters of a project's core functions.



This brief seeks to provide examples of what the DETAC partners are currently doing to engage families around competitive employment and to offer recommendations for expanding that effort.

Perspectives from DETAC's Partners

To ensure that the information contained in this brief is reflective of the core requirements and experiences of DETAC's primary audience, the authors conducted a series of interviews with national experts from a P&A, UCEDD, Council, TBI Grant Project, and CIL. These experts were asked about what they are doing currently to engage families in employment and what they think their fellow agencies *could do better* to engage families in the future. The authors would like to thank them for their time and expertise.

The Pivotal Role of CILs in Encouraging Families to Proactively Support Employment of Individuals with Disabilities: Highlights from Able SC



Staff of CILs may feel conflicted when considering their role in engaging families around the issue of competitive integrated employment (CIE) for their loved one with a disability. CILs are consumer-controlled and consumer-focused, meaning their primary audience has always been individuals with disabilities. However, given our interdependent nature, it is important to acknowledge the role families play in supporting a person's employment success. [Able SC](#) staff believe that CILs can honor their commitment to remain consumer-driven while providing valuable information to families about supporting employment success. It's all about who's driving the bus.



“In our transition work, our focus is the student, but families are crucial to the process. We say families can be a part of the services we offer as long as the individual wants them involved,” says Makenzie Allison, Education and Transition Advocate at Able SC. Families often will come to CILs as a source of information and referral for their loved one, and this includes seeking information about employment resources. Instead of turning them away, Sandy

Jordan, Able SC's Director of Employment Services approaches it as an opportunity to build the capacity of families to help their family member envision their own future and be the main driver of the steps to get there. “Our role is to work with the families to make sure the individual is driving their own services, and sometimes this means having difficult conversations with families.” reports Jordan.

Able SC has created a family page on their [website](#) with information about employment and self-determination and conducts statewide workshops for families on benefits planning and employment. Jordan recognizes that CILs can leverage the energy of both individuals with disabilities and their families as partners in changing policies and practices related to employment services.



Promoting Family Awareness and Engagement in Employment as a Council: Strategies from the Kansas Council on Developmental Disabilities



The [Kansas Council on Developmental Disabilities](#) is active in efforts to improve employment for persons with a disability in their state. They see families of persons with a disability as an important partner in the success of employment for their family member. To this end, the Council has partnered with the University of Kansas UCEDD to develop a Family Employment Awareness Training, which is provided to families on an on-going basis by [Families Together](#), the Kansas Parent Training and Information Center.



Steve Gieber, Executive Director of the Kansas Council on Developmental Disabilities, points out that school-based disability-related services at the K-12 education levels are mandated, whereas post-education employment services are not mandated. As Gieber describes, “By the time a student with a disability reaches transition age or exits the school system, the families are tired. They see graduation is a time to relax. They don’t realize it’s a time that they need to be more involved and advocating for the services and supports their family member will need as an adult.” In addition to the Family Employment Awareness Training, the Council provided [Charting the Life Course](#) materials and resources, which guide families in focusing on the current situation and stage of life and help people look ahead to think about life experiences that will help move them toward an inclusive, productive life in the future.



Promoting Employment First Systems-Change at the State-level: Promising Practices from Disability Rights Indiana

[Indiana Disability Rights \(IDR\)](#) is the state’s P&A organization. The P&A organization’s mission is to protect and promote the rights of individuals with disabilities through empowerment and advocacy. IDR has been involved in making Indiana an *Employment First* state by educating legislators and others on the implications and benefits of focusing publicly financed services on supporting individuals with disabilities to pursue and obtain CIE. Now that Indiana is an *Employment First* state, IDR is participating in interagency discussions on how to implement policies and allocate resources consistent with their *Employment First* directives. IDR works closely with the Indiana Governor’s Council on People with Disabilities to promote policies and provide education to improve employment for persons with disabilities.

IDR has been involved in assessing why working in a sheltered workshop or participating in Day Services was being chosen over CIE. Emily Munson, Senior Attorney for Health Care and Policy at IDR, indicated that in many cases, the person in the sheltered workshop or day habilitation program stated that their guardian was choosing not to consider CIE.





Munson emphasized, “When a child with a disability is young, parents should set high expectations for their child and advocate for the plan or services that are needed. As the child grows older, parents need to help the person with a disability learn decision-making skills so they can advocate for themselves. A person with decision-making and advocacy skills is better suited to a supported decision-making agreement than a guardian.”

Munson emphasized that school transition counselors, case managers, community rehabilitation providers, families, and persons with a disability would all benefit from training on client rights and confidentiality.

Encouraging Individuals with Brain Injury to Pursue or Return to Work: Learnings from Minnesota’s Department of Human Services

The Administration on Community Living (ACL) currently funds 27 TBI State Partnership Grants around the country. The grants are charged with improving access and service coordination for those experiencing a TBI, planning for sustaining key improvement activities once federal funding ends, and engaging in systems change so states can evaluate and improve current systems. Eileen Kelly is the Grant Manager for the Minnesota TBI State Program Project, which leverages collaborations throughout the state, including Centers for Independent Living, to provide training and advocacy. Among the key audiences are families of those impacted by TBI. Kelly reports that Social Security benefits and health care tend to be major issues when people are considering going back to work after experiencing a TBI. Her project partners with the Disability Hub MN™ to provide information to families, self-advocates, and professionals surrounding the impact of work on benefits and conversations around employment.

Kelly states, “A lot of people who are brain injured don’t believe they can work. They need somebody to help them see that it can happen.” This need extends to families, who often have trouble envisioning how employment can happen after skill set changes or the need for accommodations based on chronic pain or new sensitivities. To meet this need, the TBI project participates in online “Work Is Possible” seminars that lead families through key resources and strategies to provide information and address questions. Not all TBI grant projects are required to focus on employment issues, but Kelly suggests that the ones who do consider creating a centralized source for families to get information and support. This would have to be done in partnership with a Center for Independent Living or another advocacy organization. She also cautions that work conversations need to be flexible based on the cultural background of the family.



Educating Families of People with Disabilities on the Benefits of Employment: Examples from the University of Illinois-Chicago's Institute on Disability and Human Development



The [Institute on Disability and Human Development \(IDHD\) at the University of Illinois, Chicago](#) is part of a national network of UCEDDs. These Centers can be vastly different, with some operating in the medical world while others being more community-based in their activities. However, regardless of their operating focus, the UCEDDs all can play a crucial role in supporting and informing families of individuals with a disability about CIE. In fact, Robin Jones, Instructor at the University of Illinois-Chicago's Institute on Disability and Human Development, see multiple ways families can be supports within the core functions of the UCEDDs.



“Where we are most effective is when we provide accurate and impartial information so families can navigate the service systems in their state and see the bigger picture of how it all works together,” says Jones. Many UCEDDs employ staff from the disability community who have previous experience working for CILs or Community Rehabilitation Providers. This approach allows them to train families from an informed place. In addition to parent training, UCEDDs often are contracted by other entities (such as Councils) to create and deliver quality training to families.

Some other ways Jones believes UCEDDs can support family engagement is to push for expanded research, especially looking at what impacts employment outcomes and expectations. Another option is to create opportunities to train pre-service students on strategies to build effective family partnerships. If the UCEDD is more medical-focused, they can explore ways to connect people to needed technologies and promote links between employment and medical management plans.

Recommendations

While each category of AoD grantee has unique contributions it can make to furthering state employment systems change and improving CIE outcomes for individuals with disabilities, the following recommendations are applicable for any AoD grantees who are considering how to engage and support families in the employment conversation:

1. Recognize that you play a role in advocating for competitive employment options and informing and supporting families towards that goal, regardless of your funding stream or core project activities. You can improve your ability to collaborate with individuals with disabilities by finding ways to effectively engage their families.
2. Many of those interviewed utilized partnerships to enhance their engagement of families around employment. Consider collaborating with [Parent Training and Information Centers](#), disability-specific advocacy organizations, or multicultural community organizations. They can help access families and be a trusted avenue for information dissemination.



3. Seek interpersonal and interactive ways to support and train families. This includes participating in parent workshops in the community or offering one-on-one support on employment issues via telephone or chat. Printed resources and websites are good options for some families, but they don't serve to coach or connect to resources the way in-person interaction does.
4. Acknowledge that many families are apprehensive about exploring competitive employment and their apprehension is often rooted in real fear and lowered expectations. Address family fears about employment in a respectful manner and make it a goal to raise expectations that real work is possible.
5. Leverage your roles to improve policy and practices within employment systems that positively impact families and their ability to support their loved one towards employment success. This may include organizing families to give testimony to elected officials, creating projects that offer information and referral to underserved communities, or sponsoring professional development that helps employment providers better understand and partner with families.

Summary

Families play a vital role in helping guide their loved one with a disability towards competitive employment. However, families of individuals with significant disabilities often have real fears about community employment and may make decisions that favor safety over self-determination. The agencies served by the DETAC all play a unique role in promoting systems change and furthering the idea that real jobs at real wages should be the goal for all people with a disability who desire it. But they also should envision themselves and playing a part in supporting families and raising expectations that real work in the community is attainable. This includes partnering to provide on-demand information and referral, creating effective trainings for families, preparing our future professionals to build relationships with families, and advocating for lasting positive changes in policy and practice.

