



The Voice of Families: Exploring Perspectives on the Pathways to Integrated Employment

"I'll be honest, sometimes it feels like a full-time job trying to get in touch with resources and figuring out what we can do."

~Mother of 21-year-old daughter with IDD

This research study was supported through funding from the Rehabilitation Research and Training Center (RRTC) on Employment of Persons with Intellectual and Developmental Disabilities. The VCU-RRTC is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant #90RTEM000301-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).

Like anyone else, youth and adults with intellectual and developmental disabilities (IDD) want to participate fully in the life of their community. Although there are many different avenues for community inclusion, finding a good job may be among the most impactful. A satisfying job provides opportunities to develop new friendships, share one's talents, meet the needs of others, learn new skills, and assume valued roles. Moreover, a regular paycheck provides resources for meeting personal needs and makes involvement in other community activities possible. A good job can make a powerful difference in the lives of individuals with IDD!



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The Challenge

Yet far too many individuals with IDD lack the encouragement, opportunities, and supports needed to find a great job doing something they enjoy. In fact, the employment outlook across the country remains as concerning as ever. Across the United States, less than one fifth of adults with IDD hold jobs in their local community. Here in Tennessee, only 16% of working-age adults with IDD are employed.¹ These outcomes certainly do not reflect the aspirations of individuals with disabilities. Indeed, youth and adults with IDD are quite clear about their desire to share their gifts and talents in the workplace.²

What will it take to change the employment landscape for individuals across our state and around the country?

The Contributions of Families

Parents, siblings, and other relatives are deeply committed to the flourishing of their

“I’m a mama bear. And so a lot of what I’ve learned is trial and error, and hunting and pecking and emailing. And I have spent unbelievable amount of hours, and I still don’t have all the answers.”

~Mother of 22-year-old son with autism

family members with IDD. Indeed, families can be instrumental in helping them prepare for and pursue jobs in their local community. For example, research finds that the expectations and investment of families can bend the employment trajectories of individuals with IDD in positive directions.³ Families also have valuable experiences and insights into the employment pathways of their members with IDD. Inviting their perspectives and listening to their recommendations is absolutely essential when developing new approaches for elevating employment outcomes.

Study Overview

We are committed to hearing from families about the pathway to integrated employment. The purpose of this qualitative study is to examine the perspectives and recommendations of parents and siblings regarding the employment of their family members with IDD.

► RESEARCH QUESTIONS

We are exploring three primary research questions:

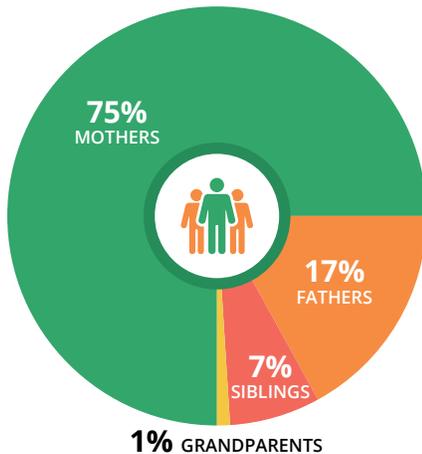
1. How do parents and siblings define and prioritize “meaningful employment” for their family members with IDD?
2. What barriers to integrated employment do they identify for their family members with IDD?
3. What do they say is needed to facilitate integrated employment for their family members with IDD?

1. Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J.. (2019). *StateData: The national report on employment services and outcomes*. Institute for Community Inclusion.

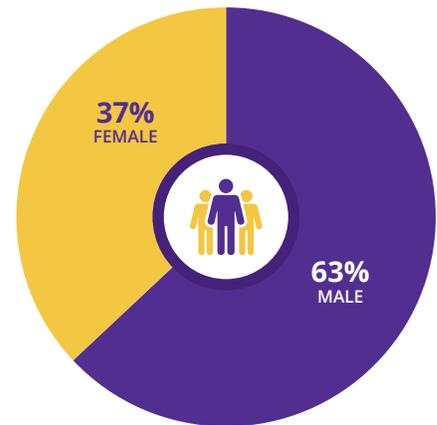
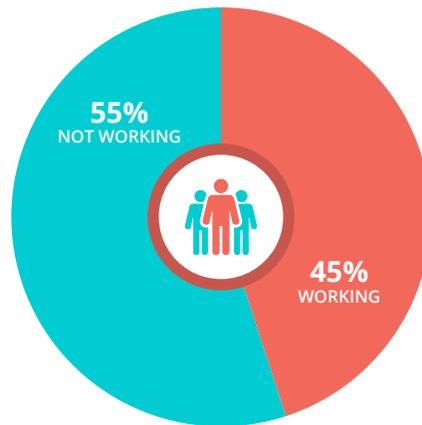
2. www.nationalcoreindicators.org; Lipscomb, S., Haimson, J., Liu, A. Y., Burghardt, J., Johnson, D. R., & Thurlow, M. L. (2017). *Preparing for life after high school: The characteristics and experiences of youth in special education (Vol. 2)*. U. S. Department of Education.

3. Carter, E. W. (2015). *What matters most: Research on elevating parent expectations*. Boston, MA: Institute for Community Inclusion

Participants



Family Members with Disabilities



► PARTICIPANTS

We have already interviewed 60 parents and siblings of individuals with IDD (ages 16 and above). We partnered with our project's advisory committee and over 50 organizations to recruit participants. All participants were from Tennessee, with the majority living in urban or suburban communities. Most were mothers (75%), 17% were fathers, 7% were siblings, and 1% were grandparents. Their average age was 56 (range 24 to 81) and one third were non-White.

Their family members experienced a range of disabilities, including intellectual disability (65%) and/or autism spectrum disorders (50%). Most (63%) were male and 37% were female. Their average age was 27 (range, 16 to 60). Almost half (45%) were working in the community at the time of our interviews. Those jobs spanned a range of industries, including food preparation, retail, entertainment, custodial positions, and child care.

► INTERVIEWS

We used a combination of individual interviews ($n = 31$) and focus groups ($n = 6$) to solicit the views and recommendations of participants. These conversations typically lasted between 60-90 minutes. With the onset of the COVID-19 pandemic, we held many of our interviews using Zoom. We developed a semi-structured interview protocol that addressed all of our research questions and invited participant feedback on an initial version of our proposed intervention.

► ANALYSES

We are analyzing these data in light of our three primary research questions. Subsequent project briefs will highlight key findings and implications related to each of these areas. In addition, full research reports will be submitted for review in relevant journals.

Next Steps

We are drawing on the experiences, advice, and stories of families to design a new intervention that will be both effective and feasible to implement. The information parents share will shape how we approach all aspects of the study—from recruitment to intervention delivery to the evaluation of outcomes.

The study is the first phase of a five-year research project focused on equipping parents to address the employment outcomes of their family members with IDD. Specifically, we will:

Develop a practical mentoring intervention package that provides parents with relevant information and personalized support

Evaluate the package's impact on employment outcomes within a rigorous study

Examine how the intervention is implemented across contexts

Package and disseminate the intervention in widespread ways through our extensive state and national networks

The research is being conducted by a team from Vanderbilt University and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (VKC UCEDD). We are also receiving guidance from a strong advisory board comprised of individuals with disabilities, family members, professionals, and state leaders.

This research is one component of the *Rehabilitation Research and Training Center (RRTC) on Employment of Persons with Intellectual and Developmental Disabilities*. Collaborators include Virginia Commonwealth University, University of Wisconsin-Madison, Kent State University, and Vanderbilt University/VKC UCEDD. More information can be found at idd.vcurrtec.org.

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"He wants to be independent. He enjoys it. He loves his job. He's very happy as he comes out of that job and he tells me about what he's did during the day. It impacts him positively."

~Father of a 22-year-old son with autism