

Engaging Families Effectively:

Results From a Forums and Facebook Group Qualitative Research Study

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Context

- Supported employment was introduced with the Developmental Disabilities Act in 1984; amended in 1986
- Demonstrations of best practices
 - Self-employment and customized employment for individuals
 - Providers offering only competitive employment
 - States adopting Employment First policy and strategy

Employment gaps persist

- Numbers of people being served in integrated employment have not increased for 15 years.
- Participation in nonwork programs is growing.
- Supports are not implemented with fidelity.

ThinkWork!

- RRTC on the Advancement of Employment studies ways to advance best practices at all levels
 - Sharing knowledge with and supporting individuals and families around employment.
 - Increasing the effectiveness of employment consultants
 - Building capacity and supporting organizational change for community rehabilitation providers
 - Furthering policies and practices of high-performing state employment systems.

Sharing knowledge with individuals and families and supporting them around employment

- The first study: Scoping review of all the literature in this area
- Second study: Forums, interviews and focus groups
- Third study: Intervention based on study findings

Employment and family involvement: What we know

- People with IDD want to work [Show NCI data from 2016 about this].
- Families engaged with the employment process and showing cooperation, interest, encouragement, planning and support = positive outcomes for people with IDD in employment and other life goals [Rowe and Hirano, 2015].
- Family members, i.e. parents and siblings, often provide support to people with IDD over the course of their lives

What we don't know

- As important as family engagement is, we don't know how to do it effectively
- Tools and training have been developed [Explore, Prepare, Act; Let's Get to Work; FEAT] but are they scalable, sustainable and accessible to all families?

What we learned from our scoping study

Families are trying to do a lot of the work

- Families' role-modeling and expectations shape positive experiences and perceptions of employment
- Family engagement with the service system leads to employment-focused decisions
 - Parents as teachers, advocates and case managers
 - Siblings as socializers
- Family and individual demographics are related to employment decisions and patterns

Forums, focus groups and interviews

- Learning how to engage families
- 80 people were recruited for diversity of age, geographical region and cultural background.
- Focus groups and interviews in five states
- Online engagement through discussion forum and private FaceBook group

Benefits of using these methods

- Enriched our scoping review data
- Gave us data from a total of 80 participants
- Collected in-depth individual narratives from interviews.
- Collected many perspectives from focus groups.
- Asynchronous conversation was convenient and organic for forum and Facebook participants

Challenges and lessons learned

- Be persistent about recruitment, especially online participants.
- Remind online participants to post.
- Be careful of bias and responses building on one another in focus groups.

Finding 1. Confusing guidance and low expectations from the service system

- People receiving services expected to transition to receiving new services.
- State assessments don't offer full picture of individuals' potential.

Finding 2. Slow service, inconsistent rules

- Service delivery is cut off too soon or slowed down by the need to reapply
- Rules, waiting lists and job opportunities are inconsistent across education, VR and DD systems

Finding 3. Limited capacity of the service system to continue serving people with IDD and their families as they have been doing

- Limited staff training
- Growing waiting lists of people needing services
- It can be a struggle to achieve an employment outcome if everything is left up to the service system.
- Participants did talk about specific professionals who were helpful within the service system.

Finding 4. Success through self-reliance and family engagement

- Success seemed more likely when people with IDD and their families drove the employment process, learned about funding sources and networked with other families for more advice and information about services.
- Participants seemed to find more success when using the service system along with other resources, finding jobs on their own or finding funds to start their own businesses.
- Individuals and families did their own process of discovering their strengths, skills and interests and envisioned and planned for employment before engaging the service system and used the system as needed.

Discussion

- Findings from this study once again confirmed the importance of family engagement with the service system.
- Findings confirm a strong sense of frustration with services
- The question remains how other individuals and families can find the success experienced by some study participants.

Recommendations

- Training for service professionals on the importance of fostering relationships through individualized and face-to-face interactions; use social media to defray possible costs of this increased amount of individualized attention
- Increase communication between local stakeholders to coordinate the information families receive from them.
- Develop a plan for sustaining families: Learn from them what works for them and share their solutions with other families



Keep in touch!

A project of
ThinkWork!
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