DRAFT

RRTC on Advancing Employment for Individuals with IDD

July, 2017

State of the Science Paper – Engaging Families

Brief Summary

Introduction

Since the introduction of supported employment in the Developmental Disabilities Act of 1984 and the Rehabilitation Act Amendments of 1986, there has been continued development and refinement of best practices in employment services and supports. Despite these achievements, the promise of integrated employment has not been realized for many individuals with IDD. The number of individuals supported in integrated employment by state IDD agencies has remained stagnant for the past fifteen years, participation in non-work services has grown rapidly, and individual employment supports are not implemented with fidelity to a consistent model or expectations (Butterworth et al, 2016).

Responding to this need, the Rehabilitation Research and Training Center (RRTC) on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a research project housed at the Institute for Community Inclusion (ICI) at the University of Massachusetts Boston. It is part of the ICI's ThinkWork! initiative, a group of projects promoting community employment for people with IDD.

The RRTC's work covers 4 main strands:

Strand 1. Sharing knowledge with and supporting individuals and families around employment.

Strand 2. Increasing the effectiveness of employment consultants

Strand 3. Building capacity and supporting organizational change for community rehabilitation providers

Strand 4. Furthering policies and practices of high-performing state employment systems

This brief addresses findings from Strand 1: Sharing knowledge with and supporting individuals and families around employment.

Background

Families can be the most influential component in successful employment and life planning, often leading people with disabilities on the path to employment by serving as role models for work ethic and behavior. Yet, families often lack the required knowledge to move employment from an abstract belief to a real job. While a growing body of research suggests the positive effects of family engagement on employment, much of this work focuses on increasing the knowledge and capacity of families around employment. Though a laudable approach, it may add burden to families. There is a relative lack of research exploring the best methods for not only sharing information with families but involving them in the employment process. This brief summarizes a paper (State of the Science: Engaging Families, 2017) that explores the role of families in individuals' employment outcomes through a scoping literature review, as well as findings from a qualitative study involving family members and individuals. We hypothesize that an important reason employment outcomes have not improved despite

increased adoption of Employment First across states is that families get uneven, inconsistent information from systems that changes regularly. We ask two main questions: 1) What does the literature say about successful strategies in engaging families in employment?; 2) What types of information are useful to families whose child is going through a transition to employment in the community?

Findings from the Scoping Literature Review

To investigate what the literature says about successful strategies in engaging families in employment, a scoping literature review was conducted. Three main themes emerged: 1) Family members' modeling of roles and expectations shape positive experiences of employment for people with IDD; 2) Engaging with families leads to employment-focused decisions; and 3) Family and individual demographics are related to employment decisions and patterns.

Facebook Forums, and Focus Group (FFFG) Study Methods

Building on the results from the scoping literature review, this study addressed the following questions:

1. Where do individuals and families seek information on employment?
2. What types and sources of information about employment do individuals and families find most useful? What formats for information-sharing do they find most useful?

3. How do individuals and families interact with the service system to pursue employment outcomes? How does this interaction vary based on family cultural background?

Eighty people with IDD and their family members were recruited through extensive outreach. Online engagement occurred through general discussion forums, as well as a private Facebook group through which researchers posed questions around employment, allowing participants to interact and introduce new topics over time. In addition, telephone interviews and in-person focus groups were conducted in five states to ensure that we were covering the breadth and depth of individuals' experiences.

Findings from Forums and Focus Groups

Finding 1. Family members identified confusing guidance by and low expectations of the service system and culture in general as a persistent problem. Government-funded services are viewed as the only option for those with limited resources. Perceived system rigidity and lack of ease of navigation make utilizing this system difficult. Failure to realize a satisfactory employment outcome through the government system leaves families feeling as though they have exhausted all options and thus employment is out of reach.

Finding 2. There is a lack of alignment and continuity in services. Families report feeling disheartened when a successful employment outcome is not achieved and their case is closed by the state agency tasked with assisting them. Further, they report, that to re-enter the system, they must begin the application process anew. Compounding systemic navigation is the lack of alignment of priorities, expectations, and goals among

varied state entities (e.g., school system, developmental disability service agency, and vocational rehabilitation).

Finding 3. The system lacks capacity and seems unable to meet individuals' needs. While specific professionals have been helpful, families indicated that lack of employment training provided to personnel and low system capacity due to funding streams and organizational structures have hindered goal attainment. Such ongoing challenges lead to frustration for job-seekers and their families.

Finding 4. Self-advocates had more positive comments when they described relying on themselves and family member engagement, and not solely on employment services. The bright spots in this study mostly appeared when people with IDD and their families were driving the employment agenda and outcome, learning about funding sources, and networking with other families. Some participants saw the most success when they chose to use the service system in combination with other resources, found jobs on their own, or used funds from other programs to start a business.

Discussion

The themes that emerge from this work evoke a sense of frustration of people with IDD and their families about systemic inefficiencies, but also offer some hope. Participants both expressed that the current system feels like it may never be able to meet demand, and that employment can happen with perhaps no system help or, at the very least, much lighter involvement.

    Taken together, these themes and the results from our scoping literature review confirm the importance of family involvement/engagement in employment planning, but

also indicate families' feelings of frustration with the process. It is likely that, as employment systems continue to be challenged by budget shortfalls and competing priorities, parents and other family members may be expected to know more and engage in greater advocacy towards successful employment outcomes.

Recommendations

Recommendation 1: Train staff on how to foster partnerships with families through face to face and individualized interactions. Explore methods of increasing social capital through low-cost activities such as social media and through private messaging (e.g., texts, emails, etc.). This will build in a sense of community between families and employment specialists through increased familiarity and understanding of family contributions to employment outcomes.

Recommendation 2: Increase communication among the local stakeholders. Activities aimed at unifying information into a single source for families would decrease confusion and inconsistencies among state agencies.

Recommendation 3: Develop a plan for sustaining families; learn from them about what works. Families are a source of knowledge and expertise around their members with IDD. It is possible to learn from them, not just about their personal knowledge as a family member, but from their long-term experiences in navigating supports and working strategically within a resource-deficient system.