

Choosing Employment:

Factors that Impact Employment Decisions for Individuals with Intellectual Disabilities

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### **Abstract**

Little is known about the factors that shape the employment-related decisions of individuals with Intellectual and/or Developmental Disabilities (ID/DD). This article presents findings from qualitative interviews with individuals with ID/DD, their family members and employment-support professionals from four Community Rehabilitation Providers (CRPs) throughout Massachusetts. Recognizing the value of participatory action research, this study also included a co-researcher with ID/DD who participated in all facets of the research process. Findings revealed a collection of people and factors considered influential in employment-related decision-making. The family in the formative years, school-based staff and early employment experiences, the culture of the CRP, the job developer, and personal preferences all played a role in the decisions participants made. Through an understanding of these persuasive elements, and the parts of the employment process at which they occur, critical intervention points surfaced. Recommendations are offered to those in the ID/DD field to optimize employment choices and outcomes.

Key words: individuals with ID/DD, employment, decision-making

Policy shifts over the past 20 years have signaled a commitment to integrated employment for individuals with disabilities yet unemployment of this group continues as a pressing public policy concern. Recent analysis suggests that 28 percent of working-age adults with disabilities are employed, compared with 70 percent of people without disabilities (Current Population Survey, 2009). For people with intellectual and developmental disabilities (ID/DD) the disparity in labor market participation increases. In FY2003, only 26 percent of individuals with ID/DD supported by community rehabilitation providers (CRPs) worked in integrated jobs (Metzel, Boeltzig, Butterworth, Sulewski, & Gilmore, 2007). At the same time, participation in sheltered or facility-based employment and non-work services has grown steadily for this group (Winsor & Butterworth, 2008; Mank, 2003).

As CRPs continue to offer options from supported employment to sheltered employment, a significant critique of the service system is that it provides either no choice, or no meaningful choices (Storey, 2006). Informed choice involves education about available resources and the opportunity to choose a preferred option. Wehmeyer (2005), suggests that the goal of self-determination is to enable individuals to “act volitionally, and to become causal agents in their lives, *to make things happen*” (p. 120, emphasis added).

In recent years, research has begun to focus on the decision-making capacities of people with intellectual disabilities, although research on self-determined behavior remains limited (Shogren, Wehmeyer, Buchanan, & Lopez, 2006). Much of the literature has shown that individuals often have restricted opportunities for expressing self-determination as they are limited by communication and congregate work settings that curtail opportunities for choice and decision-making (Powers, 2005; Storey, 2006; Wehmeyer & Bolding, 2001).

As researchers consider choice-making among individuals with ID/DD, the interaction with a host of critical players throughout their employment journeys must be considered. Research highlights the roles of family members, who often introduce the idea of employment and are sought out for advice (Ankeny, Wilkins & Spain, 2009). Other family contributions include intentional career-related guidance and modeling of work values, especially during the transition years (Way & Rossman, 1996). Families of individuals with ID/DD also provide significant practical and moral support in maintaining competitive employment, compared to families in other disability groups (Dixon & Reddacliff, 2001).

Along with families, school-based experiences are critical during the development of employment goals, although the support provided varies widely. For example, Trainor, Carter, Owens, and Swedeen (2008) found that special-education teachers reported no designated responsibility for

helping transition-age students work toward their goals beyond academics. Employment-preparation for students with disabilities also appear limited to classroom settings rather than real-world work experiences (Guy, Sitlington, Larsen & Frank, 2006). Finally, well-established transition-planning programs also appear to be rare (Rutkowski, Daston, Van Kuiken, & Riehle, 2006).

As clear differences exist in school-based employment-related supports, considerable industry-wide variation exists in the quality of CRP service provision as well (Surdick, Pierson, Menz, Hagen-Foley, & Ussif, n.d.). As individuals with ID/DD receive services from CRPs, they come to rely on the job-search and job-placement skills of direct-support professionals. Although research has investigated the competencies in residential settings (Larson & Hewitt, 2005), very little has been done to examine the same for professionals who assist job seekers with ID/DD. This is surprising, as direct-support staff face complex responsibilities, ranging from navigating a business world driven by profit to addressing the personal needs of people with disabilities (Test, Flowers, Hewitt, 2004; Wehman & Targett, 2001).

While family, school, and employment-support systems and staff are critical players during the employment journey, other factors, such as positive previous work experiences, supportive work environments, and social integration with coworkers, likely play a role as well (Carter & Ditchman, 2010; Novack & Rogan, 2010). These factors often come up against barriers such as inaccessible transportation and perceived family concerns about safety and long-term placement of the individual (Migliore, Grossi, Mank & Rigan, 2008).

This literature review suggests that individuals with ID/DD continue to experience employment-related underachievement and limited opportunities to exercise choice about work-related concerns. While family members, school-based staff, and adult-employment staff represent critical players in the employment journeys of individuals with ID/DD, the quality and quantity of supports provided varies widely. Less evident is exactly how such critical players influence employment-related decision-making for individuals with ID/DD, to what extent those individuals' preferences correspond to existing employment options, and how this influences their decision-making. This study intends to address these issues by answering the following research questions:

- What factors influence the employment-related decision-making of individuals with ID/DD?
- To what extent do their preferences correspond to existing employment options and choices?

### **Methods**

The following methods section will review a) recruitment procedures and b) the data collection process, and will describe the (c) sample, and d) data-analysis process. A methodological goal of this

project was to fully involve an individual with ID/DD as a researcher, and the role of this team member will be described. *Co-researcher* is the term that the team used to describe the individual with ID/DD who was hired to work as a researcher on the project.

### **Recruitment Procedures**

Recruitment for this project occurred in three phases: a) recruiting the co-researcher, b) recruiting community-rehabilitation providers, and c) recruiting individuals, their families, and staff members. Each phase is described in more detail below.

**Recruiting the co-researcher.** Participatory Action Research (PAR) has been of increasing use to researchers and members of marginalized populations (Wallerstein & Duran, 2003). The research team in this study hired a co-researcher as a way of breaking down barriers between the researcher and participant and developing collaborative solutions to problems. Researchers have advocated that PAR be used to include individuals with IDD who are often otherwise excluded from the research process (Walmsley, 2001; Prilleltensky & Nelson, 2002). Several studies have illustrated the involvement of people with intellectual disabilities in many facets of research including collecting data (Knox et al. 2000), conducting member checks, or making sure that the researchers “got it right” (Mactavish et al. 2000). Individuals with IDD have also co-authored research articles (Townson et al. 2004) and self-advocacy resources (Ward & Townsley 2005). Consideration of such literature clarified the team’s rationale for the creation of a co-researcher position. Furthermore, an additional manuscript dedicated specifically to the involvement, importance, and impact of the co-researcher on this research project is forth coming.

Recruiting the co-researcher was done first so that she could participate in each subsequent step of the research process. The team created a job description, which was advertised through professional networking at the research organization. Applicants for the job were not required to have previous research experience, only an interest in working with a research mentor to learn about the research process. It was recommended that applicants: (1) have an interest in learning about how people find jobs, (2) have the desire to participate as a member of a research team, (3) self-identify as someone with ID/DD, and (4) have the capability to work with team members. There were twenty-three inquiries to the job description and thirteen candidates were considered. The group selected one finalist and two alternates. An orientation, training, and support plan was developed to ensure that this staff member was a fully integrated and successful member of the research team.

**Recruiting Community Rehabilitation Providers.** As a first step, the research team compiled a list of twelve CRPs in Massachusetts based on nominations from field-based trainers. When requesting nominations, researchers required a range of CRP sizes, regions, and cultures. From this list of twelve, the team selected four agencies to participate in the study, based upon agency size, geographic location, and diversity in mission and philosophy. The co-researcher was fully involved in the team's consensus.

Potential CRPs were first contacted over the phone. Researchers provided an overview of the project and requested the CRP's participation. Each CRP was given a fact sheet summarizing the purpose of the project and the data-collection process. In these initial phone calls, CRPs were asked to identify participants served by the CRP, and to collaborate with research staff to coordinate recruitment. A staff member at each CRP was offered a \$100 stipend in exchange for identifying individuals and facilitating the team's visit to their location to conduct interviews.

**Recruiting individuals and their contacts.** The process for recruiting individuals with ID/DD began with recommendations made by key contacts at each CRP. Each CRP contact was asked to select four individuals working in a range of employment settings (explained in more detail below). Staff from the CRP initially approached each individual and inquired about his/her interest. Additional eligibility criteria included: (1) an understanding of one's own employment process; (2) the cognitive capacity to understand the study and to consent to participate; (3) the desire to be interviewed; and (4) employment in the current setting for at least six months.

Upon each individual's interest in participating, one team member contacted the individual to explain the purpose and expected duration, as well as the potential risks and benefits. Individuals were also told that they would be asked to identify a family member as well as an employment-support professional to be interviewed about the individual's employment process. If a family member or CRP staff person chose not to participate in the study, the individual could still participate.

Since individuals in the study have ID/DD, researchers used a fact sheet to ensure clear communication and full participant understanding. Researchers also emphasized that at any time during the study, respondents had the option to end their participation. After individuals understood the nature of the study and agreed to participate, research staff scheduled an in-person interview.

### **Data Collection**

Data collection began with an accessible consent process, continued with an in-person interview with each participant with ID/DD, and ended with follow-up interviews with family members and employment-support professionals identified by the individual.

**Consent process.** As people with ID/DD are considered a vulnerable population when participating in research, care was taken to develop a consent process that used concrete terms and jargon-free language. This adapted consent procedure was created under the guidance of the co-researcher with support from her project mentor. This process was conversational in nature; the researchers stopped after each piece of information and requested that the individual verify her/his understanding. Furthermore, the written and verbal explanations were accompanied by pictures of each concept. To scrutinize the accessibility of the consent procedure prior to actual data collection, researchers piloted the consent forms. The pilot also provided an opportunity for the co-researcher and the other primary interviewer to practice the consent process.

**Interviews with individuals with ID/DD.** An in-person visit to each CRP occurred and included a series of face-to-face individual interviews that lasted approximately one hour each. A semi-structured protocol guided each interview, but researchers encouraged a free-flowing discussion. The protocols were piloted using the same process as the consent forms. Each individual was asked about a) personal background, including living situation, work history, and employment goals and preferences; b) circumstances or factors that influenced the search for their current job; c) challenges and how they were overcome; and d) level of satisfaction with their employment situation. The co-researcher and primary interviewer conducted all face-to-face interviews. The co-researcher's project mentor also participated in the first two site visits.

Researchers then asked the individual with ID/DD to identify one family member and one employment-support provider who could give additional information about the individual's employment process. These people were then contacted by phone and asked for their consent to participate in an interview. Upon verbal consent, the research team scheduled interviews. They were asked about a) their role in identifying the employment preferences of the individual with ID/DD, b) the individual's work history and employment options, c) their role in the individual's decision-making process around employment, and d) their level of satisfaction with the current employment situation. All interviews with family members and with employment-support staff were digitally recorded and sent to an independent transcription agency.

### **Sample Description**

The sample for this study consisted of 16 adults with ID/DD, 7 of whom worked in a sheltered-employment setting and 9 of whom were employed in competitive employment. Researchers also

conducted a total of 13 interviews with family members and 15 interviews with employment-support staff. Please see Table One for more details on the sample description.

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## **Data Analysis**

Interview data was analyzed using a qualitative approach. The following steps were employed during data analysis: a) coding, and b) memo writing.

**Coding.** Coding is an early and ongoing way of labeling data to sort it and assign meaning (Miles & Huberman, 1994). Operational definitions for each code were developed in order to ensure that all members of the research team had a shared understanding of the code. The definitions described the code as the cases emerged. As the coding list was developed, the co-researcher periodically reviewed it and provided feedback on its clarity. Through the provision of routine feedback, the co-researcher became acquainted with the code list prior to actually participating in the coding of transcripts.

A qualitative software program (Atlas.ti for the PC) was used to conceptualize themes, store coded transcripts, and sort data. Initially the researchers met on a regular basis to reconcile codes and reach consensus on code usage. Once the coding process was established, team members were assigned documents to code in Atlas.ti, and then these documents were secondarily coded by another team member. The co-researcher independently coded and reconciled these transcripts with various team members. The researchers simultaneously coded and analyzed the data, often meeting as a team to compare specific passages, improve the team's understanding of the data, and explore the similarities and differences between people's employment experiences (Charmaz, 2000).

**Memo writing.** Once all transcripts were primary- and secondary-coded, Atlas.ti was used to generate "query reports." The data from the reports was used to write memos. Memo-writing helped to organize themes from the data. The memos allowed the research team to further develop, interpret, and analyze the data (Creswell, 1998). The researchers met regularly to discuss the memos generated. The team's co-researcher created memos collaboratively with other team members and reviewed memos written by other team members to provide feedback, and in order to remain abreast of key themes emerging in various coding reports. Overall, data analysis focused on notable trends that warranted investigation while building cumulatively upon findings.

## **Findings**

Findings showed a collection of people and factors considered influential in employment-related decision-making for individuals with ID/DD. These distinct groups of people and circumstances

appeared consequential at different points in time over the course of the employment journey. The following findings section will review the impact of the following on decision making: a) family in the formative years, b) school-based staff and early employment experiences, c) the culture of the CRP, d) the job developer, and e) personal preferences.

### **The Role of Family in the Formative Years**

When individuals were asked who had been the most influential person in their life regarding work, they typically identified a family member. Families were influential because they a) role-modeled employment and b) instilled the belief that work was an expectation of adulthood.

**Role-modeling.** Family members served as role models for employment throughout the individual's childhood and adolescent years. Through role-modeling, family instilled the belief that work was an expectation for adulthood. One individual's family set the expectation that he was to become a hardworking adult just like the other adults in his family. His mother and sister role-modeled that employment can start during the adolescent years by discussing their first employment experiences with him.

Family members were often the first to talk about work as a means to achieve independence. Through role-modeling, family members showed that employment is the typical means of earning income, and that work allows for independence and personal satisfaction. One family member explained this idea in more detail:

He knew I've always worked. He grew up knowing that I was at work every day. Never missed work. Always had to do it. And I always told him I have to work so I can support you. I have to work so you have a roof over your head. I said, "You're going to have to do the same." And it's just how I brought him up.

This individual shared similar thoughts of his family member:

...my father always said to me that I could have a good life if I try and get a job and I could have money to spend, like my own money to spend...he also said to me that working will give you a great opportunity if you want to get another job.

Lastly, another individual talked about following his older brothers' lead. Watching his brothers grow up and get jobs was influential for the individual as he observed that earning money let his brothers be independent and move out of the house. The individual said of his siblings, "... neither of them sits in front of the TV and [watches] all day."

**Instilling the value and expectation of work.** Through years of role modeling, expectations about employment became deeply rooted and ingrained. One family member said, "[working] is what he

sees around him, and he thinks that's the normal way to grow up." Other families also provided examples of how they instilled the value of work. A staff person explained that one individual's mother had long-established aspirations that her daughter would work, and as a result the individual had strong employment-related goals. The parents and siblings of another person in the study held high expectations that the individual would be successful in employment, which paved the way for the development of robust career goals.

### **The Role of School-Based Staff and Early Employment Experiences**

Teachers and other high-school staff provided the first exposure to work that often set the individual in a particular employment-related direction. These early employment experiences shaped the way individuals thought about employment, influencing preferences, career planning, and self-confidence related to work.

**School-based staff provides first exposure to work.** Several of the staff interviewed mentioned teachers as being influential when it came to initial work experiences. As one individual's staff person said, "I think in high school—[it was] his teachers in high school...who first started giving him work experience. I think they were obviously an influence." Another individual's staff member explained that his Special Education teacher was likely important in the individual's decision to go to work in the community, as he taught all of his students about what it was like to work.

In the case of another individual, teachers were crucial in providing encouragement. While realistically reminding her that she would need to work hard, the individual's high school teachers also told her she was capable of doing anything she wanted in life. This individual started planning for employment in her last year of school, talking with one of her teachers about what it might be like to work in the community.

**Shaping work preferences.** All of the individuals had at least one previous work experience (either paid, internship, or volunteer) that shaped their employment preferences. The data showed that most of the individuals had a previous work history of a fairly limited range of jobs, including housecleaning, dishwashing, bagging groceries, and retrieving shopping carts. This may be because in the past the focus was on helping individuals to obtain work experience, as opposed to finding a job match. A staff person explained why he felt that these jobs were sometimes necessary: "You just can't put anyone anywhere. You know? We were just trying to get him that first-time job."

Although most participants had held such jobs, these early experiences led individuals to refine their employment interests and preferences. One individual who worked in a park in high school continued

searching for job that was active, outdoors, and with a variety of responsibilities. About the individual's early experiences, his father noted, "he had some jobs and some responsibilities that he enjoyed. He did some lawn work and grass mowing and maybe directed the visitors around the area. He was very proud of his work there." At the time of the interview this individual was working in a sheltered workshop and in enclave work on yard clean-up crews, but was anxious to find a permanent job in the community that measured up to his first employment experience working in a park.

**Shaping career goals.** Other individuals had early experiences that helped them determine not only the type of job they wished to obtain, but a specific career they wished to pursue. One individual began his career planning early when he expressed interest in working at his high school's bakery. Through this work, he determined that he wanted to pursue culinary arts. Another individual had early experiences caring for small children and decided she would like to pursue a career in childcare. These career goals were shaped while the individuals were still in school and led them on a path towards pursuing community employment in these industries.

**Shaping self-confidence.** Early employment experiences also impacted individuals' confidence in their ability to work in the community, and left some hesitant to pursue future jobs. For several individuals, the difficulty occurred because they were placed in positions where they could not complete the required responsibilities; their first employers did not know how to train a person with a disability, and they were quickly asked to leave. The impact of poor initial work experiences led some individuals later to choose sheltered employment. However, other individuals were able to move past negative experiences because they were strongly self-motivated, or supported by family members or professionals to understand that the previous positions were not failures but just poor job matches.

### **The Role of the CRP's Culture When Offering Options**

The CRP's culture affects the way staff perceives and offers employment options. The CRP's culture is comprised of its a) mix of services and b) philosophy about job readiness.

**Mix of services provided.** Three of the four CRPs in this study offered a mix of employment settings, including sheltered workshops, enclaves and work crews, and community employment. Only one of the CRPs exclusively offered community employment. At the three CRPs that provided a mix of services, individuals often revolved through community employment, enclaves, and sheltered employment depending on the availability of community jobs. In addition, individuals who were in community jobs at these three CRPs often simultaneously worked in enclaves and/or sheltered workshops. This was a clear difference compared to the CRP that only offered community employment,

whose staff described its business as "...a vocational program...we find employment and then we support them in their choice of careers."

The services provided by the CRP affect the way staff perceive and offer options. For example, staff from one CRP that offers a mix of services noted that they direct job-development resources only to individuals who *want* to work in the community. While they encourage community employment for all individuals they support, there is no expectation for someone to leave the sheltered workshop. A staff member noted: "I see it as important to get more and more jobs in the community and make the distinction of who is going to work and who is not, and putting 100% of the job development resources into those people."

In the CRPs with sheltered workshops, participants talked about the workshop as a safety net that individuals can return to if they lose their jobs. This can lead to gaps in employment history and affect the development of good employment skills. In the CRP that only provides community employment, individuals are encouraged to stay at a job that is not a perfect fit until a new job can be found, because the alternative is unemployment. A family member said "they worked with her to stick it out until they could find something else, to help her transition into [a new job]." Staff at this CRP explained that job changes are planned carefully. Staff supports individuals to not simply quit their present job before finding another, encouraging them to develop skills to responsibly transition between the two.

**Philosophy about job readiness.** Three of the four CRPs believed that individuals needed to meet prerequisites to be considered job-ready. These were the CRPs that offered a mix of employment services. Therefore, the existence of multiple workplace settings facilitated assumptions about prerequisites needed for community employment. For example, individuals at one CRP shared that the piecework in the workshop kept them working until they were ready for jobs in the community.

One CRP in particular appeared to be very concerned with determining whether individuals were ready to work in the community. A staff member noted that the sheltered workshop may be the best employment placement for people who have challenging behaviors: "We have clients who behaviorally, you know, they've been in a sheltered workshop, and it's worked for them because they don't have the capability to be out in the community." One family member commented that an individual had to be determined by the CRP to be ready to "work outside" before seeking community employment. In discussing one individual who wanted to work in the community, the staff noted, "Up until recently, he really wasn't ready for working competitively. He did the work crews. He did the internship, and this has all kind of helped him become ready for a job." Another quote demonstrates how an individual's

career goals can be hampered by staff perceptions: “[There are a lot of] examples of what she would like to do that are out of reach right at this point.”

The beliefs of the three CRPs regarding the need to learn and practice skills in the workshop before pursuing community employment contrast greatly with the employment-only CRP. Staff from this CRP commented, “We look at all people with disabilities [believing] that [they] can enter the workforce. Everyone basically is job-ready.” Another staff member at the same CRP noted, “Everyone is pretty much job-ready as far as if you have a mind, body and spirit, you can work. We feel that it’s gainful employment for all, everyone.” At this employment-only CRP, the process of identifying career goals and opportunities begins quickly. Their focus is to support the individual to participate directly and immediately in the employment-planning process.

The three other CRPs provided opportunities for individuals to learn tasks in a sheltered environment as preparation for community employment. Work-preparation courses are offered that included training on computers, cash-registers, remedial reading and writing, customer-service, and stocking shelves. Some of these skills were practiced in the CRP’s cafeteria, bathroom, or mailroom. Staff felt this curriculum was valuable because it would allow individuals to obtain skills that would make the transition to the workforce easier.

Another CRP included internal short-term training opportunities and internships in the community to increase job-readiness, addressing issues such as distractibility and social skills. Additionally, individuals could work on a crew doing grounds-keeping. One individual who was participating in these activities noted that this model led him to be “sitting around waiting for work.” However, staff felt that these activities prior to the job search was necessary as one said, “We have a lot of assessments that we do on people...social and behavioral assessments. With this individual, you wouldn’t even need to do one to realize he wasn’t ready.” Overall, staff members understood that some individuals wanted other jobs, but a “progression” to community employment was necessary.

### **The Role of the Job Developer in Decision-Making**

The job developer emerged as the most influential person during the job search often directing decision-making about employment choices. Individuals and family members often viewed their job developer as responsible for finding employment, and thus were only minimally engaged.

**Employment staff influences decision-making about job choices.** Staff explained that when they presented a job opportunity using positive language, the individual typically responded positively and wanted to accept the offer. Additionally, when individuals were apprehensive about employment, some

staff noted that they had a very strong influence on whether the individual would accept or reject a job offer. In other cases, staff made an effort to serve as an advisor rather than a decision-maker, helping the individual to weigh the pros and cons of a potential job match.

One individual who described making her own decision about work shared that it was the job developer who convinced her to apply. This job developer noted the balance she tried to strike between supporting the individual to make a good decision and allowing the person to assert independence. The job developer said that often, individuals “are looking for you to make the decision for them. I think that’s a learned behavior. So that when you give people more options or when you talk to people about what they like to do--I think there’s a certain amount of decision-making that’s a 50-50 type thing.”

Another example of shared decision-making involved the desire of an individual to take on a second job. This individual sought out the position on his own (a rare occurrence in the sample); he then brought the opportunity to his job developer and they discussed the impact of having two jobs on his schedule. Another job developer described her influence:

If he needs my help, I give him advice. I advocate for him. I also help him--if he has to make a decision, I kind of help him do the pros and cons. We sit down together. We talk about it. And I ask him what his main goals are, you know, what he really wants. And usually he already knows what he wants; he just needed to hear it out loud.

In certain instances, however, individuals felt they had either no choice or limited choice in their job placement. One individual explicitly reported that he had no choice in the decision to accept his job in the workshop, while waiting for a job in the community. When asked why he chose the job, the individual explained, “Because it’s ...the only paying job they could offer me right now until they could start looking for me for a real job. So basically this job I’m working at now was put onto me for now until I get a new job.” The individual went on to express his dissatisfaction with this outcome:

I was actually kind of planning to get a job at maybe a convenience store, but then they stuck me into the sheltered workshop job. And at the beginning, I was kind of bummed out, because I didn’t want to work at a place where you sit down; I wanted to work at a place where you could walk around.” He went on to say, “I had to complain a lot...After a couple of complaints saying that, they finally started looking for me [for] a new job.

The feeling that the individual lacked any choice when accepting a job also occurred for community-employment placements. One family noted that the individual did not have a lot of input in choosing his job. Another family noted that they had strongly influenced an individual to accept a job while waiting for a job that better matched her employment goals.

**Limited engagement of the individual and family.** Individuals and family members often viewed their job developer as responsible for finding employment and preparing to start work. Family members in particular perceived employment staff as more knowledgeable and skilled than the family could be in helping the individual find employment. While family members appear to be influential in instilling the value of work, they are less engaged in the process of job searching.

In some cases, family members were only minimally engaged; although clearly interested in and supportive of the job search, they were not aware of the details. In other cases, family members were not involved in career planning at all. Several of these families expressed an interest in being more involved, though they cited barriers including not wanting to be viewed as a hovering parent, receiving limited communication from employment staff, and feeling as though employment staff were the experts in career planning. One parent noted how she balanced her desire to be involved with the need to respect her daughter's independence and the job developer's expertise:

I liked the fact that they prepared her and taught her how to interview, because she respected what they said a lot more than what we said because, of course, we're Mom and Dad. We don't know anything about interviewing, and what we would say is not the right way to say it. So sometimes input from an outside source on certain issues like that, these people are trained. They know better; you don't. They work much better. So coming from them, they were the job people so she thought that they had all the answers.

When asked about their involvement in the individual's decision to accept a job offer, most family members said that they were minimally involved. This parallels the finding that family impacts whether or not the individual pursues employment, but are less involved in the specific aspects of the job search and placement.

### **The Role of Personal Preferences**

Individuals' personal reasons for work also influenced employment-related decision-making. These were a) earnings, b) productivity, c) the admiration of others, and d) the quality of social relationships.

**Earning money.** Individuals in this study said that their primary reason for working was to earn money to pay bills, contribute to their households, pay for hobbies or interests, and save so that in the future they could live independently. Of one individual, it was noted that earning money would give him the independence to make his own decisions:

...he wants to be as independent as possible. He wants to have an apartment. He wants to have a car. He wants to have all the things that his brothers and sisters have and his family has. And he wants his independence and wants to make decisions in his life.

Several individuals also reported that the realization that one could earn more money working in the community was a motivator for leaving the workshop. Individuals reported being dissatisfied with the low wages of the workshop. One individual noted that they were at the CRP from 9 a.m. to 1:30 p.m. and only earned about \$3 per day. Another individual preferred working on a work crew to the workshop because the work crew offered better wages.

**Productivity.** Individuals noted that they wanted to work so that they could be productive members of the community. Many individuals reported accepting a job because if they did not work they would feel bored, and would spend their time sitting at home and watching TV. Individuals wanted to feel useful and valued and to feel as if they have a reason to get up and a place to go. As noted by one individual, “I needed to keep busy. I like to keep busy. I used to help [my mom] around the house and stuff like that, but I needed more of an outlet in my life.”

Individuals who felt productive at work reported that they were more likely to remain at their jobs. Individuals cited having tasks they enjoyed, always having enough work to do, being able to be physically active on the job, being able to work at their own pace, and feeling confident in their job responsibilities as reasons to remain employed. One individual said, “I felt like a ‘somebody’ working in higher enterprise and going to work and then coming back. I felt like a person, like someone normal would feel like in a job and everything. And I’m helping the community, helping people with their groceries. I felt good about that.” Along with the opportunity for greater earnings, individuals in sheltered work were motivated to try community employment because of the increased productivity and the greater variety of responsibilities it would entail.

Individuals and their families in particular noted the desire for an increase in work hours, another indicator of the preference for productivity. CRP Staff was aware of this concern, but noted that they felt uncomfortable approaching employers about expanding work hours because such an increase could require individuals to take on more complex responsibilities or earn special certifications.

**Admiration from others.** How friends, family members, coworkers, and customers perceived the quality of an individual’s job and performance impacted choices. Having a high-quality, community-based job that was worthy of bragging about resulted in a sense of pride. In fact, several individuals who transitioned from the workshop to jobs in the community received praise on their accomplishment from individuals and staff at their CRP, influencing others to consider integrated jobs as well.

Being identified as a valuable part of a team by coworkers was another factor that led individuals to either choose or to remain in community employment. One individual shared praise he had received

from the employer: “You’re a real good worker and you’re helping all of us. We appreciate you, and we really trust you to do everything.” Another said that even though he worked a busy Saturday at one retailer, he loved the job because he was a part of a team that gave 100%.

Being respected by customers also influenced the choice to remain in community employment. One individual’s employment staff noted, “The clients know her name and have brought her gifts. The business owners have also shared that their clients like the individual and would miss her if she wasn’t there.” Another individual who works in retail was recognized for providing outstanding customer service: “I’ve seen him at his absolute best at Christmas time when people are searching around for something to buy for their child. And he will give them a suggestion or give them advice on something, and they’re just amazed.”

**On-the-job social relationships.** Positive relationships with coworkers were critical to choice-making. Friendships in the workshop between employees with disabilities were found to provide a sense of camaraderie and social connection. Friendships in the community between individuals and their coworkers without disabilities were also found to provide these benefits.

Perceived social acceptance, especially from coworkers without disabilities, appeared important. One individual’s coworker made her mix CDs of music that they both enjoyed listening to. Staff noted that another individual not only chooses to eat lunch with her coworkers instead of returning to the CRP to eat, but that together they joined a craft committee. One individual employed in a community job noted that she teases her boss and coworkers because “I love my boss. And I love my coworkers. They love me. And I love the way we all get along good with one another.” Another individual shared that he was satisfied with his job because his coworkers treated him with respect.

Staff also acknowledged the importance of taking the time to determine opportunities for social connectedness. They reported the importance of a supportive job environment and a workplace culture where coworkers are accepting, employers are flexible, and there is a willingness to provide natural supports. For one person, a job that provides opportunities to be with peers without disabilities can provide expansion of social networks. For another, a good match might be a community job that helps to retain the friends developed in the workshop, such as having the proximity to return for lunch.

Interestingly, when social connectedness was perceived in community-based jobs, it was described as hard to find and requiring the right fit. Although individuals in our study were described as well-liked, given a lot of attention, and fully included in holiday parties and gift-giving, the depth of the relationships appeared superficial or limited at times. One staff member noted,

“...he has some relationships at work. I think work is a strong base for his sort of feeling of belonging and feeling of value. And he has some people there that he has a relationship in that sort of way. I’m not sure he has any strong, really social relationships at work of, ‘Hey, the weekend’s coming up. You want to get together and go do something?’ kind of level.”

In certain cases, strong social connections made in the sheltered workshop influenced choices about community employment. Individuals who were considered to be “higher-functioning” in the sheltered workshop often chose to stay there because it offered the individual the opportunity to feel like an expert, achieve a certain status, and be revered among peers. For example, one staff member commented that an individual “gets his self-esteem” in the workshop, and that he “is so popular...he would prefer to stay.” Another staff member at another CRP noted that one individual feels a sense of exclusion and difference when he is out in the community because of his intellectual disability. However, when the individual is in the workshop, “he may as well be staff. He helps everybody out; he helps people who are lower-functioning. People look up to him. You know? And when he would go out into the community, he had some issues with that, because his disability was apparent.”

Friendships with peers in the sheltered workshop can become a barrier to choosing community employment. Staff noted that individuals miss their friends in the workshop and that they work hard to support individuals to believe that they can make friends in the community. Not only can the fear of missing one’s friends inhibit individuals from pursuing work in the community, it can lead individuals to thwart their own success in community-employment placements. One staff member said,

They look for that camaraderie [in the community] and they’re afraid they’re not going to get it on the outside. And you know what? Some of them probably don’t, and that’s why they come back. They sabotage the job. They miss their friends here.

### **Recommendations**

Findings showed a collection of people and factors considered influential in employment-related decision-making for individuals with ID/DD. Furthermore, distinct groups of people and diverse circumstances appeared consequential at different points in time over the course of the employment journey. Families emerged dominant in the formative years, because they role-modeled employment and instilled the belief that work was an expectation of adulthood. School-based staff provided the first exposure to work that shaped preferences, career planning, and self-confidence. The CRP’s culture, comprised of its service mix and philosophy about job readiness, affected the way staff perceived and offered employment options. The job developer became especially persuasive during the job-search,

perceived by individuals and family members as responsible for job-finding and resulting in decreased engagement. Finally, personal reasons for work, such as increased earnings, productivity, the admiration of others, and the quality of social relationships swayed individuals' decisions about staying in a current position and about whether to pursue community or sheltered work.

Each of these factors impact the ways in which the individual thinks about and makes choices along the employment path. Through an understanding of these persuasive elements, critical decision-making points surface. These are the pivotal areas in which the most effective interventions can occur. How do we seize these opportunities as they come forward, maximizing the chances for the best employment outcomes? The following recommendations are offered to those who provide employment support in the ID/DD field.

### **Engaging Families: Start Early, and Support the Family So They Stay Involved**

Participants in our study often reflected on the impact that family members had during their early years, and on their family's influence in shaping employment expectations. The experience of employment expectations being "taught" by family members and becoming deeply ingrained in one's upbringing is consistent with previous research (Way & Rossman, 1996). As our participants began searching for employment, families, individuals, and job developers agreed that the practicalities of the job search be left to the professionals. Family members often expressed the desire to become more fully involved but felt unqualified to do so.

One must question what is lost if families are only peripherally engaged at the time of job-search and placement. Other authors have found the family, as part of an individual's social network, to be a critical piece in the job-search (Gould, Hasnain, Bose & Butterworth; 2005). Hoff, Gandolfo, Gold & Jordan (2000) also point out the important role of families in job-development, both for networking and to help the job developer get to know the individual and his/her interests. Moreover, the very nature of the career-planning process described by these authors places the individual at the center of a process that encompasses family, friends, and community resources to achieve meaningful employment.

Ensuring that families be connected to and participate in the job-search process is sometimes no easy task. A stronger emphasis on personal networking strategies during the job search help this to occur naturally. Furthermore, strategies such as the "30-Day Placement Plan" (Condon, Gelb & Gould, 2005) make certain that core family members are actively engaged in the job-search and planning process, at the specific time at which our research shows the potential for family disengagement.

### **Creating Stronger and Earlier Links Between Schools and Employment Systems**

Findings showed that school-based staff becomes the conduit to early employment experiences that shape the individual's choices and confidence about employment. Other research does indicate that strong teacher advocacy for work experience does correlate positively with successful integrated-employment outcomes for transition-age students (White & Weiner, 2004). As teachers and others can be pivotal in providing such employment opportunities to their transitioning students, providing education about the value of integrated employment and the importance of job matching is critical.

Education personnel also need not only an increased knowledge of providers and the local service system, but also to understand how to connect their students to the CRPs that will best support goals for employment. Ensuring that the optimal connection is made will require that teachers are aware of the differences in philosophies among local CRPs and employment outcomes.

Building relationships between service coordinators from the state's ID/DD agency and local schools will open the lines of communication about employment opportunities and supports available. Engagement between both parties in activities such as CRP tours before graduation or jointly sponsored transition fairs would both increase exposure to the range of service options and philosophies and broaden expectations about the employment choices available.

### **Providing Technical Assistance to CRPs to Enhance Knowledge and Skills**

Three of the four CRPs in our study appeared to be only partially committed to the idea of employment for all, holding preconceived notions about whether an individual was "ready" for community work. Beliefs like this are often rooted in the culture of the CRP. Butterworth, Fesko, and Ma (2000) found that a catalyst for the changeover from facility- to community-based employment was to change organizational values to include the belief that all individuals are ready to work.

Shifting notions about job readiness requires a critical review of the paradigms that have shaped employment service delivery for this population. The principle of least restrictive environment (LRE) has been operationalized as a continuum model in human services (including employment service delivery), which has linked severity of disability with segregation (Taylor, 2004). The flawed nature of such as paradigm is that it lacks reference to concepts such as self-determination, consumer-directedness and community integration among other things (Taylor, 2004).

Replacing this is the concept of supported employment, which assumes job training can take place on the job; there are no prerequisite skills for employment, and workplace support can occur over the life of the job (Hill & Wehman, 1983). Furthermore, concepts such as the 30-day placement plan (Condon, Gelb & Gould, 2005) combine the tenets of rapid placement, team based job finding, and job

seeker directedness, and apply it to all disability types, regardless of severity. Shifting negative assumptions about an individual's readiness to work in the community can only enhance the search for a creative job match. Beliefs about job-readiness affected how CRP staff described their employment-planning strategies, and focused the individuals on "skill-building" activities before beginning the job search. This mindset also influences how job developers interact with and present job opportunities to individuals with whom they work, based on their notions about what type of employment experiences may or may not be successful.

Training on the most promising job-creation and job-search strategies for individuals with ID/DD, such as customized employment, job carving and creation, resource ownership, and micro-enterprise, are especially constructive (NCWD/A, 2006). Migliore, Winsor, Butterworth & Hall (2010) found a disconnect between the job-development activities recommended and those implemented by employment specialists, indicating a need for more targeted training. CRP administrators also need to be aware of these techniques and to support their employment staff to use them more widely than was found in this study.

### **Supporting Informed Choice**

Findings showed that job developers are perceived as the ones responsible for leading the job search, which led family members and individuals to rely on them. Job developers are also perceived as directing choices, especially concerning the decision to accept a job. Finally, they are seen as the expert, which can negatively influence individual and family engagement in the job-search process.

Ideally, individuals should be offered more than one job to choose from, although this is not always possible to do even for people without disabilities. Individuals need to have multiple opportunities to try out non-stereotypical jobs to determine what roles and responsibilities they enjoy, and should have the opportunity to try out a potential job for a short period of time before formally accepting it. This is a different mindset from encouraging job trials solely for the benefit of the business; it allows the individual to gain experiential knowledge and to use this knowledge to make informed decisions. Individuals who feel confident making their own choices will be better prepared to participate in the job-development process and to decide for themselves whether or not they want to accept a job.

Professionals providing employment supports must consider core self-determination principles in their work, and use their perceived influence wisely. Principles include the freedom to choose employment options, authority over resources, the ability to select support systems, the responsibility to spend public resources wisely, and confirmation about the quality of their experiences (Neirney &

Shumway, 1996). Professionals need to see self-determination as a fundamental ingredient of employment support. They must know that, for some job seekers, understanding that choices are available, making decisions, and owning the responsibility for decisions are skills that need to be learned. Self-determination can be taught by clarifying expectations and consequences, remaining in a facilitator role (even if it makes the process slower), allowing and respecting job-seeker decisions even if they seem counterproductive, and using the assessment phase as a platform to gauge the job seeker's comfort level with self-determination (Brugnaró & Timmons, 2007).

### **Create Opportunities to Build Social Connections Outside of the Workshop**

Findings from individuals clearly showed social connections as being a central reason for work. The camaraderie and acceptance experienced at the workshop was reported as a disincentive to community employment, remaining consistent with other literature (Cohen, 2005). The inability to maintain these connections upon entering community employment could lead individuals back into the workshop. The difficulty individuals had keeping their friends after leaving the workshop or making new friends with coworkers in community jobs limited their work choices.

Literature on integrated employment indicates that one of the most important outcomes of community-based work is the level of social integration of the worker (Yan et al, no date). Furthermore, social networks are positively related to labor force participation and groups who are unemployed and underemployed can use their social networks to increase opportunities for employment (Acquilara, 2002). Relationships with co-workers contribute to enhanced quality of life and higher levels of satisfaction for employees with intellectual disabilities (Mank, Cioffi, & Yovanoff, 1999).

However, research indicates that it is often the case that workers with intellectual disabilities have limited interactions with coworkers, and when they do interact, the quality of these interactions are substantively different than interactions among non-disabled workers. For example, Ohtake and Chadsey (1999) found that nearly all of the participating non-disabled employees reported work acquaintances, work friends, and friends in their employment setting, but none identified coworkers with disabilities as social friends. Findings from our study mirrored such barriers.

Limited connectedness beyond the workshop, therefore, is more related to the problem of social isolation experienced by many with disabilities than to a true need or desire to be in the workshop. Individuals need to be supported to make friendships in community employment, as well as to maintain their friendships from the workshop. People with disabilities need opportunities to form relationships with individuals who share common interests and hobbies rather than just a disability. Employment

planning must include efforts to sustain relationships, offering systematic strategies for people to connect as they move to community employment. Professionals can alleviate the fear of losing contact with friends from the workshop by supporting individuals to maintain phone or email communication and to engage in social activities outside of workshop hours. Other concrete options for building social connections outside of the workshop include volunteering, joining a self-advocacy group, or serving one's community through programs such as AmeriCorps (Sotnik, 1995).

### **Conclusion**

Individuals with ID/DD still remain underemployed compared to other disability groups. Those working with them need to consider the people, circumstances, and experiences that become consequential and persuasive at different times over the course of their employment journeys. As the employment agenda for this population pushes forward, targeted interventions at well-thought-out decision-making points will maximize the chances for the most meaningful employment options and outcomes for individuals with ID/DD in the years to come.

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Table 1

*Sample Description*

CRP location	Individuals in community employment	Individuals in sheltered employment	Family members	Employment support staff	Total interviewed
Metro Boston	2	2	4	2	10
Suburban Boston	0	4	3	2	9
Western Massachusetts	4	0	3	3	10
Southeastern Massachusetts	3	1	3	2	9
Total	9	7	13	9 <sup>1</sup>	38

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<sup>1</sup> Several individuals identified the same employment-support staff member to be interviewed. For this reason, 9 staff members were interviewed about the employment processes of 15 individuals.