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Beyond Training: Engaging Families in the Transition to Employment (Bringing Employment First to Scale, Issue No. 12)

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By John Kramer, Jennifer Bose, and John Shepard

Introduction

Families can be the most influential factor in successful employment and life planning for people with intellectual and developmental disabilities (IDD), often leading them on the path to employment by serving as role models for work ethic and behavior. Yet families often lack the 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, it often emphasizes trainings to improve engagement. There may be other strategies worth exploring.

We conducted an extended search of trainings provided by state agencies and service providers that are targeted towards families. Trainings in the form of written material (handbooks, brochures and computer-based courses) or given in person by service professionals, peers and others have been found to raise expectations that family members with IDD can become employed in their communities. While an extensive review of these materials is beyond the scope of this brief, we surmise that they continue to be useful in changing families' level of knowledge about employment possibilities, job search strategies, job accommodations, and benefits planning. However, training on its own, without deeper engagement with families, may add to families' burdens and questions around obtaining employment. There is a lack of research exploring the best methods of both sharing information with families and engaging them in the employment process.

In spite of perceived benefits offered by trainings, it is not clear that they work well for every family. There remains a persistent gap in information and services for many families, and a further gap in employment for people with IDD. This brief summarizes findings of a scoping literature review (Kramer, Bose, & Winsor, in preparation) on the engagement of families in individuals' employment outcomes. We explore the gaps in services, information and employment and the different engagement strategies used.

What did we learn?

To learn about ways to engage individuals with IDD and families to develop employment visions and outcomes, we reviewed what other experts have found. This review confirmed that there is a relationship between family engagement and employment of people with IDD. Some selected references are included in this brief.

Family engagement in employment appears to occur in a few overarching ways, all related to improving employment outcomes for people with IDD across the life course:

1. Family members' role modeling and expectations shape positive experiences of employment for individuals.
2. Advanced knowledge and capacity within families leads to employment-focused decisions.
3. Family and individual demographics are related to employment.

Family engagement is a critical factor leading to good employment outcomes, and the resources and strategies used by families are well described in the literature. However, the focus of this research is limited to families of transition-age youth. This

> *Employment...[is] about the whole person...understanding what's needed, what the resources are, and how to get there.*

age group is important, but limits knowledge around family involvement in employment. It leaves out younger children, does not address building foundational skills and values and expectations earlier in life, and excludes people who are past transition age.

Recommendations

Taking these findings into consideration, we offer the following recommendations to guide people with IDD and their families toward employment:

Connect with families earlier to shift employment expectations. Findings indicate that the service system should connect with families earlier to shift employment expectations. Modeling of work roles by family members has a positive impact on employment for people with IDD, and family members' early expectations are powerful. Thus, the earlier service professionals and families can engage around employment, the sooner a positive vision of employment can be created.

Offer post-training follow-up. Although most studies of training opportunities for people with IDD and families described the development of the training and what took place, only a few studies evaluated the effectiveness of the trainings and raised important points about retaining gains in knowledge, expectation, and motivation to act.

Individual follow-up is critical, whether immediate or long-term. Knowledge gained from written material is easier to retain and act on if people can spend time reviewing it or asking a trainer questions about it. People also need encouragement to take advantage of any long-term technical assistance following a training.

Follow-up offers the opportunity to individualize the training experience. If some participants need a higher level of support or need more information about local resources, the opportunity to follow up relatively quickly with a trainer will increase the value of the experience.

Create long term relationships, stay engaged with families. Families with advanced knowledge of the service system and the capacity to develop partnerships with service professionals are likely to see successful outcomes for their family members

with IDD. Service professionals should identify parents in these families as taking on the roles of teachers, advocates, and case managers of a range of services to smooth out the transition process, while siblings can support the socialization of their brother or sister with IDD.

Be aware of the relationship between demographics and employment patterns. For some families with financial challenges or members with high support needs, managing day-to-day logistics is a more critical concern than focusing on the future. Language barriers may prevent families within immigrant communities from engaging with the service system, although they are frequently interested in learning about services and adopting new ideas or models, such as the practice of self-determination. As you encounter these obstacles, be persistent and respectful. Families may be more interested and engaged than they seem to be.

What's next?

This literature review suggests that individuals and their families have reached "oversaturation" from trainings and programs related to employment. Although these initiatives provide information on accessing supports and services, and raise employment expectations, they can also leave families with more questions. At the same time, while service professionals acknowledge that families are important to the successful transition of individuals with IDD, they remain unclear on how to engage them (Chappel, 2010).

> *...organizations [should] understand what other related organizations do so that they can direct families to their services when necessary.*

To understand more about pros and cons of various engagement strategies, we are conducting an intervention to study the effect of using social media and text messaging with families on their motivation to use The Arc's Build Your Plan tool during the transition to employment. **Visit www.thinkwork.org/ for more details.**

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The 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.

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