Title: Engaging Families in Employment: Individuals and Families' Retrospective Transition Experiences with Employment Services

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In the United States, employment experiences of people with intellectual and developmental disabilities (I/DD) have been dominated by discrepancies between recent policy shifts promoting integrated employment for people with I/DD and the stagnation of the employment rate in integrated settings for this population. Although there is no direct source for labor force participation for individuals with I/DD in the general population, data from the National Core Indicators Project suggest that in 2015–2016, only 19% of working-age adults supported by state I/DD agencies worked in one of the three forms of integrated employment – group-supported, individual-supported, or competitive (individualized and without supports). Twelve Percent (12%) worked in competitive or individual-supported employment and 7% worked in group-supported employment (Hiersteiner, Bershadsky, Bonardi, & Butterworth, 2016). In addition, individual employment supports have not been implemented with fidelity to a consistent model or set of expectations, and participation in non-work services has grown rapidly (Winsor et al., 2017; Domin & Butterworth, 2013; Migliore, Butterworth, Nord, Cox, & Gelb, 2012).

Despite the low level of employment participation, people with I/DD expect to work in the general labor market. Analysis conducted in partnership with the National Core Indicators Project suggests a majority of the 85% of individuals supported by state I/DD agencies who were not working in 2012–2013 expressed (a) the desire for a job in the community and (b) the preference for integrated over sheltered employment. Moreover, Transition-age individuals with I/DD have a strong expectation that they will work in adulthood (Wagner, Newman, Cameto, Garza, & Levine, 2005). Other studies of employed people with I/DD have also indicate higher rates of preference for community over sheltered employment options (Gilson, Carter, Bumble, & McMillan, 2018; Migliore, Mank, Grossi, & Rogan, 2007). This preference for community over sheltered employment has been supported by research on the decision-making capacity of people with I/DD and the principles of self-determination and informed choice (Wehmeyer, 2005; Storey, 2005), and has been expressed regardless of the severity of disability (Winsor et al., 2017).

Families are influential in the employment process. Previous research has found that family engagement is a key component in successful employment and life planning because family members serve as role models for work ethic and behavior (Dixon & Reddacliff, 2001; Timmons, Hall, Bose, Wolfe, & Winsor, 2011; Whiston & Keller, 2004). Researchers have found that people with I/DD are more likely to be employed when their parents want them to be employed and believe that they can work (Dixon & Reddacliff, 2001; Freedman & Fesko, 1996; Taylor & Hodapp, 2012). Additionally, researchers have documented that family members may provide logistical support, coaching and advice, help with planning and organizing work schedules and activities, transportation, as well as other resources to support the employment of their family member (Timmons & Wolfe, 2010; Whiston & Keller, 2004). Carter, Austin, and Trainor (2011) found that the factor most predictive of paid work experiences in school was parental expectations.

However, as noted by Self-Advocates Becoming Empowered (SABE), families can act as both supports and barriers to employment success. In its policy statement on employment, SABE acknowledges the important role of families and the need to persuade them to support employment: “Get families on board. When family members are scared about the workshop closing, their fear spills over to their son or daughter. Families are still stopping people from working because they are afraid a person will lose their social security or Medicaid benefits” (SABE, 2009, p2.). Research findings have confirmed that many families are afraid of people with I/DD losing benefits if they become employed (Hall & Kramer, 2009; Luecking & Wittenburg, 2009; Winsor, Butterworth, Lugas, & Hall, 2010). Furthermore, researchers have found that when families lack information or are misinformed about work incentive programs such as the Plan for Achieving Self-Support (PASS), Impairment-Related Work Expenses (IRWE) plan, and Blind Work Expenses (BWE) plan, they are less inclined to be supportive of efforts to secure their family member a competitive job (Kregel & O'Mara, 2011; Sulewski, Kugler, & Kramer, 2010). In fact, this type of misinformation has been shown to negatively impact the expectations of parents about work in general (Carter, Austin, & Trainor, 2011; Lindstrom, Doren, & Miesch, 2011; Timmons et al., 2011).

The dynamic emerging from these findings is one in which people with I/DD who are supported by their parents desire employment, but run into a system that sometimes gives inconsistent support and inaccurate information. Furthermore, as families encounter a wider range of employment support professionals, as well as agency and government workers, they tend to amass a wide range of information that is difficult to parse into a coherent and cogent employment plan (Kramer, Bose, & Shepard, 2017).

Many employment service staff share the view common to self-advocates that family members can be a barrier to employment, and they are therefore reluctant to engage them on this topic (Hall, Bose, Winsor, & Migliore, 2014). As common as this perception of family members may be, other research findings on the resourcefulness of families points to their knowledge of the capabilities of their members with I/DD, and the possibilities of engaging other supports and seeking opportunities beyond the service system (Petner-Arrey, Howell-Moneta, & Lysaght, 2016; Sanderson, Burke, Arnold, Urbano & Hodapp, 2017). It may be that these families have a more complete grasp of the whole picture, which includes reconciling inconsistent and incorrect information. In this sense, family ambivalence about employment may be a product of the inconsistent information they have received about employment. Although researchers (Timmons, Hall, Bose, Wolfe, & Winsor, 2011), practitioners, and self-advocates (SABE, 2009) have sometimes noted parental attitudes, including reticence, about employment as an explanation for the low number of individuals with I/DD who are employed, it might be that these parents have formed this opinion because confusing information has led to disruption in the past (Kramer, Bose, & Shepard, 2017). It seems plausible, for example, that parents whose children lost benefits for a time after having been employed might be more cautious about the next opportunity (Sulewski, Kugler, & Kramer, 2010).

Despite research findings that have shown the importance of parent involvement to successful employment outcomes, much less work has focused on the type and delivery of information that parents and families receive about employment (Francis, Gross, Turnbull, & Turnbull, 2015). The purpose of this study was to explore the experiences of individuals with I/DD and family members as they used information and supports to develop an employment vision, and move from that vision to an employment outcome.

Method

To understand the experiences of families and individuals with I/DD, we engaged with working-age individuals with I/DD and family members in four ways: an asynchronous online forum into which we posted questions participants could respond to or discuss, a Facebook group in which we posed identical questions participants could respond to in their own time, in-person focus groups facilitated by a member of our research team, and phone interviews between an individual or family member and the lead researcher. We focused on participants’ experiences looking back on the individuals with I/DD during their transition-age years.

We addressed the following research questions:

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?

We wanted to know, from the perspective of individuals with I/DD and family members, what was found to be the most useful information about employment, and how they had received this information. Although we suspect that many families receive conflicting information, we wanted to know on a more basic level how individuals and family members experienced interactions with the service system.

Participants

Recruitment. All recruitment and consent procedures used in this study were submitted for full board review to the University of Massachusetts Internal Review Board (IRB). The IRB's permission to use these procedures was granted before recruitment of participants began. Recruitment involved extensive outreach to sources known to the research team. We presented the study to our Center's advisory panel and asked for their help reaching potential participants. Two members of our research team also conducted a presentation and distributed flyers about the study at a conference. We distributed an email version of the flyer to national listservs and mailing lists that target adults with I/DD and their families.

Recruitment took place in several waves. For the first recruitment wave, we reached out nationally for participants to engage in the online forum. In the second recruitment wave, we set up a Facebook group and reached out to the same sources for participants to engage in facilitated asynchronous discussion of their experiences interacting with the service system. In the third recruitment wave, we recruited participants from the online forum, the Facebook group, and the other sources listed above to participate in a phone interview with the lead researcher or another team member. In the fourth recruitment wave, we recruited purposive samples of participants through contacts we worked with closely in other states (Arizona, Maine, Massachusetts, and Washington, D.C.). Participants in all recruitment waves were recruited for diversity of age, geographical region, and cultural background. Participants were offered a $20 Amazon gift card for participating in one of the in-person focus groups, and a $10 Amazon gift card for participating in either the online forum, Facebook group, or phone interview.

Characteristics. Participants were eligible for this study if they were either (1) an individual with I/DD, or (2) a family member of an individual with I/DD. We designed two consent forms, one for each category of participant. Consent forms were available online as well as in printed form. Both consent forms required participants to self-identify as a member of one or the other category, and provided a description of the purpose of the study. The online consent form allowed participants to sign up to participate in the study through the format of their choice (in-person focus group, asynchronous online forums / Facebook focus group, or one-on-one interview). The online consent form also provided distinct confidentiality content depending on the participant's choice. This study offered both in-person and online asynchronous focus groups to account for barriers to participation such as distance, transportation costs, respite care, and employment schedules. The online focus groups also allowed participants to purposefully reflect on employment issues and respond in detail at times convenient to them.

The sample for this study thus consisted of 33 participants: 3 individuals with I/DD and 30 family members. A summary of participant type is presented in Table 1. A summary of the demographic characteristics of this sample can be found in Table 2.

Data Collection Procedures

For this study, we used four qualitative data-gathering strategies to suit the different strengths and interests of participants. These strategies included online forums, Facebook focus groups, and phone interviews. Table1 shows the number of family member and self-advocate participants for each data collection modalities. We used a "topics and questions open format approach" for the online forums, Facebook focus groups, and phone interviews. Table 3 presents a list of the questions we posed in this format.

Online forums. We used online forums in this study because focus groups hosted online are both virtual and "asynchronous" (Moloney, Dietrich, Strickland, & Myerburg, 2003; Oringderff, 2004; Ping & Chee, 2001). Virtual focus groups allow maximum flexibility to recruit participants nationally from a population that is difficult to access (Moloney et al., 2003; Oringderff, 2004; Ping & Chee, 2001). We hoped that the online forum approach would allow for the best chance of recruiting individuals with I/DD and family members with a variety of experiences with employment. In addition, we valued the asynchronous nature of the online forums, which would allow participants more time to purposefully reflect on employment issues and respond in detail, in addition to reducing barriers to participation such as transportation costs, respite care, and employment schedules.

Participants who signed up to participate in the forums received a username and password to access the forums. The forums consisted of four sub-forums: Family Members Only, Forum for People with I/DD and Family Members, General Discussion, and Job Seekers and Employees with Disabilities. Participants' access to a particular sub-forum depended on whether they identified as an individual with I/DD or a family member of an individual with I/DD. All members had access to the General Discussion forum and the Forum for People with I/DD and

Family Members. Only individuals with I/DD had access to the Job Seekers and Employees with Disabilities forum, and only family members of individuals with I/DD had access to the Family Members Only forum.

We facilitated discussion and engagement through the frequent posting of topical questions to each sub-forum (e.g., How do you learn about employment options for your family member?). Members were sent an email when a new question or comment was posted, and participants had the opportunity to respond and discuss the question with one another. Participants within each sub-forum also had the option to create their own posts about topical questions and discuss them with one another. Over time, topics developed from themes arising from user participation.

Participants in the Facebook focus group were invited to do so by the research team. The private Facebook group allowed us to maintain a network in which participants could respond without their responses being seen by anyone not part of the group. Weekly, we posted topics to this group’s page. All posts and threads on this page remained available for the duration of the study so that participants could comment freely on them. Over time, topics developed from themes arising from user participation. All posts and threads were included in our data analysis.

Phone interviews. Two participants who elected to participate in phone interviews were contacted to schedule times that would best suit them. There were others who initially expressed interest in doing an interview, but later decided against participating. The interviews lasted between 45 and 90 minutes, with a mean duration of 60 minutes. The interviews were recorded, and data were analyzed from extensive notes of the interview recordings written by the interviewer and other research team members. We chose not to transcribe the interviews and do line by line coding of interview transcripts because of limited time and finances. Furthermore, in team discussions with the funder’s project coordinator and in reviewing other research on the the utility of transcribing and coding large amounts of data (Asevedo et al, 2017; Tilley, 2003), we determined that detailed notes, which included transcription of all of the quotes and posts from participants that consisted of one long sentence or more, would be as useful in this exploratory study as naturalized transcripts in drawing out themes addressing the research questions.

Although we used multiple platforms to engage participants, we sought a consistent qualitative approach by using the identical semi-structured protocol. Important themes emerged in participant conversation, but the content of our topics questions was identical whether we asked them in the online forum, Facebook group, or phone interviews (Cresswell, 2009).

Data analysis procedures

Data from interviews and online focus groups were analyzed using a qualitative, “constant comparative” strategy (Corbin & Strauss, 2014). Summaries from focus groups, including researcher notes, were imported into ATLAS.ti version 7 (ATLAS.ti 7, 2013), a robust qualitative data analysis software package that allows researchers to sort large amounts of data to extract emerging themes. Documents were organized into categories in ATLAS.ti 7, which identified the document type and significance within the study. Two researchers coded the documents and developed a series of themes that comprise our findings for this study. Coding is an early and ongoing way of labeling data to sort it and assign meaning (Miles, Huberman, & Saldaña, 2014). Operational definitions for each code were developed to construct a shared understanding of the codes. The two researchers simultaneously coded and analyzed the data, continually comparing specific incidents, refining concepts, and exploring relationships (Charmaz, 2000). We also met as a team on a regular basis to reconcile codes and discuss the emerging data. Table 4 shows the linkage between primary codes, secondary codes, and themes.

Findings

Four main themes emerged from this study: (1) *family members expressed feeling unable to meet the expectations to fulfill an employment vision;* (2) *family members' experiences led them to mixed feelings about employment services;* (3) *there is an array of misalignments and discontinuities in services that feel stuck in the past;* and (4) *government programs have very little capacity to meet demand.* Examples of success reported by participants in this study were few and, at times, seemed to occur when the person with a disability and their parents decided to no longer engage in the service system.

Family Members and Expectations

Over the course of the forums, family members described interactions with a variety of people from multiple governmental agencies including education, vocational rehabilitation (VR), and developmental disability services. Family members expressed feelings of being unable to meet expectations associated with receiving services from governmental agencies, and difficulty with the agencies' culture in general. Participants spoke about systemic low expectations and lack of change. One individual with I/DD spoke about how "government-funded service programs are presented as the one-and-only resource for people who have few other options." This participant continued, "when they work, providing a program like Summer Youth Employment, they seem even more like a resource to depend on . . . however, when they do not work well, they can prevent people from moving forward in their employment-related goals. They often do not have the skills or knowledge to get out of this situation." A parent whose son lived several states away believed, strongly, that her son was underemployed. She spoke about persistent feelings of inadequacy, feeling that she had neither the time nor the expertise to help him improve his situation. She stated:

> I feel like I'm not doing enough. The distance is hard, but he is where he wants to be, and he's happy. … I've learned that my son has always known best what will work for him in his transition from high school, college, and home. What has worked is my supporting him in following his "heart" or "gut" in letting him be where he wants to be. It's not perfect, and there are problems, and I worry all the time that I haven't done enough. But I think it was the best way for us.

Ambivalence about Employment Services

Family members and individuals with I/DD spoke about how services too often focused on things that felt irrelevant to their employment goals. Family members recounted experiences with VR, education, and community rehabilitation professional staff that led to frustration. For example, an individual with I/DD recalled that "they never want to give me anything to do that I would enjoy doing, [or] that would make me happy." She continued that when she told her VR counselor she wanted to work as a counselor herself, or a psychologist, the counselor said that because she had anxiety issues, she was better off not working out in public, or if she were working, she should work alone and segregated, not with others. Her mother elaborated that VR requested a psychological evaluation and picked the psychologist, who returned a report making her daughter look mentally challenged and "like a moron . . . They described her clothes as too bright, dressed juvenile—she was wearing something pink that day."

A family member found that the testing process to secure employment services was burdensome. "One challenge I found was with the testing process as we began our adventure [with her son's VR agency]. They attempt to determine what would fit him best and what the job market looked like in the field he thought he wanted to go into." For this participant, the results from the testing and analysis they had to go through were not linked to his chosen educational path.

An individual with I/DD spoke about lack of progress using his state's VR agency, the Office of Rehabilitation Services (ORS):

> I never had much employment success with working with ORS. They seem to like to spend funds on me which do nothing for me in the long term. 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.

There were two elements to this participant's story. First, she felt that the focus on her services was more about getting her case closed rather than reaching long-term employment goals that met her career desires. Second, she believed there was little to no institutional memory about the services she had received before.

Individuals who primarily needed support with workplace social skills described another challenge. An individual with I/DD spoke about a similar misalignment in other services in his experiences. He reported that he "tried to get help at the … job center before I went to voc rehab," but later concluded that it "was mainly just applying for jobs on my own with a slight bit of advice here or there." He continued that "there really is no agency prepared to work with high-functioning people with social skills deficits to get them jobs. They need the help of a job coach but jobs that challenge them mentally." Therefore, this participant felt he was being routed to take more intensive services than he wanted.

Misalignments and Discontinuities

Other participants had personal and professional experiences with the service system that influenced their perspective on their individual situations and the system as a whole. These participants commented on the antiquity of the services around employment. For example, one family member described how employment services are nested within contexts and communities that have not caught up to modern expectations about what people with I/DD can do:

> inconsistencies in employment options and their attitudes about what is possible are largely reliant upon the [employment service] organization's expectations ... 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?

Her observations suggest that misalignments are nested within each other and mutually reinforcing. Community agencies might continue routing people into more constrictive, sheltered work because they have (a) not been exposed to community employment alternatives and/or (b) serve people with disabilities whose parents and families have not demanded a changes to services. She also maintains that this is all influenced by the way funding is structured. Another family member extends this idea more, declaring that "there does not seem to be cohesion or the same set of rules, expectations or waiting/priority lists, job opportunities", which links to our next theme of the limited capacity of employment provider organizations to address people's desire for community-based employment.

Very Little Capacity to Meet Demand

Participants identified that there is little capacity to meet the overwhelming demand for employment services. This is seen in lack of updated skills from employment specialists. For example, one family member said that "there is also the different issue of personnel training—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 picture painted by participants suggests a workforce that does not have the skill capacity to meet the changing expectations of employment services. This is, in part, due to the lack of funding mechanisms, both in terms of dollar amounts and how the funding is structured. One family member recalled how this example is seen in Medicaid-funded I/DD agencies:

> 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.

From this participant's perspective, policy changes that allow for greater flexibility do not address the shrinking funding pool for all the services. She concludes her thought, somewhat pessimistically:

> 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.

Limitations

We cannot generalize findings from this sample to all people with I/DD and their family members; this was not our goal. The participants we recruited into this study were, based on their stories, likely more knowledgeable about the system than most individuals and families. However, we consider the participants' experiences to be reflective of many of the barriers to employment documented in the literature (Nord et al., 2016; Timmons, Hall, Bose, Wolfe, & Winsor, 2011). The nature of our methodology probably attracted a certain type of participant, a fairly articulate, well-educated, and technologically savvy person. We take the view that these participants are ideal to include in an exploratory qualitative study of a bounded topic since they will more likely be able to accurately describe their experiences within a broader context.

People within this demographic were also those who could participate comfortably in a social media/online forum format. Although social media usage is commonplace in today's culture, it is not accessible to everyone, nor does it include those who are nominally on social media but rarely use it. Our findings might reflect participants who are better able to network than those who do not use social media, and thus are possibly more empowered to go it alone without needing to access services.

Finally, a limitation within our study relates to our finding about participants' ambivalent feelings toward employment services. It is worth noting, however, that we could have attempted to recruit more people currently accessing employment services who feel positive about their experiences. Future researchers may wish to purposively seek out people with ID/D who have had a positive experience with government agencies such as VR, and/or community level provider organizations to examine factors that contribute to making both services, and relationships, successful. Also, it is possible that some participants in our study did not need long-term supported employment services for any number of reasons, including the possibility that they had already developed more independent skills by avoiding dependence on the service system. We cannot, based on our method, determine the extent to which our participants were or were not good candidates for long-term employment supports.

Discussion

As with previous research (Hetherington, Durrant-Jones, Johnson, Nolan, Smith, Taylor-Brown, & Tuttle, 2010; Taylor & Hodapp, 2012; Walker, 2011; Winsor et al., 2017), the findings in this study paint a picture of individuals with I/DD struggling to find employment. The findings also highlight families' role investing their time and other resources to support individuals with I/DD in general and in their employment pursuits—a role cited in numerous studies (Bianco & Garrison-Wade, 2009; Burke, Waitz-Kudla, Rabideau, Taylor, & Hodapp, 2018; Sanderson et al., 2017.) We attempted to set this study apart, however, by taking a granular look at the ways in which individuals with I/DD and families receive and use information from the service system to work toward an employment vision and outcome. Carrying out this plan required us to examine the interactions between individuals with I/DD and their family members with service professionals whose jobs involved helping people with disabilities obtain or transition into employment. Our goal was to provide multiple platforms through which individuals with I/DD and family members could reach us easily to tell us how they engaged the employment service system for information and support, what information was useful to them from the service system, what factors influenced interactions with employment services, and how or whether that information was used to turn an employment vision into an outcome.

The themes and findings of this study raise some difficult questions that people with disabilities and their families consider when looking at employment options. The participants spoke at length about experiences with employment services that were frustrating on multiple levels, both structurally and at a state or even federal policy level. For example, some of the participants spoke of the persistent problems related to the funding of employment support for people with I/DD in their state, including the ability to access funding for long-term supported employment services, move efficiently between integrated employment and wrap-around support services, and in some situations receive funding through their state’s Medicaid waiver system. This is an important finding because many states are currently making significant changes within their Medicaid waiver systems to prioritize integrated employment over other non-integrated employment services. However, for these changes to be successful they must also address the availability of Medicaid waiver supports, funding for long-term supported employment services, and the need for many individuals to receive both integrated employment and wrap-around services (Winsor et al., 2017).

This presents a macro context that is troubling. From a top-level view, policy changes will increase demand for employment services by people with disabilities and their families. Yet, when they try to access Medicaid Waiver services they can experience waiting lists for services, a result of state budget decisions. A secondary challenge for new entrants and individuals who already receive services can be the way in which individual service needs are assessed and individual budget allocations are developed. Many individuals and their families perceive that they do not have adequate funds within their waiver allocation to purchase all of the support services they feel they need, including employment services (Winsor et al., 2017). Friedman and Rizzolo (2017) reported that people who receive supports through Medicaid waivers often do not change to waiver-funded employment services. Winsor et al. (2017) found that this is often the result of states failing to undertake a comprehensive approach to revising funding structures for employment and day supports, including separating funding for transportation from funding for services. These authors note that fragmented changes to one or two service rates is not sufficient to address the underlying waiver funding issues faced by service providers and service recipients, and that states that experience better employment outcomes work to revise their entire funding system to ensure that individuals receive services that support a whole-life, individualized, community-centered approach.

The broad context is that these funding structures leave little room for service users, let alone service providers, to find and maintain a competently trained workforce. Participants in this study spoke at length about how frustrating it was to seek services from a service provider and be asked to fill out the same paperwork over and over again. Moreover, it was frustrating to encounter staff who appeared unaware of what the employment aspirations of the person with I/DD are, despite previous staff having asked about these aspirations in previous years.

Across our participants, there was recurring mention of a general dissatisfaction with VR services. Common complaints included the repetitious nature of applying for VR services and the lack of employment expertise for the I/DD population. Individuals with I/DD and their family members reported that working with VR agencies to create and maintain an employment vision, or even improve a person’s employment situation, was a constant struggle. Furthermore, the participants in this study were not optimistic that VR services would improve in the future. Their views and perceptions are supported by research over the last decade on longstanding systemic weaknesses in employment service provision for people with I/DD. Butterworth, Nord, Migliore & Gelb (2012) demonstrate the ongoing need for staff training and development to strengthen service providers expertise in supporting people with I/DD in employment. The need for staff development is also critical because as innovations in service delivery are developed to expand opportunities for people with I/DD to attain community employment, staff must understand how to implement these models and how to support others who may encounter more barriers to benefiting from them, as Christensen and Richardson (2017) demonstrate in their study of adults with I/DD attempting to participate in a Project Search program following long-term employment in sheltered workshops. Undergirding the need to address these challenges are the state-level changes that must be made to rate structures to fund employment services for people with I/DD adequately and more consistently (Hall, Freeze, Butterworth & Hoff, 2011; Hewitt, Agosta, Heller, Cameron Williams & Reinke, 2013), and the policy-level changes that must be made to establish the expectation of employment for people under guardianship and with more significant support needs (Nord, Hamre, Pettingell & Magiera, 2018),

Hopelessness and Frustration

Collectively, data from our study paints a picture of people with ID/D and their family members feeling hopeless and frustrated based on their interactions with staff at the ground level. They perceive staff to be poorly trained to assess the capacities of people with ID/D, as well as ill equipped to work with employers and people with disabilities to secure good job matches. Findings from the individuals with I/DD in this study suggest a palpable sense of futility in chasing government-funded employment-related support, yet they feel compelled to do so. Part of the frustration came from the lack of progress, despite many repeated attempts at accessing services. For example, one individual with I/DD recalled,

> 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.

In this case, the person was able to secure interviews, but he expressed frustration with the lack of interest on the part of employers following his interviews. This participant said that he did work on his own to try to open up new opportunities for himself and continues to work with a case manager, to little avail. He continued,

> 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 is 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. Because you don't want to get the job and then find out you can't function …

This participant's experience suggests a "go it alone" approach that is not working in practice. Regardless of his ability to independently engage with his own career development with some help from an ID/D case manager, he is left with the feeling that it is not worth pursuing employment supports and that he does not have the skill level to manage this task effectively. Although it is important, for self-determination and practical purposes, for job seekers to be independent and exert choice, people with ID/D will likely continue to need some sort of ongoing cognitive supports over the course of their lives (Burke et al., 2018).

Implications:

Due to shifts in policy, the system of services for individuals with I/DD and their families has the flexibility to appropriate funds toward employment services. At the same time, however, the service system is too underfunded to serve people well, and it is not likely to expand to meet the need. At this time in particular, the emphasis in policy is on directing individuals to access employment services, legitimizing the use of public dollars on supporting individuals with I/DD to achieve employment outcomes rather than participate in nonwork programs. However, some participants in our study have determined that their time is better spent with help from resources outside the service system. These participants have decided to “go it alone” because the amount of paperwork and oversight is not commensurate with the employment outcomes they have experienced. We find this a problematic and troubling implication for two reasons: (1) it is not clear that all families have the economic capacity, social network, or access to alternate sources of help to shoulder this task effectively, and (2) families who can “go it alone” are likely not representative of the families who need the most help.

That being said, future research should investigate families who have decided to seek employment for their relative with I/DD outside of the service system to find out what makes them successful. We feel strongly that doing so would give families valuable information and examples to work from, and would also let employment services staffers better understand how to adapt lessons learned from positive family examples to their work.

Another focus of future research should be on laying the intellectual groundwork to justify funding of services that provides people with ID/D long-term employment supports. Public funds need to be adequate, but also need to be efficiently used to improve employment outcomes and avoid unproductive service approaches. Finally, and most important, future research should focus on finding the adaptive, flexible capacities of people with I/DD from the time they are born through transition age so that the system can supplement gaps in their education and better prepare them and their families for future employment opportunities.

References

Table 1: Participant Breakdown by Group

Method	Family-Member	Self-advocate
Forums	15	0
Facebook	13	3
Interview	2	0

Table 2: Demographic Information (n=33)

		Participants
Age		
	20-29	2
	30-39	3
	40-49	10
	50-59	13
	60-69	5
Gender		
	Male	3
	Female	30
Race		
	White	28
	Black or African American	3
	Hispanic	1
	Asian	1

Table 3. Qualitative Research Protocols

Interview, Forum and Facebook Question Topics

- What are different employment options for people with disabilities?
- How do families provide support?
- Family conflict: what happens when family and people with disabilities disagree about employment possibilities
- What are systems barriers that prevent people from achieving their employment goals?
- What are attitudinal barriers that prevent people from achieving their employment goals?
- What efforts are being undertaken to address these barriers?
- What is employment development for people with disabilities?
- How do employment professionals engage families about supporting employment?
- What products and materials are most effective and/or popular?
- Life course of families of people with disabilities
- Key transition points throughout the life course
- Family relationships and perspectives implications for employment
- How can family members can play a networking role?
- Why can employment empower family members?
- Recommendations for tools: given what we know, what can we put together to increase family stakeholder commitment to employment?

Table 4. Primary *Codes, Secondary Codes, and Themes*

Primary Codes	Secondary Codes	Themes
Employment Support	Inefficient Outdated tech Post transition problems Restructure	Array of misalignments and discontinuities in services that feel stuck in the past
System Engagement	History of engaging with system Purposeful Support of nonwork Examples of early work exp Acquired Knowledge of other service options Knowledge of work options Networking with system Just got newsletters Planning systems should communicate, but don’t Web-based model	Family members’ experiences led them to mixed feelings about employment service Array of misalignments and discontinuities in services that feel stuck in the past
System Disconnects	Education Systems VR	
Family Engagement in Employment	Discontinuous system impact Engagement in employment Changing minds Hands off Inadequacy Leaving out older pwd No options System doesn't listen Family remains unknown to system	Family members expressed feeling unable to meet the expectations to fulfill an employment vision
Improving Outcomes	agency capacity early work experiences networking Parent expectations improving Other predictors Using supports	
Improving Visions	learning about resources helps negative employer attitudes	Government programs have very little capacity to meet demand

negative professionals
perception of disability
pessimism about
employment options