**RRTC State of the Science:**

**Engaging individuals and families in employment planning and supports**

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**ABSTRACT**

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. 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. This contributes to disenfranchisement and doubt in families trying to support employment for their relative with I/DD. 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. While 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 paper 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.

**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. Progress includes demonstrations of creative outcomes for individuals with significant support needs, including customized jobs and self-employment, community rehabilitation providers that have shifted emphasis to integrated employment, and states that have made a substantial investment in Employment First policy and strategy. Despite these achievements, the promise of integrated employment has not been realized for many individuals with I/DD. The number of individuals supported in integrated employment by state I/DD 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 I/DD.

The RRTC’s work covers 4 main areas:

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

2.  Increasing the effectiveness of employment consultants

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

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

This paper addresses the topic: Sharing knowledge with and supporting individuals and families.

**Background**

We know that people with I/DD want to work (Hiersteiner,et al 2016), but that desire has not translated into individual goals and outcomes. Families are often on the periphery of the employment process, but we know that when they are involved, there can be positive consequences. Research shows that family involvement has a positive effect on educational outcomes of students with I/DD and their pursuit of postsecondary education and other life goals, similar to their peers without disabilities (Fourqurean et al., 1991; Field & Hoffman, 1999; Bianco & Garrison-Wade, 2009). Families’ knowledge of transition services, involvement in transition planning, and demonstration of cooperation, interest, encouragement, planning, and support promote the post-school success of students with I/DD (Rowe & Hirano, 2015). Research on engagement strategies (the *how*, as opposed to the *what),* which could increase family involvement and effectiveness of involvement, is less well-known. It is important to note that while the definition of “family” may be different for different people, for the purposes of this study, the concept of family was limited only by the participants’ personal interpretation.

Because parents, siblings, or other relatives close to people with I/DD are likely to provide many forms of enduring support across the lifespan, engaging family members in their transition process early and often increases the likelihood of a smooth transition and a positive outcome (Fourqurean et al., 1991; Ferguson et al., 2005; Rosenthal et al., 2012). While all high-school-age students may benefit from family support during these transitional years, students with I/DD may have an additional need for help as they move into a more complex, eligibility-based adult service system that can be difficult to navigate (Bianco & Garrison-Wade, 2009; Ferrel, 2012).

Researchers and professionals have developed a vast array of resources and training tools, particularly over the last decade, to address families’ needs for information and to raise their expectations about people with I/DD becoming employed. For some examples of these, see the Explore-Prepare-Act curriculum and video developed in Massachusetts in 2011 by self-advocates for self-advocates (Thomas & Robbins-Cureau, 2011); the "Let's Get to Work" family trainings in Wisconsin, which resulted in increased parental expectations for employment (Wisconsin Board for People with Developmental Disabilities, 2014); and the Family Employment Awareness Training in Kansas, which led to increased knowledge and more positive perceptions of employment (Francis et al., 2013). Yet more research is needed to understand if these approaches are scalable, sustainable, or accessible to most families.

Our research studies addressed two main questions:

* What does the literature say about successful strategies in engaging families in employment?
* What types of information are useful to families whose child is going through a transition to employment in the community?

**Scoping Literature Review Methods**

We followed the six stages of a scoping literature review (Arksey & O'Malley, 2005; Levac et al., 2010). These stages are identifying the research questions; identifying relevant studies; study selection; charting; collating, summarizing, and reporting results; and expert consultation.

**Findings from the Scoping Literature Review**

Several themes frame this section: 1) Family members’ modeling of roles and expectations shape positive experiences of employment for people with I/DD; 2) Engaging with families leads to employment-focused decisions; and 3) Family and individual demographics are related to employment decisions and patterns.

***1) Family members’ role modeling and expectations shape positive experiences.***

People with I/DD and family members who observe others at work or participate in work themselves have greater expectations as a result. Modeling of work roles by family members has a broad positive impact on the vision and expectations around employment for people with I/DD (Timmons et al., 2011; Lee & Carter, 2012). Individuals with I/DD who have adult mentors as role models also appear to have increased employment expectations and a vision of themselves as employed (Lindstrom & Kahn, 2013).

***2) Engagement within families leads to employment-focused decisions.***

Families with advanced knowledge of the service system (a sophisticated understanding of how it works and what services are available from whom) and the capacity to develop partnerships with service professionals are likely to see successful outcomes for their family members with I/DD. Service professionals 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 I/DD (Gillan & Coughlan, 2010; Lindstrom et al., 2007; Petner-Arrey et al., 2016).

***3) Family and individual demographics are related to employment decisions and patterns.***

For some families with financial challenges or members with high support needs, surviving from day to day is a more critical concern than focusing on the future (Timmons et al., 2004). 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 ideas or models that may be unfamiliar, such as the practice of self-determination (Zhang & Benz, 2006). Additionally, gender may relate to differing expectations and patterns of employment; young men are initially employed at higher wages, have fewer work interruptions, and left the labor force more frequently after a job loss, while young women received more encouragement about financial independence and responsibility, had more work interruptions, and returned to work after more lengthy gaps in employment (Lindstrom et al., 2010). One unresolved gap that emerged was that no studies looked at the efficacy of different types of strategies used to engage with families. To date, most of the research on engaging families has been focused on describing how families are involved in employment and how to boost family knowledge of employment using training approaches.

**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?

1. 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?
2. 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 I/DD and their family members were recruited through extensive outreach using various channels, including the Center’s Advisory Panel and partners, and national list servs and mailing lists that target adults with I/DD and their family members. Participants were selected for diversity of age, geographical region, and cultural background.

Online engagement occurred through general discussion forums, as well as a private Facebook group. The asynchronous nature of this type of engagement allowed for researchers to pose questions around employment, and for participants to interact and form new topics amongst themselves organically over time. A number of common themes developed from the ensuing discussions. In addition, we conducted telephone interviews and in-person focus groups in five states to ensure that we were covering the breadth and depth of individuals’ experiences.

**Findings from the Facebook Forums and Focus Groups**

The responses from these interviews portray the challenges and some successes individuals and family members continue to have with employment services. These challenges were most often spoken about as lack of alignment, discontinuities, and slowness of services. Family members’ responses focused on how this experience often creates doubt and distrust in the system and, notably, that the families may not be equipped to handle some of the responsibilities expected of them in supplementing what employment services does not provide

More specifically, the number of themes from this portion of the study suggest that family members are ambivalent in their view of the service system’s effectiveness. In general, families feel confused about the information they receive from the employment service system, and uncomfortable with the responsibilities the service system wants them to carry out.

***Finding 1) Family members identified confusing guidance by the service system.*** Families found services difficult to access and navigate, and frequently commented about the rigidity of the system. According to two participants, often government-funded service programs are seen as the one-and-only option for people with few resources. If individuals are not successful getting jobs through the service delivery system, families feel as though they have no other options and cannot move forward with their employment vision.

A parent who became more educated about options for her son describes a professional’s cursory interaction with her about her son’s transition to employment:

*The transition specialist handed me a two-page list of service providers… (and) there was no explanation about what I should do with this list. It was all about: I'm preparing to pass the baton from the world of entitlement to the world of eligibility [for services].*

***Finding 2) Families were concerned about the low expectations of the service system.***

Issues related to low expectations of staff about what individuals could accomplish were pervasive. A parent describes how a service program’s low expectations of her son’s employment options were not aligned with his actual potential:

*The results (from the state’s testing of my son) were less than enthusiastic for his chosen educational path. . . My son managed to ignore the naysayers. . . fortunately, the education he enrolled in helped him to see how what he liked to do could fit into what he could do.*

***Finding 2) There is a lack of alignment and discontinuity in services that people access throughout the lifespan.*** Some participants noted that it took repeated efforts from different agencies to finally arrive at an employment outcome. For example, a participant with disabilities noted that she “…never had much employment success with working with ORS (Office of Rehabilitation Services)…ORS's goal is to close my case as soon as they see a little bit of success. When I need more services 3 or 4 years later, I have to reapply, and the whole cycle starts over. It's very frustrating to work with ORS.”

Moreover, participants observed that rules vary across different services throughout the system, where expectations, priorities, and goals of the system do not align. For example, regarding experiences with education, developmental disabilities services, and vocational rehabilitation (VR), one parent summarized, “There does not seem to be cohesion or the same set of rules, expectations, waiting/priority lists or job opportunities.”

***Finding 3) The system lacks capacity and seems unable to meet individuals’ needs***. Participants indicated that there is little sense of capacity for providers of employment services, both in terms of staff training and capacity, to operate within the current structures and funding streams offered to them. For example, one parent explained:

*…inconsistencies in employment options and their attitudes about what is possible is largely reliant upon the organization's expectations as well as the community settings in which they operate. For instance, there are some staff that look at sheltered employment settings as the right option. Why? Because they have not been exposed to new models, new ideas, and fresh thinking. Why is that? Because their agency has not invested in a process of considering evolving their employment programs. Why is that? Because their current funding stream and physical plant is not malleable and they have difficulties making significant change without the resources outside of their current funding streams to do so. In addition, agencies may not be changing if parents and families do not demand change - as in consumer demand and purchasing power. Why is that?*

In general, parents spoke positively about specific professionals that helped them, but consistently expressed doubts about the ability of the service agencies to meet the employment outcomes. Once participant stated:

*… The existing system of supports and services is dwindling in terms of volume and quality. Many states have implemented creative waivers for individualized supports for people with disabilities--and that's a good thing--but with less money, and growing waiting lists, fewer and fewer people with disabilities are going to have the chance to utilize these funds. I am also becoming more and more doubtful that our continued rage at an unfair and largely inaccessible system for people with intellectual disabilities will ever result in what we want and need.*

The findings from our literature review that engaging families leads to employment-focused decisions were somewhat at odds with the findings from our Facebook group and forum study, which suggested that families were successful after they *disengaged* with the system or in spite of it. On the one hand, there was a sense that the employment-focused system could be better positioned to achieve better outcomes. On the other hand, participants expressed reservations about the system as able to produce the outcomes envisioned by people with I/DD and their families. It also could be that our qualitative findings represented perspectives of participants that had that had unique or better than average skills around employment.

These issues, from parent and family perspectives, are complex and multifaceted. One parent participant noted that, on the ground level, problems will continue to feel insurmountable as long as CRP and DSP staff continue to have inadequate skills around employment. This participant notes that “if a staff person has not been trained to seek out and identify employment potential and match employment options to an individual with disabilities, that staff will be a barrier to that individual's employment.”

The feelings of lacking capacity and staff skill create significant challenges, mirroring the feelings of hopelessness and frustration, expressed by self-advocates. Self-advocatesviewed the employment search as an unceasing challenge, and mostly confirmed what parent participants expressed about the ongoing frustrations and inconsistencies in the system.

One self-advocate illustrated the ongoing, sustained nature of this challenge in addressing generally low expectations:

*It's been hard. I'm doing the applications, and there's been some stress around job interviews, but I've been managing them OK. Just preparation with employment specialists. With the interviews, I find that I'm not getting any call-backs. … It's not going anywhere. I get the responses and do the interviews. I'm also doing some stuff on my own with USAJOBS. ... I don't know what the missing piece is. I've been out of work for three years. My case manager arranges the companies that I interview with now. They arrange things and it's up to you to follow up with them. … Making sure you're OK with doing the interview, that you're not becoming overwhelmed--that kind of thing.*

***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 I/DD 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.

One participant, a parent working in employment services herself, described how her son got clear on what he wanted in a job. After working with an employment specialist, he walked over to his old school and told the principal he was interested in a job there; the principal created one for him part-time. A sibling participant described how her sister started and ran her own business through family support and funds from VR and other programs to get her started.

Indeed, a theme among individuals with a successful employment outcome was a concerted effort to discover their strengths and interests prior to seeking employment supports, and then if necessary, using those supports to augment their own job search. Many participants who attained integrated employment had family members who mapped out their individualized needs and resource requirements before seeking help finding a job. A parent describes this approach:

*Choose a different process. A process that did not involve a social service agency or government support, but one that assessed the interests and talents of the young adult and figured out a way to blend designed supports around their customized role in the community. Just like everyone else, but with the needed supports that the person requires. This approach utilizes social capital, family time, and creative thinking and scheduling. It also requires families to take on an even greater commitment to their children in that there is no stream of financial funding coming from the government to pay for residential care or day hab services or similar services.*

Families with robust employment visions and outcomes helped their family members self-advocate and develop a plan for the future prior to meeting with employment service providers.

**Discussion**

The themes that emerge from this work evoke a sense of frustration of people with I/DD 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.

In our scoping literature review, we found that the ability of family members to be meaningfully engaged in the employment process probably may be related to differences in demographic and socioeconomic life course variables (Wagner, Newman and Lavitz, 2014). It is possible that parents with fewer financial resources may not have the time or social capital to contribute to an individual’s employment process as compared to family members with greater access to resources. Though the current study did not collect extensive information on SES of families, future research studies should have a diverse sample because of potential differences in experiences and interactions with employment services among families with varying SES.

***Recommendations for different and innovative strategies***

Policy and programmatic recommendations in an era of shrinking budgets and scarcity are difficult to advance. Nevertheless, there is room for significant innovation within employment service delivery through family engagement. We present the following no- or low-cost recommendations for community employment providers as well as state systems to engage families and to encourage their involvement in the employment process.

Recommendation 1: *Train staff on how to foster partnerships with families through face to face and individualized interactions.*

While there is no doubt that increased individualized attention can increase costs to employment service providers, we can do more to increase the frequency of contact with individuals and family members to maintain a sense of continuity that carries little or no cost. For example, using social media as a way to organize parents and people with I/DD to build social capital is an investment of time, but one that could lead to dividends in the future for families and the employment professionals with whom they interact. Also, using secure and private messaging over smartphones, tablets with individuals with I/DD and family members can be an inexpensive, yet personal way to build long term awareness and relationships with families. It would carry the cost of staff time, but reduce travel and other incidental costs.

Other RRTC research (Migliore et al, in development) shows that despite being identified as an effective practice in job development, employment consultants spend very little time interacting with family members. Specific training on the importance of these partnerships, as well as the development of a culture within community providers that values the contributions of families, can do much to address these issues.

Recommendation 2: *Increase communication among the local stakeholders*

While there have been sustained, national efforts to build better partnerships between state agencies around employment, these efforts may not always drill down to the local level in which service providers operate with family members. For example, many of the participants’ responses suggested that the communication between VR and education was not just sparse, but often contradictory, which produces confusion. Future work with states might focus on tools for families that can unify some of the information from these agencies into a single source that would be relevant to different localities or even a place where community members could share experiences and knowledge with each other.

Recommendation 3: *Develop a plan for sustaining families; learn from them about what works.*

One of the findings from this study is that families sometimes “go it alone” and feel that they see more success than they would have gotten using the service system. Families are a source of knowledge and expertise around their members with I/DD. It is possible to learn from them, not just about their personal knowledge as a family member, but from their long-term experiences in maintaining high expectations, navigating supports and working strategically within a resource-deficient system.

Recommendation 4: *Encourage high expectations among individuals, their families, and of the systems that provide them with supports.*

Our research showed that family members often felt that the system had low expectations for community employment. However, self-advocates and others have also talked about the problem of low expectations of family members who may be overprotective or worried about their children’s future. Research consistently shows the concerns parents have about their children’s future employment (e.g., Blustein Gilson, Carter, McMillan, 2016), often related to discrimination, loss of critical benefits, and safety. Early engagement and discussions about what’s possible are critical so that the families can foster opportunities to build employment aspirations, skills and mindset. Professionals need to be trained on having conversations about the idea of employment and the early stepping stones that foster these expectations.

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