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Knowledge Translation and Support for Individuals and Families (Bringing Employment First to Scale, Issue No. 5)

ThinkWork! at the Institute for Community Inclusion at UMass Boston

Knowledge Translation and Support for Individuals and Families

Introduction

With the persistently low competitive employment rate for working-age people with intellectual and developmental disabilities (IDD), a main focus area for the field of disability research has been on the interaction between the individual and the service system. Yet we know much less about the interaction between systems and families around employment.

Family engagement is key to successful employment and life planning, often leading individuals with disabilities on the path to employment when family members serve as role models for work ethic and behavior.[2] Family members may also provide logistical support,[3] including coaching and advice, help with planning and organizing work schedules and activities, and transportation and other resources.[4] Moreover, research has shown that a person with IDD is most likely to be employed when their parents want them to be employed and believe that they can work.[5]

Despite these findings, we also know that parents often lack adequate knowledge to support their child's transition to adult life. Family factors found to influence outcomes include lack of information about work incentives and fear of losing benefits.[6]

What do we know about the importance of service system/family engagement?

Research has shown that since at least one parent, sibling, or other relative close to an individual with IDD is likely to provide some form of support, the disability service system's engagement of that supportive person early and often increases the likelihood of smooth transitions and a positive outcome.[7] The frequent engagement of family members over time provides opportunities for families, individuals, and service professionals to build trusting relationships and a sense of partnership; communicate about individuals' support needs, preferences and goals; and review information about navigating services and options.

This brief:

» Summarizes what we know about the effectiveness of strategies being used to inform, engage, and support individuals with intellectual and developmental disabilities (IDD) and their families in the development of a positive employment vision.

» Introduces a new line of individual and family engagement research that culminates in the development of a "small touch" intervention and strategy. This strategy addresses unemployment of people with IDD as an information mismatch between service systems and the family system. Addressing this mismatch can result in improved engagement, expectations, education, and outcomes in community employment.

What are the barriers to family engagement?

For a number of reasons, families do not take advantage of programs and services available to their family members with IDD. While it might be easy to assume that families choose not to approach the service system, circumstances including financial challenges, a language barrier, or a focus on day-to-day coping and providing for family members with high support needs may be the cause for this disconnect.[8] In addition, families and service providers may not have a shared understanding of the importance and purpose of collaboration.

A recent review has identified a number of online and in-person trainings and curricula to help families acquire advocacy skills and support their family members to navigate service systems.[9] While families have reported that these trainings have raised their expectations for employment, and have educated them about how to access supports and services, they can also leave individuals and families with more unanswered questions. Why haven't they learned about these options earlier? How might these services apply to their family member's unique situation? What resources are available as they continue on the employment planning path?

As noted by Self-Advocates Becoming Empowered, families can act as both supports and barriers to employment success: "[We need to] get families on board…Families are still stopping people from working because they are afraid a person will lose their Social Security or Medicaid benefits."

How will this project support the disability service system to engage families in the pursuit of successful employment outcomes for individuals with IDD?

The Rehabilitation Research and Training Center on Advancing Employment for Individuals with IDD is designing a "small touch" intervention that will test information-sharing strategies for individuals and family members. Our study of individuals and families began with a review of literature, and a series of in-person and online interviews and focus group discussions to understand how individuals and families develop a positive employment vision, gain access to information, and locate resources to move forward on their employment paths.

What's next?

The next phase of the study will test a strategy aligned with individual and family preferences for how and when information is received, and what information is delivered. It will be designed based on findings from the literature review, interviews, and focus groups. The first phase of the study will develop a comprehensive information, outreach, and support framework and define a concrete intervention. The framework will define a holistic strategy and range of options for providing information to individuals and families, and engaging them in creating an employment vision that emphasizes ready and timely access to information throughout the lifespan and respects individual and family differences in culture and preference.

In the second phase, we will refine, test, and implement an intervention with individuals and their families in two to three geographic areas, and collect both quantitative and qualitative data from participants. The project will use an experimental design supplemented by qualitative analysis.

This research will test the impact of a six-month intervention on knowledge, attitudes, and behaviors around employment. It will also track progress toward an employment-related outcome. The intent will be to provide a package of strategies and resources that supports both individuals and their families in the pursuit of community employment. This initial intervention study will begin with a more limited target population and build plans to scale up in future research.

What's the goal?

» To provide a package of strategies and resources that supports both individuals and their families in the pursuit of employment.

How will we get there?

» Conduct a thorough review of both academic and more mainstream literature on effective strategies to inform, educate, and engage families and individuals.

» Host online and in-person discussions with individuals and families about strategies, barriers, and gaps in support and knowledge.

» Develop an intervention that shapes knowledge, attitudes, and behaviors of individuals and family members around community employment.

Our research questions:

» What should be included in a comprehensive information, outreach, and support framework for individuals and families?

» What is the outcome of this intervention in changing knowledge, attitudes, and behaviors of individuals and their families?

What is the RRTC on Advancing Employment?

The Institute for Community Inclusion (ICI) conducts research on state-level policy and practice around integrated employment. In 2014, ICI received a grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), to develop the Rehabilitation Research and Training Center (RRTC) on Advancing Employment for People with Intellectual and Developmental Disabilities. The purpose of this research is to identify strategies to support state agencies, providers, advocates, individuals and families to make the philosophy of Employment First a reality.

Sources

1 Petner-Arrey et al., 2016.

2 Dixon & Reddacliff, 2001; Timmons et al., 2011; Whiston & Keller, 2004.

3 Kramer & Timmons, 2014.

4 Timmons & Wolfe, 2010; Whiston & Keller, 2004.

5 Dixon & Reddacliff, 2001; Freedman & Fesko, 1996; Taylor & Hodapp, 2012; Carter et al., 2011.

6 Winsor et al., 2010; Hall & Kramer, 2009; Luecking & Wittenburg, 2009.

7 Fourqurean et al., 1991; Rosenthal et al., 2012.

8 Timmons et al., 2004.

9 Spann et al., 2003.

10 Francis et al, 2013; 2014; Field and Hoffman, 1999; Test and Rowe, 2010; Yamamoto et al, 2014.

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ThinkWork!

ADVANCING EMPLOYMENT AND OPPORTUNITY FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities.

For more information:
John Kramer | john.kramer@umb.edu
Research Associate | Institute for Community Inclusion

www.ThinkWork.org/rrtc