



A project of

ThinkWork!

at the Institute for Community Inclusion, UMass Boston



Family Experiences in Engaging in Employment: How Do We Improve Outcomes?

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SSSP 2018 Annual Meeting

Friday, August 10

The Landscape

- ❖ The institutional history of disability
- ❖ Deinstitutionalization meant...
 - Living in the community
 - Working in the community?
- ❖ Closure of sheltered workshops

What was supposed to happen v. what happened

Supposed to happen

- ❖ More jobs in the community
- ❖ More hours for work, less time in custodial care
- ❖ Higher wages
- ❖ Private benefits
- ❖ More independence

What happened

- ❖ About the same
- ❖ Less hours
- ❖ Wages OK per hour
- ❖ Still needs government support
- ❖ More dependent on family over a longer period as the service system recedes
 - Education, Vocational Rehabilitation, DD agencies, etc.

The reliance on family

- ❖ Research suggests that family involvement is essential to employment outcomes
 - Form beliefs about employment
 - Shape expectations, work culture
- ❖ Central tension...
 - Services, asking more of families
 - Families confusing experiences...

Our studies on family

- ❖ 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



Family Engagement

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.

❖ Engaging families earlier

- National clearinghouse with employment materials
- Focus on expectations and experiences
- Anticipatory guidance
- Misunderstood expectations
- Parents as partners in authentic engagement

❖ Address inconsistency and lack of cohesion

- “Lack of cohesion between schools, VR, and adult agencies needs to change”
- Use simplified, consistent language
- Discontinuity in funding

Reduce incomplete guidance from system

- ❖ *“I feel if service providers could meet with families earlier they could build relationships”*
- ❖ “I would love to see a national clearinghouse or resource center that is devoted to materials for families as well as the person with a disability to use.”

Communication Gaps with Vocational Agencies

“I found out accidentally by asking guidance about a Workability class at HS. It was about how to work at a first job and often accompanied a student working in retail which sometimes the counselor helped you find and other times you found with your family's help.”

Misunderstood expectations of system

- ❖ “The disability field offers incredible supports, services and innovations for people with developmental disabilities in all areas of life. However, we are starting to recognize that we have created a false sense of security and dependency that the bureaucratic system itself is the only answer to supporting good lives and the lives we want for people with disabilities.”

Confirming and aligning ideas

- ❖ Start earlier, much earlier
- ❖ Clarify expectations about what a system can and should do
- ❖ Consistent communication - addressing feelings of unfairness
- ❖ Reframing work - understanding modern employer needs

Prioritize

❖ Collaborative activities

- “I think another way families can be brought in earlier are through Collaboration for Success Nights (open to educators, providers, families, students), which may allow for relationships to form much earlier than the transition time frame so that come the traditional age of transition there isn't a system overload for families”

❖ Start early and often focusing on expectations and experiences

❖ Think of the end user when creating materials, training and engagement strategies.

❖ Moving from vision to outcome



Policy



Engagement: Policies that help people get jobs in the community

	Ideas	Votes	Comments
Areas we need to improve our understanding of state policy and strategy that will lead to better employment outcomes	6	33	19
Ways to improve communication and collaboration across state agencies and services	2	15	4
Examples of how employment related policies prioritize employment or get in the way of employment that need to be addressed	2	19	11
Ways the state agencies can support providers to develop and implement creative and effective employment supports	2	30	15
How might states communicate with and support families more effectively to think about and plan for employment?	2	9	3
What else do we need to focus on?	1	7	6
	15	113	58

❖ Data

- Need a “deeper dive” into existing data
- Longitudinal data
- What comprises “data”
- Triangulation at all levels

❖ Creative, effective supports

- Needs funding
- You get what you pay for
- Advanced training

❖ Improve communication across agencies, services

- Shared agendas
- Teamwork – shifting from competition to collaboration
- Better state-level communication

❖ Prioritize employment

- Supporting informed choice
- ratings/evals of job developers?

Implications

❖ Closure of she

Rehabilitation Research and Training Center on Advancing Employment
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