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**Families and Employment of People with Intellectual and Developmental Disabilities:
Results from a Scoping Study**

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Families and Employment of People with Intellectual and Developmental Disabilities: Results
from a Scoping Study

People with intellectual and developmental disabilities (IDD) have persistently high unemployment rates compared to the general population and people with other types of disabilities (Butterworth et al., 2014; Petner-Arrey et al., 2016). As recent policies and initiatives prioritize employment for people with IDD (e.g., WIOA, 2014), and as more is learned about how families facilitate employment opportunities and help individuals advocate for preferred work environments (Migliore et al., 2007; Petner-Arrey et al., 2016), the systems that serve people with IDD must learn how to interact with families to maximize the benefit of their involvement toward their loved ones' successful employment outcomes.

Although there is a growing literature base on family involvement in employment for people with IDD, a scoping study has yet to synthesize what is known about the interactions of family members with the systems supporting people with IDD in employment. Research has centered on the importance of individual factors such as skills, interests, and educational attainment, or service system factors such as the supports available to individuals from schools, community rehabilitation programs (CRPs), and vocational rehabilitation (VR) agencies (Carter et al., 2012; Chappel & Somers, 2010; Yamamoto et al., 2014). The benefits of family involvement on the educational outcomes of people with IDD have also been well documented (Bianco & Garrison-Wade, 2009; Field & Hoffman, 1999; Fourqurean et al., 1991).

The most common area of focus in literature that has focused on family engagement is transition age youth. While all high-school-age students may benefit from family support toward reaching their goals, students with IDD frequently need an increased level of support from family members and educators, especially at this time of transition from a system of education-

based entitlement services, to which they are legally entitled up to the age of 22, to an adult service system based on eligibility requirements (Bianco & Garrison-Wade, 2009; Ferrel, 2012). A review of the literature on the transition from high school finds that families' knowledge of transition services, involvement in transition planning, and demonstration of cooperation, interest, encouragement, planning, and support promote the post-school success of students with IDD (Rowe & Hirano, 2015). Research further recommends that since parents, siblings, or other relatives close to people with IDD are likely to provide some form of support, engaging family members in the transition process early and often increases the likelihood of a smooth transition and a positive outcome (Fourqurean et al., 1991; Ferguson et al., 2005; Rosenthal et al., 2012).

There are many resources and strategies to educate, inform, and support individuals and families around employment at different points in life or the employment process, for example, Explore-Prepare-Act (Thomas & Robbins-Cureau, 2011); "Let's Get to Work" (Wisconsin Board for People with Developmental Disabilities, 2014); and Family Employment Awareness Training (Francis et al., 2013). Despite the existence of programs such as these, a summary of their common elements or effectiveness at engaging individuals and families in the employment process has not been published. This paper describes a study examining the state of the academic research in peer-reviewed journal articles on family involvement in employment of people with disabilities. The study aims to provide educators and service professionals with an informed perspective on the vision and expectations of individuals with IDD and families around employment, and with strategies and recommendations for involving families as partners in employment success after high school or further along in adulthood.

Method

We conducted the study as a scoping literature review to map a wide range of literature on a broad set of questions (Arksey & O'Malley, 2005). Levac et al. (2010) point out the importance of a scoping review as a tool for evaluating the quality of sources and their findings, and others have called for this type of systematic approach to prioritize key research areas and drive policy change (Daudt et al., 2013; Sarrami-Foroushani et al., 2015; Trico et al., 2016). In this vein, our scoping literature review is part of a knowledge-to-action sequence of studies to increase effective individual and family engagement with the disability service system.

We followed the six stages of a scoping literature review as originally laid out by Arksey and O'Malley (2005) and developed further by Levac et al. (2010). What follows is an explanation of our process of conducting each of these stages: (1) identifying research questions; (2) identifying relevant studies; (3) study selection; (4) charting; (5) collating, summarizing, and reporting results; and (6) expert consultation.

Stage 1: Identifying Research Questions

The broad topical questions that framed this scoping review were as follows:

Q1 What resources and strategies exist to inform individuals and families about employment?

Q2 How is family involvement related to employment?

Q3 What do the research and evaluation findings indicate are effective ways to support individuals and families to a) develop an employment vision and b) move from an employment vision to an employment outcome?

Q4 What research or evaluation has been performed to assess the effectiveness of strategies?

We further divided these questions into two categories: descriptive and evidence-based. The descriptive questions (Q1 and Q2) examine the literature's description of the ways in which

families currently engage with the service system around employment. The evidence-based questions (Q3, Q4) examined studies that had measured the effectiveness of strategies or information in moving to more focused employment visions and increased outcomes.

Stage 2: Identifying Relevant Studies

The scoping review included peer-reviewed journal articles published between 2005 and 2015 about involvement of families of people with IDD in the employment service system. We established this time limit to focus on articles written in the context of growing demand for expanded employment opportunities and featuring resources most likely to be available at the present time. The articles needed to a) address participation in employment; b) be used to support people with IDD and/or their family members; c) be based on a standard approach, agenda, or curriculum; and d) describe an intervention/program that had been written about strategies used, or trainings offered more than once.

The methodology used in identifying studies for this scoping literature review follows a 4-step process that closely resembles the process described by Landa et al. (2010) and went as follows.

Identifying Step 1: Define and refine the search terms. This initial collection of literature produced a robust set of keywords (see Table 1).

[insert table 1 here]

From these keywords, the researchers formed four conceptual blocks based on the research questions (see Table 2). These conceptual blocks created word pools from which the researchers chose terms to create different combinations of keyword searches in electronic journal databases.

Identifying Step 2: Identify databases and search engines and queries using search terms. The research team conducted searches of the following EbscoHost databases: Academic

Search Complete, Medline, PsycArticles, PsycInfo, Teacher Reference Center. Table 2 presents the search terms used.

Identifying Step 3: Apply the inclusion and exclusion criteria filters. The researchers began the search by inputting combinations of the conceptual block keywords (see Table 2), beginning with an initial search term and adding a second, a third, etc.

[insert table 2 here]

Identifying Step 4: Verify that the sub-selection is representative. The research team used a strategic screening process to determine whether to include each article in the post-query article selection. If an article's title and subject contained the search terms or variants of the search terms used in the query, the article was selected for the second screening process. Once they were identified, we proceeded to stage 3 of our 6 stage process.

Stage 3: Study Selection

The next step of the article screening process was for researchers to read the article abstract to determine relevance to one of the study's seven research questions. If the abstract did not address any of the research questions, the article was excluded from the study. Articles that addressed one or more of the research questions were included in the study.

Stage 4: Charting

The charting process consisted of recording key information about each resource or strategy (Arksey & O'Malley, 2005). Two researchers developed a rubric for the research team to record each article's journal citation; a thematic analysis of the entire article; the number of research questions addressed in the article and details supporting how each research question was or was not addressed; notes on the quality of the article; and, based on this information, a yes/no determination of whether the article should be included in the scoping study (See Table 3).

[Insert table 3 here]

Stage 5: Collating, Summarizing, and Reporting Results

Upon completion of the charting process, two researchers sorted the articles and entered those to be included in the scoping study into a database within ATLAS.ti v.7 (2013), a program that analyzes qualitative data to uncover both small details and broader relationships between ideas. Sixty articles were assigned into the Atlas.ti database from the original total of 80 articles.

Stage 6: Expert Consultation

For this stage, we consulted with the project advisory board, which consisted of people with IDD and members of a prominent parent advocacy organization, on a phone call during which emerging themes were shared and clarification on existing themes was sought.

Findings

Our findings from the literature review are presented in the following themes: 1) There is a relationship between family involvement and employment, 2) Individuals and families can be supported effectively to develop an employment vision and expectations; and 3) There are effective ways to move from a vision to an employment outcome. Each of these themes will be summarized below.

There Is a Relationship Between Family Involvement and Employment of People with IDD.

Family involvement in employment appears to occur in a few overarching ways, all of which are related to improving employment outcomes for people with IDD across the life course. These include: 1) Family members' role modeling and expectations shape positive experiences of employment for individuals; 2) Advanced knowledge and capacity within families leads to

employment-focused decisions; and 3) Family and individual demographics are related to employment.

Family members' role modeling and expectations shape positive experiences of employment for individuals with IDD. A common finding was that people with disabilities who observed others at work or participated in work experiences raised their expectations around employment. This finding corroborates other research noting the broad positive impact on employment expectations and vision of people with disabilities from family members modeling work roles (Timmons et al., 2011; Lee & Carter, 2012). Individuals with IDD who have adult mentors as role models also appear to have increased employment expectations and a vision of themselves as employed (Lindstrom et al, 2013).

Advanced knowledge and capacity within families leads to employment-focused decisions. Research has noted the important role played by engaged families- those who understand the transition process and have a sense of partnership with the disability service system. These families are in good communication with transition specialists and other professionals and support their efforts to help their relatives with IDD become employed. Service professionals identify parents in these families as taking on the roles of teachers, advocates, and case managers of a range of services to smooth out the transition process, while siblings support the socialization of their brother or sister with IDD (Gillan & Coughlan, 2010). Furthermore, families engaged in shaping and supporting early work experiences see better employment outcomes for their family members with IDD (Lindstrom et al., 2007; Petner-Arrey et al., 2016).

Family and individual demographics are related to employment decisions and patterns. Although people with disabilities were found to have better employment outcomes when their families were engaged, some research points to differences in families' capacity to

interact with employment services. Some families with financial challenges or members with high support needs report that surviving from day to day is a more critical concern than focusing on the future and transition (Timmons et al., 2004). Language barriers may prevent families within immigrant communities from engaging with the service system, although they are frequently interested in learning about services and adopting ideas or models that may be new to them, such as the practices of self-determination (Zhang & Benz, 2006). Additionally, one study found that the individual's gender was related to differing expectations and patterns of employment: Young men were initially employed at higher wages and had fewer work interruptions, while young women were more frequently encouraged to be financially independent and responsible and were more persistent at returning to work after gaps in employment (Lindstrom et al., 2010).

Individuals and Families Can Be Supported Effectively to Develop an Employment Vision and Expectations

The intervention studies cited above addressed individuals' and families' level of knowledge and experience related to employment. Of these studies, Gross et al. (2013) most directly addressed expectations through the Family Employment Awareness Training. A few studies highlight the importance of informed, engaged families, noting that family members' direct support to individuals is a factor in the success of individuals' early work experiences (Hamm et al, 2014), or because families' use of their social networks has facilitated employment outcomes for some individuals (Petner-Arrey et al., 2016).

Some studies offered recommendations for engaging families in the general transition process, reporting, for example, that it was invaluable for families to experience ongoing in-person communication with at least one service professional with whom they had built trust

(Timmons et al., 2004; Howland et al., 2005; Canha et al., 2014). Parents in these studies report that good communication and relationship-building over the long term with a transition specialist or other professional was important to their becoming engaged with the transition process. They also reported that service professionals who communicated with them easily, displayed a genuine sense of care, especially for their family members with IDD, and helped them connect with other families navigating the transition process were critical to family engagement in the development of an employment vision and outcome. This was true regardless of parents' overall impression of their experience with the transition service system (Timmons et al., 2004; Canha et al., 2013).

Families were shown to increase and retain their knowledge of the service system and the transition process through self-paced computer-based instruction (Test & Rowe, 2010) and written and in-person training (Young et al., 2016). In Carter's study, the central role of parents as advocates and facilitators of systems change was recognized through a program in which they were trained to lead community conversations around increasing opportunities for the inclusion of people with disabilities in employment and community life (Trainor et al., 2012). Beyond these exceptions, most studies were focused on actions families could take and resources to connect with during transition.

There Are Effective Ways to Move From a Vision to an Employment Outcome

Once again, our review indicates that there is very limited evaluation of the supports and strategies available to families to help them facilitate positive employment outcomes. Some articles presented a resource or strategy such as the Start on Success transition program (Sabatino & Macrine, 2007) or the Project Search internship program (Ham et al, 2014). Francis et al. (2015) developed, carried out, and evaluated the Family Employment Awareness Training, and noted that the individuals and families who attended reported that the training not only increased

their knowledge and raised their expectations about employment, but influenced them to take action toward an employment outcome. Furthermore, although they could not attribute employment outcomes to the training alone, the researchers reported that seven individuals had found competitive employment and eight had found volunteer or internship positions after completing the training.

Discussion

We know that family members play an essential role in supporting employment outcomes of people with IDD for an extended period across the life course (Docherty & Reid, 2009; Hirano et al., 2015.) We also know that family members frequently support individuals by networking for them to find jobs and helping them to prepare for interviews or travel to and from work each day (Petner-Arrey et al., 2016; Lindstrom et al., 2007).

The dynamic of the parent as the primary advocate for the individual's receipt of supports and services is clear to families. In our review, parents expressed that ultimately, it is up to families (usually parents) to assume the responsibility for a successful transition by taking on what researchers have referred to as the "linchpin role" of coordinating all the information from the school system, the service system, Social Security, and any other sources (Timmons et al., 2004; Canha et al., 2013). Hirano and Rowe (2015) identified parents as taking on the roles of evaluator, collaborator, instructor, and advocate as they navigate their children's transition to the adult service system and life after high school.

Despite cultural differences in the degree of independence parents expected their children with IDD to have as adults, they expressed the view that they would likely support their children informally through many facets of life, including employment (Rueda et al., 2005; Docherty & Reid, 2009; Povenmire-Kirk et al., 2010). These same parents also expressed the view that they

would have benefited from more frequent, organized, informative communication from the service system as they provided daily support to their children and tried to imagine a, meaningful future ahead of them.

Family involvement is cited as a critical factor leading to good employment outcomes, and the resources and strategies currently used by families are well described in the literature. Missing from the literature are evidence-based strategies to engage with families around creating expectations and visions of future employment and working from those visions toward desirable employment outcomes.

Limitations

Although we used an evidence-based process to collect and screen the literature, we may have overlooked keywords that would have elicited further intervention studies. We also imposed limits on geography, time of publication and inclusion in a peer-reviewed journal that may have precluded us from discovering other ways in which families are becoming informed about and planning for employment. Additionally, there is the possibility that our approach played a role in limiting the focus of our findings to families of transition-age youth, excluding studies pertaining to families of younger or older individuals with IDD.

Often, when families discuss their current experiences with the transition process, or when they reflect on this experience years later, they note that transition specialists or other service professionals did not engage in discussion or planning about the individual's life beyond school later than families would have liked and offered limited options for the future (Canha et al., 2013). This critical, frequently repeated reflection from parents drives much of what we recommend for future directions in research and changes to the interaction between disability service professionals and families. It is necessary that future research fill in the gaps by

conducting intervention studies and including families of individuals of wider age ranges. It is our hope that this future research will inform and engage families prior to transition, before they can become discouraged and develop nonexistent or very low employment expectations.

Implications

The frequent engagement of family members over time provides opportunities for families, individuals, and service professionals to build trusting relationships and a sense of partnership; communicate about individuals' support needs, preferences, and goals; and review information about navigating services and options and implementing plans for transition and beyond. Research on fostering employment visions and outcomes for individuals with IDD and their families offers a rich description of the challenges and solutions in the transition from school to competitive employment. The critical influence of engaged family members on the employment process has also been well established. What remains is for research to move beyond descriptive studies that set forth the barriers and focus on developing and testing solutions to increase family engagement around employment. Future research should focus on what strategies increase family engagement with employment planning which will, in turn, close the persistent employment gap for people with IDD.

However, based on our extensive review of the literature, we suggest that individuals and family members have reached oversaturation in trainings and programs designed for employment. While families have reported that these trainings have raised their expectations for employment after transition and have educated them about how to access supports and services, they can also leave individuals and families with more unanswered questions about why they might not have learned about employment options earlier, and how the services might apply to

their individual situation, or with the desire for more opportunities to discuss transition plans with service professionals.

Research has given attention to innovative opportunities that the service system is beginning to provide for individuals with IDD to transition into community employment and has recognized that families' input contributes to the success of these types of efforts (Ham et al., 2014; Trainor et al., 2012). While service professionals acknowledge that families are important to the successful transition of individuals with IDD, they remain somewhat unclear on how to overcome the challenges of engaging them (Chappel & Somers, 2010).

What we might strive to create through intervention research is a service system that communicates frequently with individuals and families, starting early in the lives of the individuals to help prepare them, step by step, for the future. This research must highlight findings on the successful early engagement of families around the future expectation of employment, and evidence-based strategies for partnering with families that contribute to good employment outcomes.

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Table 1: Conceptual Blocks by Search Terms

Conceptual block	Search terms that comprise block
disability	Disabled OR disability OR disabilities OR autism OR mental retardation OR learning difficulty OR Down syndrome OR Asperger's
employment	employment OR job OR vocation OR work
family	family OR families OR familial OR parent* OR sibling* OR grandparent* OR brother* OR sister* OR aunt* OR uncle*
transition	transition OR training OR plan* OR informed choice OR education OR planning OR knowledge translation OR decision OR choice OR information OR high school

Table 2: Search Steps/Methodology (Process Table)

Step 1 (initial search term)	Step 2 (block added)	Step 3 (2 blocks added)	Step 4 (3 blocks added)
disab*			
disab*	+ transition		
disab*	+ transition	+ transition AND employment	
disab*	+ transition	+ transition AND employment	+ transition AND employment AND support
disab*	+ transition	+ transition AND employment	+ transition AND employment AND parent*
disab*	+ transition	+ transition AND employment	+ transition AND employment AND famil* Post-Query Filters: Exclusion & Inclusion Criteria
disab*	+ transition	+ transition AND employment	+ transition AND employment AND decision
disab*	+ transition	+ transition AND employment	+ transition AND employment AND choice
disab*	+ transition	+ transition AND employment	+ transition AND employment AND training
disab*	+ transition	+ transition AND employment	+ transition AND employment AND intervention
disab*	+ transition	+ transition AND employment	+ transition AND employment AND high school
disab*	+ transition	+ transition AND employment	+ transition AND employment AND information

disab*	+ transition	+ transition AND employment	+ transition AND employment AND planning
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Table 3: Study Selection Framework/Rubric

Title:

Author(s):

Journal:

Exclude: (Y/N)

Inclusion criteria notes: Does the study answer the research questions? Which ones:

Research question	Present in journal (y/n)
What resources and strategies exist to inform individuals and families?	
What research or evaluation has been performed to assess the effectiveness of strategies?	
What do the research and evaluation findings indicate are effective ways to support individuals and families to develop an employment vision?	
What do the research and evaluation findings indicate are effective ways to support individuals and families to move from an employment vision to an employment outcome?	

Quality notes:

Findings/themes present:

Other ideas/findings/thoughts:

Appendix A: Code list

Research question codes

Authors

Disincentive

Early link to support agencies, work experience prior to transition age

Effectiveness of employment strategy

Evaluation findings on employment outcome and/or vision

Exclude

Exclude/scoping review method article

Family engagement finding

Family expectations

Family expectations of work

Family expectations of work/early link to support agencies

Findings/effective ways to develop vision

Findings/employment outcomes

Findings/themes present

Follow-up

Include

Journal

Legislation

No: research that assesses effectiveness of strategies

Other ideas/findings/thoughts

Quality notes

Quality note – method – type

Research and evaluation that assesses effectiveness of strategies

Research findings on employment vision/outcome

Resources and strategies to inform families around employment

Title

Transition to adulthood

Vision