Intellectual and Developmental Disabilities

Parent Perspectives on Meaningful Work for Individuals with Intellectual and Developmental Disabilities

--Manuscript Draft--

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Abstract:	Increasing employment outcomes for individuals with intellectual and developmental disabilities (IDD) remains an enduring emphasis of research, policy, and practice. Parents are often primary partners in the pursuit of work for their family members with IDD. This qualitative study examined the views of 55 parents regarding the importance of this pursuit and the features of employment that matter most. Participants discussed a range of reasons they valued employment for their family members with IDD, including factors that extended beyond a paycheck. Likewise, they described multiple features that they considered to be important to their family member's thriving in the workplace (e.g., inclusivity, match with interests, opportunities for growth). We offer recommendations for promoting integrated employment and conceptualizing employment outcomes.

Dear Dr. Thompson,

Thank you for the opportunity to revise our manuscript, *“More Than a Paycheck”: Parent Perspectives on Meaningful Work for Individuals with Intellectual and Developmental Disabilities.* The comments of the two reviewers were very helpful in strengthening the manuscript. We detail below how we responded to each of their comments. We look forward to the next round of feedback.

REVIEWER 1

The reviewer commended us for a well-structured manuscript and rigorous study and offered only a few minor suggestions to enhance the manuscript.

1. In the introduction, the reviewer suggested summarizing research that has been done to understand important aspects of work from the perspective of people with disabilities.

We have folded this information into page 4, drawing primarily upon key findings in the systematic review by Kocman and Weber (2018). In addition, we return to these findings in the discussion (pages 18 and 19).

2. The reviewer suggested we define the phrase “meaningful work” in the introduction by appealing to definitions appearing in the larger vocational psychology literature

In making other requested revisions, we dropped the particular reference to “meaningful work” in the introduction. However, we have incorporated citations to this broader vocational psychology literature elsewhere in the introduction when addressing how the job features people with IDD value align with what people without disabilities value (pages 5 and 17). Likewise, we return to the concept in the discussion by letting the findings from participants inform an answer to this question.

3. The reviewer suggested we also define what we mean by employment positions that are "high quality" or a "good fit," acknowledging that a definition of "meaningful employment" might support this definition.

We agree that these phrases were vague, as concepts like quality and fit are almost always individually determined based on the person and employment context. We provide a brief definition on page 6.

4. The reviewer asked us to be more explicit about what we meant by “emphasis” in Figures 1 and 2.

When presenting the findings, we attempted to order codes based on their emphasis within and across interviews. Specifically, we considered both the frequency with which each code was raised, as well as the amount of attention (e.g., short statements versus extended discussion) and weight (e.g., passing mention versus emphasized importance) reflected within the coded quotes. We emphasize that such ordering should be interpreted with caution, as parents were not asked to rank order a full list of benefits and features of work. Moreover, they often highlighted only one or a few areas in response to our related questions. This process is detailed now on page 11.

REVIEWER 2

The reviewer considered the large number of family members who participated to be a strength and noted that understanding their perspectives is essential.

1. The reviewer asked why we elected to use the word "parents" to describe participants when some participants were siblings or grandparents. They suggested using a phrase that more accurately depicted the roles of all participants.

Our overall project did involve a small number of siblings and grandparents (*n* = 5). After reflecting on this recommendation, we decided to focus this manuscript only on the 55 parents in our project. In addition to addressing this recommendation, it would ensure that findings that were largely derived from parents are not overgeneralized to siblings or grandparents, who were represented in very small numbers. As a result, we also changed the title to reference “parent perspectives” rather than “family perspectives.” This resulted in a slight reduction in the number of codes related to RQ2 and replacing sibling/grandparent quotes with parent quotes.

2. The reviewer suggested we mention the overarching project earlier in the article and say more about the relationship of this study to that multi-year project.

We have moved this information to the end of the introduction after explaining the research questions (page 6).

3. The reviewer suggested we use the word “prioritize” more consistently throughout the manuscript.

This was a good suggestion. We have revised the manuscript to this end, which included clarifying the research questions to avoid confusion. `

4. The reviewer suggested we make a stronger case for researching the preferences of parents of adults with IDD in relationship to employment. While acknowledging the value of these preferences, the reviewer asked why would we not just consider the perspectives and priorities of the people with IDD themselves?

We have addressed this case in the introduction (page 5) and discussion (pages 19-20). We absolutely agree that it is important to understand the perspectives of individuals with IDD regarding this topic. Indeed, several studies have already adopted this focus (see review by

Kocman & Weber, 2018). At the same time, decisions about community jobs are often made jointly in consultation with parents and other caregivers. For the large numbers of individuals with IDD who live with their families, decisions about when, where, and how they work directly impact family supports and routines. Likewise, some individuals with IDD have complex communication needs that make it difficult for them to communicate their priorities in understandable ways. Thus, best practices advocate for the involvement of family members in decisions about work in ways that supplement, but do not supplant, the views of individuals with IDD. Because our intervention development focus on a parent mentoring employment intervention, we needed to understand how parents viewed the importance of employment and its salient features. We have tried to be more explicit about how parent insights can be considered in concert with those of individuals with IDD.

5. The reviewer encouraged us to rely more heavily on previous research throughout the introduction.

Unfortunately, this is an area in which there is very limited prior research. However, we have folded in a number of additional citations when available and appropriate throughout the manuscript. The statement called out by the reviewer (“the extent to which parents believe that employment will bring substantive benefits to their child is likely to influence the time and effort they devote to promoting this aspect of community participation.") is not a research finding, but rather a logical assumption. Thus, we have incorporated the word “could” into this sentence and followed it with a citation to work that links expectations to outcomes.

6. The reviewer suggested we cite public policy/laws/regulations related to employment rights for people with disabilities instead of stating: "This emphasis arises from the conviction that individuals with IDD should have access to the same range of valued experiences as anyone else in their community."

In this paragraph, we were trying to address the multiple foundations for the emphasis on employment. We agree with the reviewer that we should also reference basic employment rights. We have inserted a sentence addressing this good point (page 3). We have also added a reference to Wehman et al. (2018) when mentioning employment policy in the opening sentence.

7. The reviewer asked that we explain recruitment occurred in only one state and address why this state was selected.

Our original research plan involved interviewing participants in person, as we anticipated it would increase rapport and contribute to richer interviews. For practical reasons, this required limiting recruitment to a reasonable proximity of our university (e.g., a few hours). This parameter still enabled us to involve participants who resided in rural, suburban, and urban communities. It also allowed us to partner with known agencies and organizations for recruitment. The unexpected onset of the pandemic required us to shift to virtual options. Although we could have broadened recruitment at that point, we already had sufficient numbers of participants signed up to address our research questions. We have included this explanation on page 8.

8. The reviewer asked that we explain the information used to guide decisions regarding data saturation.

We ended our recruitment when additional interviews were not generating substantially new insights to our research questions (i.e., data saturation) and our sample sufficiently reflected state demographics (see page 8). Judgements regarding data saturation were not made with regard to these two research questions alone, but also in relation to other aspects of our project's interview protocol (i.e., barriers and facilitators impacting integrated employment; recommendations for intervention). Thus, we ended recruitment when relatively few new insights were coming from additional interviews.

9. The reviewer asked that we explain why both interviews and focus groups were implemented.

Although we began the project with a preference for focus groups, we also recognized that some participants might be reluctant to share their stories and perspectives in a group context. Likewise, we anticipated that the scheduling of focus groups might leave out some parents whose schedules would not align with those of other parents. Therefore, we allowed prospective participants the option to choose the format they felt more comfortable with or worked for them. In retrospect and the onset of the pandemic, we are glad we planned for this option. We have clarified this on pages 8-9.

10. The reviewer asked that we explain why a study focused on adults with IDD included participants with family members with such a wide array of disabilities.

Our overall project—and the RRTC with which it is affiliated—focused on the employment of adults with intellectual disability and/or autism. Although this reflects of more targeted subset of adults with disabilities, it is a group still marked by considerable heterogeneity. Thus, our recruitment approach explicitly sought to capture this variety, which we consider to be a strength of this study. We wondered whether the reviewer might have wished we focused on a particular type of disability (e.g., autism only, severe intellectual disability only). We have added this explanation to page 7. We have suggested on page 20 that future research studies might explore whether different views are associated with having family members with particular types of disability experiences.

11. The reviewer asked why family member of adults with IDD who had never previously worked allowed to participate in the study alongside family members of adults with IDD who had worked.

Our overarching project focused on developing a parent-focused intervention to equip them to pursue employment for their family member with IDD. Thus, we needed to hear from participants whose family members with IDD had experienced success finding employment, as well as those who had not. Although we considered dropping the small number of participants (*n* = 11) whose family member had never worked from the current analyses, we realized in the interviews that all parents still articulated clear priorities regarding the features of jobs they considered most important (RQ2). Moreover, these parents all spoke directly to why they were interested in pursuing employment for their family member, whether or not they had yet been successful (RQ1).

12. The reviewer wondered about the frequency of specific findings and suggested we include frequency counts in our figures.

When presenting the findings, we attempted to order codes based on their emphasis within and across interviews. Specifically, we considered both the frequency with which each code was raised, as well as the amount of attention (e.g., short statements versus extended discussion) and weight (e.g., passing mention versus emphasized importance) reflected within the coded quotes. We have opted not to include frequency counts in our figures, as number of occurrences was not the only factor we considered. Moreover, our accent is primarily on showcasing the array of benefits and important features parents identify, rather than communicating which may be more pressing than others. We emphasize that such ordering should be interpreted with caution, as parents were not asked to rank order a full list of benefits and features of work, but instead only highlighted one to a few in response to our questions. This is detailed now on page 11.

13. The reviewer wondered whether we observed any coding application trends among different types of family member participants based on race, age, or other demographic variables.

We did not notice any obvious patterns based on the demographic variables available to us. Instead, the views regarding benefits and priorities seem to be more closely anchored to qualities and experiences specific to their family members with IDD (page 20).

14. The reviewer suggested we expand more on the overlap between the findings of this study and those studies addressing the importance of work from the vantage point of adults with disabilities.

We agree. We have done this in two places within the discussion—on page 18 and on page 19—in relation to each research question.

15. The reviewer suggested incorporating additional implications for practitioners, researchers, or policy makers.

We have added an implications for practice section that incorporates an array of recommendations (see pages 20-21).

“More Than a Paycheck”: Parent Perspectives on Meaningful Work for Individuals with Intellectual and Developmental Disabilities

“More Than a Paycheck”: Parent Perspectives on Meaningful Work for Individuals with Intellectual and Developmental Disabilities

Abstract

Increasing employment outcomes for individuals with intellectual and developmental disabilities (IDD) remains an enduring emphasis of research, policy, and practice. Parents are often primary partners in the pursuit of meaningful work for their family members with IDD. This qualitative study examined the views of 55 parents regarding the importance of this pursuit and the features of employment that matter most to them. Participants discussed a range of reasons they valued employment for their family members with IDD, including factors that extended beyond a paycheck. Likewise, they described an array of features that they considered to be important to their family member's thriving in the workplace (e.g., inclusivity, match with interests, opportunities for growth). We offer recommendations for promoting integrated employment among families and conceptualizing employment outcomes within future research.

Keywords: integrated employment, intellectual disability, autism, quality of life

"More Than a Paycheck": Parent Perspectives on Meaningful Work for Individuals with Intellectual and Developmental Disabilities

Elevating employment outcomes for individuals with intellectual and developmental disabilities (IDD) has been a longstanding priority of both policy and practice (Callahan et al., 2014; Wehman et al., 2018). This emphasis arises from the conviction that individuals with IDD should have access to the same range of valued experiences as anyone else in their community. It is grounded in basic rights and foundational legislation (Americans with Disabilities Act, 1990; U.N. Convention on the Rights of Persons with Disabilities, 2008). Moreover, it is anchored to core values such as inclusion, self-determination, equality, and independence (Mank & Grossi, 2013). Indeed, numerous national organizations have issued strong resolutions articulating the importance of ensuring access to meaningful employment for individuals with extensive support needs (e.g., American Association on Intellectual and Developmental Disabilities [AAIDD], The Arc, Association of People Supporting Employment First, TASH). For example, The Arc and AAIDD's (2017) position statement clearly affirms that, "People with IDD should have the supports necessary from individuals and systems to enable them to find and keep community jobs based on their preferences, interests, and strengths, work alongside people without disabilities, receive comparable wages, and be free from workplace discrimination."

Unfortunately, integrated employment still remains an elusive experience for most individuals with IDD. Less than one fourth of adults with IDD have a paid job in their community (National Core Indicators, 2019; Winsor et al., 2021). Likewise, few youth with intellectual disability or autism obtain a job in the early years after high school graduation (Butterworth & Migliore, 2015). The persistence of these disappointing outcomes has renewed calls to strengthen pathways into the world of work (e.g., Wehman et al., 2018). However, ensuring individuals with IDD receive the opportunities and supports to pursue meaningful work requires the combined efforts of families, schools, agencies, employers, and local communities (Carter et al., 2016).

Parents can be primary partners in the pursuit of integrated employment for individuals with IDD (Dixon & Reddacliff, 2010; Gross et al., 2015). Indeed, their own investment in this outcome can directly impact whether or not their family member with IDD seeks and/or obtains paid employment (Gross et al., 2021). For example, the extent to which parents believe that employment will bring substantive benefits to their daughter or son could influence the time and effort they devote to promoting this aspect of community participation. In other words, expectations can shape outcomes (Carter et al., 2012). Parents whose family members with IDD have experienced integrated employment can speak first-hand about the benefits they have observed. Likewise, parents who have actively pursued employment—with or without success—can speak to their reasons for doing so. Yet prior studies have not explored their views regarding why work matters so much for their family member with IDD. Such data could help bolster the case for why families who express reluctance should consider integrated employment.

It is also important to understand which features of a potential job matter most to individuals with IDD and their families. Jobs vary widely with regard to their pay, benefits, settings, supports, and culture. Some jobs will offer deep satisfaction and reflect a great fit for a particular person; other jobs will bring discontentment and a sense of incongruity. For example, a systematic review by Kocman and Weber (2018) examined 23 studies addressing how adults with IDD viewed their own work. The availability of on-the-job support, the match with one's skills and preferences, formal and informal social opportunities, the provision of pay, opportunities for growth, and other contextual factors (e.g., hours, work environment, safety) were all identified as contributors to job satisfaction by participants. Indeed, many of these same features also contribute to valued employment among individuals without disabilities as well (e.g., Lysova et al., 2019; Rosso et al., 2010).

At the same time, decisions about community jobs are often made jointly in consultation with parents (Carter et al., 2018; Timmons et al., 2011). For example, some individuals with IDD have complex communication needs that make it more difficult to articulate their work preferences. Likewise, for the majority of individuals with IDD living with their parents (Winsor et al., 2021), decisions about when, where, and how they work directly impact family supports and routines. Best practices advocate for involving parents in decisions about community work in ways that supplement, but do not supplant, the views of their family members with IDD (e.g., Griffin et al., 2007; Papay & Bambara, 2014). Moreover, parents may be more likely to support the pursuit of positions that they feel are a strong match for their daughter or son with IDD.

Few studies, however, have examined which features of community employment parents consider most important for their family members with IDD. For example, Gilson et al. (2018) surveyed 673 parents of adults with IDD about the importance of 12 different features of a potential job. The most prioritized features included a job that brought personal satisfaction, opportunities to interact with people, opportunities to develop friendship, access to supports, and a match with their child’s interests. A higher rate of pay and high number of working hours were the least prioritized features. In their qualitative study of 21 parents of young adults with autism, Sosnowy et al. (2018) reported that “having opportunities for social interaction, to harness their child’s strengths and interests, and be involved in the community were sometimes seen as more important than financial independence” (p. 34). Likewise, Kim and Dababhah (2021) found that many of the Korean parents of adults with IDD whom they interviewed emphasized the social aspects of a job over the financial elements. In each of these studies, however, many or most of the daughters and sons of participating parents were unemployed.

The insights of parents in this area could broaden understandings of what constitutes a desirable employment outcome from a family perspective. Unfortunately, the qualitative dimensions of community employment receive less attention within research, policy, and practice. Instead, employment tends to be treated as a quantitative and dichotomous outcome (i.e., a person is either working or not working), with insufficient attention given to the quality of those work experiences. For example, schools track the percentage of young adults with disabilities who are employed one year after graduation (Indicator 14), vocational rehabilitation tracks the number of case closures with successful employment outcomes, and state IDD agencies track the percentage of individuals involved in integrated employment (Prince et al., 2018; Winsor et al., 2021). But these efforts rarely address whether and how the employment position works well or is a good fit for the person (i.e., a match with their preferences, strengths, and/or needs at a particular point in time).

The purpose of this qualitative study was to examine how parents viewed the experience of employment for their family members with IDD. We addressed two primary research questions: Why do parents value work for their family members with IDD? What features of a job are considered most important by parents? This initial study comprised the first phase of a multi-year intervention development project focused on equipping and supporting parents to pursue integrated employment for their family members with IDD. To help inform the design of a new parent mentoring program, we wanted to understand what motivated families to pursue employment and the features of community jobs that were most important to them.

Method

Participants

Fifty-five parents participated in this study. To be included, they had to (a) have been at least 18 years of age, (b) lived in [state masked], and (c) have a working-age family member (age 16-65) with IDD. Participants ages ranged from 38-81 years (M = 56.7 years), with almost half

(49.1%) of participants between 50-59 years old. Most (69.1%) were White, 16.4% were Black, 12.7% were Hispanic/Latino, 1.8% were American Indian/Alaskan, and 1.8% were Asian. Participants highest level of education included: high school or less (9.4%), some college (15.1%), 2-year degree/Associate's degree (15.1%), 4-year degree/Bachelor's degree (30.2%), Master's degree (22.6%), and Doctoral degree (7.5%). Majority (83.6%) of participants reported living in a non-rural community (i.e., suburban or urban).

Most of the participants' family members with IDD (61.8%) were male and 38.2% were female. The ages of family members ranged from 16-60 (*M* = 26.5 years), with over half (54.5%) falling between 20-29 years old. Our overall project—and the national center with which it is affiliated—focused on the employment of adults with intellectual disability and/or autism. Although this reflects of more targeted subset of adults with disabilities (i.e., those with IDD), it is a group still marked by considerable heterogeneity. Thus, we explicitly sought to capture this diversity in our sampling. Participants could select all that apply from among multiple disability labels to describe their family member. These disabilities included: intellectual disability (63.6%), autism (50.9%), speech or language impairment (21.8%), learning disability (12.7%), other health impairment (12.7%), orthopedic impairment (9.1%), emotional disturbance (3.6%), deaf-blindness (1.8%), deafness (1.8%), hearing impairment (1.8%), and traumatic brain injury (1.8%). When asked how they would describe their family member's degree of impairment, 23.6% said mild, 61.8% said moderate, and 14.5% said severe. At the time of interviews, about half (47.2%) of participants reported that their family member was currently employed. However, 80% were employed at some time in the past.

Recruitment

Our original research plan prioritized interviewing participants in person, as we anticipated this could increase rapport and contribute to richer interviews. For practical reasons, this required limiting recruitment to a reasonable distance from our university (e.g., a few hours in any direction) in a single state. Given our central location, however, this parameter still enabled us to involve participants who resided in rural, suburban, and urban communities, which constitutes a factor impacting employment prospects and perspectives (cf., Schutz et al., 2022). It also ensured that all participants were navigating employment within the same state systems.

To recruit participants with diverse backgrounds and experiences throughout [state masked], we partnered with a myriad of state and local disability organizations and programs. These groups included disability advocacy groups, inclusive higher education programs, parent and sibling groups, Arc chapters, faith-based disability ministries, employment service providers, and disability-focused sport/recreation programs. We shared multiple recruitment materials with partners (e.g., print flyers, electronic flyers, email invitations, newsletter announcements, social media posts) in both English and Spanish. We asked them to distribute these materials in ways that would be most likely to reach eligible participants. Recruitment materials described the purpose of the study, the nature of participation (i.e., a one-time individual or focus group interview), and the honorarium (i.e., a $25 gift card). A member of the research team spoke with each interested person to answer any questions and schedule the interview. Recruitment lasted six months and concluded when additional interviews were not generating substantially new insights to our project questions and our sample more closely reflected of state demographics. We followed study procedures approved by our university's Institutional Review Board (IRB).

Procedures

We facilitated both individual interviews (*n* = 29 participants) and six focus groups (*n* = 26 participants) based on the locations and preferences of participants. We began the project with a preference for focus groups, but recognized that some parents might be reluctant to share their experiences and perspectives in a group context. Moreover, we anticipated that we might not organize sufficient numbers of parents to host a focus group within certain rural locales and did not want to omit their voices from the project. When the COVID-19 pandemic restricted in-person interviews midway through the study, we quickly shifted to alternative venues. For individual interviews, we held two in person, eight over the phone, and 19 using the Zoom video conferencing platform. These interviews ranged averaged 54 min in length (range, 19-92 min). For focus groups, we held four in-person at various locations (e.g., disability advocacy organization, community-based day program, university) and held two online using Zoom. Focus group size ranged from 2 to 7 participants (*M* = 5); the smallest group was due to last-minute cancellations. Focus groups averaged 99 min in length (range, 91-108 min). They were organized based on parent interest, availability, and (when help in-person) proximity.

Our overarching, multi-year project focused on developing a new parent-focused intervention approach. To inform this work, our interviews explored the experiences, insights, and recommendations of parents related to the employment of their family members with IDD. We developed a semi-structured interview protocol (available by request) that addressed four primary topics: (a) the importance and conceptualization of employment for their family member with IDD; (b) barriers to integrated employment for their family member; (c) facilitators of integrated employment for their family member, and (d) recommendations for our intervention development. We drew upon related research when crafting questions in each of these areas (e.g., Francis et al., 2014; Gilson et al., 2018; Kramer et al., 2018). The current paper focuses on what parents say makes employment beneficial for their family member with IDD, as well as the job features they considered important. Although insights on these questions were shared throughout the interviews, the most salient interview prompts were: *To what extent do you consider employment to be an important goal for your family member? Why or why not? In your opinion, what would "meaningful" employment look like for him or her? How likely do you think it is for* *this type of employment to happen for him or her?* We used follow-up questions and probes for clarification, elaboration, and to obtain more detail.

Data Analysis

All interviews were transcribed using a professional service, checked by members of the research team, and de-identified. We adopted a team-based approach to coding that incorporated multiple rounds of analysis (Patton, 2015). Our team included two staff members who conducted the interviews, a graduate student studying in the area of special education, and one faculty member with expertise in integrated employment. We all hold the conviction that youth and adults with IDD should have the opportunities and support to join the workforce. Likewise, we recognize the central role parents play in this pursuit and the importance of understanding their perspectives and priorities. At the same time, we recognized that parents may hold views that diverge from what we—or others in the field—think is most salient or pressing. Throughout the coding process, we strived to temper our own views about the benefits of employment and the job features that were most important in order to give prominence to the voices of parents.

We used thematic analysis (Patton, 2015) to address our two research questions. Our practical goal was to compile comprehensive listings of reasons parents work mattered for their family members with IDD and the characteristics of jobs they considered to be most important. Data analysis occurred in multiple stages. First, team members conducted an initial reading of each transcript as they listened to the audio. Each identified relevant segments of the transcripts (e.g., short phrases to multiple sentences) that addressed (a) why parents valued employment and (b) the features of employment they identified as most important. We then developed and applied initial codes that captured the essence of each of these identified quotes. We utilized the constant comparison method, in which each new code was compared against all other previously developed codes. From this, we created an initial coding framework reflecting all codes. Next, two members of the research team each reviewed the first half of the transcripts independently using this coding framework, generating new codes and collapsing codes as needed. We then met as a whole team to discuss the revisions and make additional edits. The same steps were followed for the second half of transcripts. We then finalized the coding framework and reviewed every transcript again to verify that all codes were correctly assigned. When presenting the findings in our figures, we attempted to order codes based on their emphasis within and across interviews. Specifically, we considered both the frequency with which each code was raised, as well as the amount of attention (e.g., short statements versus extended discussion) and weight (e.g., passing mention versus stressed importance) reflected within the quotes. We emphasize that such ordering should be interpreted with caution, as parents were not asked to rank order a full list of benefits and features of work, but instead only highlighted one to a few in response to our questions.

We strived to carry out this study in ways that enhanced the trustworthiness and quality of our findings (Brantlinger et al., 2005). We recruited a large sample of parents, the majority of whose family members had direct experiences related to paid employment in the community. This enabled us to triangulate findings across diverse participants. We adopted a team-based approach to coding as a way of addressing individual biases and checking assumptions. We kept a detailed audit trail of our procedures. Finally, we shared back a summary of key themes with each participant as a form of member checking, asking them to indicate whether key insights were missing or inaccurately conveyed.

Findings

Why Do Parents Value Employment for Their Family Members with IDD?

Participants addressed a wide range of reasons they valued employment for their daughter or son with IDD. We present brief quotes to illustrate each of the 18 areas they indicated work matters (shown in *italics*). Figure 1 arrays each of these reasons based on the emphasis they received among the parents with whom we spoke.

For some parents, work was said to *further independence, instill a sense of responsibility,* and *contribute to financial independence.* Each of these benefits can contribute to greater self-sufficiency and autonomy. One mother of a 28-year-old son with ID explained, “[Work] is and always has been paramount to him—to be at his most independent level possible.” Similarly, another mother illustrated how having a job impacted her 21-year-old daughter with ID: “It’s given her own life, her own freedom.” Another mother explained how such independence promotes responsibility. Her 23-year-old son with ID “has a car, so he has to use [his paycheck] for gas, and food and eventually he wants to have his own apartment and so forth.” Even among individuals who needed support handling their finances, working was seen as advancing independence. “He cannot manage the money. But being able to have that money opens up other doors with housing and just daily living, food,” explained the mother of 28-year-old son with ID, “and so he understands that because he's thinking of moving out on his own, he knows he has to work.” She explained that a paycheck helps him “feel more like he’s on equal foot” with his siblings. The mother emphasized that “just being able to carry a wallet and feel that he’s a 25-year-old” is incredibly valuable for her son with ID and autism.

Other parents emphasized the ways in which work enhanced the self-worth of their family members. Some spoke of how work *instills a sense of pride.* “He gets a lot of self-confidence,” shared the mother of a 19-year-old with ID and autism, “and he just feels really good about himself when he has something to do.” The father of a 25-year-old daughter with ID echoed this point, “Just having a job gave [her] so much self-esteem!” Whereas some family members with IDD sometimes were treated different than their peers, work *makes them feel like anyone else*. One mother described the impact of a job on her 21-year-old son with ID and autism this way: “He himself says it makes him feel like he's like everybody else in the household.” Similarly, another mother shared that finding employment for her 19-year-old son with ID “is of ultimate importance to him and, from a parental perspective, that it is going to be the golden insignia for his achieving adulthood—the final rite of passage.” Employment was also recognized as a shared value within families. The mother of a 19-year-old with ID explained how her son’s employment *upholds family values* saying “our entire family value system revolves around hard work ethic and that’s just what everybody does.”

The ways in which work fostered meaningful relationships also garnered much discussion. For some family members with IDD, parents emphasized that work *creates social connections.* The opportunity to form connections with others and interact socially within the community were identified as powerful benefits. “It’s just that connection with other people,” said the father of a 23-year-old son with autism. “He’s not a great one for reaching out and he waits for people to approach him. Your work people are, for a lot of us, almost like a family.” For others, work went further and *provides a place of belonging*. A mother anticipated the benefits of employment for her 19-year-old son with ID, who was not currently working. She noted that work “will make him feel more of a sense of belonging in the community.” Similarly, the mother of a 26-year-old female with ID described the benefits of work by saying, “It helps her to the extent of feeling like she's a part of this society. She fits in and she's valuable.”

Parents also addressed the ways in which their family members’ job provided them with direction. Some valued employment for their family member because it *instills a sense of purpose*. As the mother of a 25-year-old male with autism shared, “[Employment is] one of the most important goals, because it gives him purpose and meaning.” This sentiment was echoed by the father of a 26-year-old male with ID and autism, who spoke of how work *contributes to a sense of identity*. He reflected on his son’s employment saying, “A lot of the reasons we'd want any family member to have employment, apply to our son: sense of self, sense of identity, sense of accomplishment." Participants also indicated that work *introduces valued roles*. "Their souls and hearts and minds deserve to feel invested in their community life everyone else," shared a mother of 19-year-old son with ID. A father described the impact of work experience for his 26-year-old son with ID and autism: "He feels like he is making a difference. You feel like that if he didn't show up, they would miss him. So that he is, he is part of something bigger, bigger than his family, bigger than himself."

A small number of parents highlighted the importance of increasing engagement outside of their family. Work was sometimes framed as a way of *promoting community involvement*. For example, one mother explained what was important to her 22-year-old son with autism who was currently seeking work: "His ability to be in the community and be involved and be employed is high on his list." Another mother whose 21-year-old daughter with autism was working agreed: "It's really about feeling purposeful and having that involvement in the community." Two parents bluntly added that working in the community was a way of *getting them out of the house.* For example, one mother of a 25-year-old male with ID and autism emphasized, "He needs to have a purpose *and* he also needs to be out of the house!"

The ways in which work promoted personal growth was also discussed by parents. Some shared how integrated employment *provided learning opportunities*. The father of a 26-year-old male with autism explained, "Meaningful [work], I think, is being able to be successful and learn new things that could eventually lead to others." Likewise, the mother of a 21-year-old son with autism described the deleterious impact of no longer working: "Since he lost the job, he's definitely struggled with his depression. His life skills have gone down. His confidence has gone down. So employment for him is extremely important for him long term." Others spoke of the value of their family member holding a job that *engages and challenges them.* However, not every participant felt their family member had yet found the right fit. For example, one mother described her own aspirations for her 16-year-old daughter with autism, "[A job] that pushes her to be the best she can be. One that makes her happy, that she enjoys. One where she learns and that helps her to grow as a human being."

Finally, parents also named a variety of ways in which working contributed to the overall flourishing of their family member. Some spoke of how work *sparked joy*. For example, one mother said her 20-year-old son with ID feels "very proud of having a job. There's a sense of feeling good about himself. He comes home happy from work." Another mother defined a good job simply as: "Something that will make her happy." Finding a job that *reflects something they love to* do was also important to parents. One mother—whose 21-year-old daughter with ID was working at a café—explained, "She loves [her job] because her goal is that she wants to own her own bakery." Parents shared many examples of jobs that fit their family member's interests, such as working with people, books, clothes, and within the food industry. Other parents spoke more holistically about how work *improves overall well-being*. For example, the mother of a 40-year-old with autism described why she hoped her daughter would find work, "You get a lot of satisfaction in your job. Not just the money, but it helps you improve mentally, emotionally, educationally."

What Features of a Job Are Considered Most Important by Parents?

Parents also described features of a job that they considered to be important for their daughter or son with IDD. These 15 characteristics of the job are arrayed in Figure 2 and ordered from most to least common. In the following section, we incorporate brief quotes as a way of illustrating some of these important features (shown in *italics*).

Five features related to general job characteristics. Parents identified *paid employment* and the *provision of a living wage* as important. Some parents felt part-time employment would be a good fit, while others desired full-time employment for their daughter or son. In both cases, a position that offered *sufficient number of hours* was preferred. Parents also pointed to positions that were *accessible transportation-wise* and provided *adequate supports.* The mother of a 22-year-old with autism described the individualized supports her son received at work, “He would also have various supports that would be paired alongside him, so that he could navigate some of the weaknesses that he has, but that it would allow him to flourish in his talents.” A father also envisioned supported employment for his 22-year-old-son with autism, “His work would look like a regular career for anybody else, except he needs the support of job coaches, and people around him to make each day work well.”

Other features identified by parents related to the fit between the person and the position. These included having *responsibilities aligned to their abilities*, a job that was *a match with their interests,* and a job that offered *predictability of tasks*. For example, one mother described her vision for her 22-year-old son with autism as a job where he is “actually using his gifts, his talents, his expertise” and “a job that is meeting his skill set.”

Other job features related to the work environment. Parents described an environment that is *safe* and *structured*. “For [my daughter] and us, safety is first,” explained the father of a 25-year-old with ID. Others identified the important of a *sense of community* and *inclusivity of the workplace*. The mother of a 24-year-old with ID described the ideal work environment as one where “they feel like they’re part of the industry and that they’re not just a child with a disability. So, when they’re at work, they feel included.” Similarly, parents desired environments that are *supportive* and foster *a sense of community* as important for their family members. “It would be very important that he would feel that he was part of the team” said a mother with a 22-year-old son with autism who was currently seeking employment. The mother of a 27-year-old son with autism said that a supportive environment meant “working with people that understand him, and instead of criticizing him will correct and guide and direct him and have a positive approach to training him.” *Kind co-workers* were also essential to several participants. They described ideal coworkers as accommodating, patient, and understanding. Other environmental features included having *opportunities for social relationships.*

Discussion

Most parents want their family members with IDD to obtain meaningful work in their community (Gilson et al., 2018; Migliore et al., 2007). However, the reasons for this preference and the types of jobs that might align best to this goal have received limited attention in the literature. We interviewed 55 parents about the reasons they valued integrated employment for their family members and the job features they considered important. Our findings extend the literature on promoting integrated employment in several ways.

First, parents addressed a wide array of reasons they considered work to be important for their family members with IDD. Collectively, they emphasized the ways in which working promoted greater self-sufficiency (e.g., independence, responsibility), fostered relationships (e.g., social connections, belonging), enhanced self-worth (e.g., pride, feeling like anyone else), provided direction (e.g., purpose, valued roles), increased engagement (e.g., community involvement), promoted growth (e.g., challenge, learning opportunities), and contributed to flourishing (e.g., happiness, overall well-being). Many of these points are consistent with the broader literature on the value of employment for anyone, regardless of disability status (e.g., Lysova et al., 2019; Yeoman et al., 2019). In other words, a good job produces much more than a paycheck; it introduces a host of other valued benefits. Likewise, they align with findings of several qualitative studies addressing the importance of work from the vantage point of adults with disabilities. For example, participants in a study Lysagh et al. (2009) addressed the sense of pride, satisfaction, and skill growth that came from their work, Likewise, adults with IDD interviewed by Gilson et al. (2022) spoke about the social connections, sense of purpose, and growing independence that work introduced. The multiple benefits of working identified in the current study may be persuasive for parents who are reluctant to support their family member in pursuing employment because the additional income is not considered important, needed, or worth the effort.

Second, parents described multiple features of a job that they felt were important for their family member. Some of these markers mirrored job characteristics commonly captured within the research literature: sufficient hours, adequate pay, and opportunities for advancement (Schutz & Carter, in press). But these core features were not all that mattered. Parents also emphasized other markers of meaningful work. For example, they desired jobs that provided individualized supports, aligned with their family members' interests, abounded in social opportunities, were inclusive, and/or involved working alongside caring coworkers. In other words, both the objective and subjective dimensions of work received considerable attention throughout our interviews. However, the accent was on the latter. Many of these same points have been raised in qualitative studies addressing important aspects of work from the vantage point of adults with disabilities (e.g., Meltzer et al., 2016; Pereira-Silva et al., 2018; Timmons et al., 2011; see review by Kocman & Weber, 2018). For example, Akkerman et al. (2014) found that adults with IDD also addressed the salience of social relations, working conditions, and received support in relation to their job satisfaction. Similarly, other studies have highlighted the importance of co-worker attitudes (Li, 2004), transportation (Lysaught et al., 2009), and a match with personal interests (Hall et al., 2014).

Third, the views of parents in this project varied widely with regard to each of the questions we posed in our interviews. Although common themes certainly emerged and some areas received more emphasis, there was no single perspective regarding why work matters or what might make a particular job meaningful. We did not notice any obvious patterns based on the demographic variables available to us. Instead, views regarding benefits and important job features seemed to be more closely anchored to qualities and experiences specific to their family members with IDD. As in other areas (e.g., education, independent living), parents of individuals with IDD hold a constellation of diverse priorities and perspectives related to employment (e.g., Gilson et al., 2018; Migliore et al., 2007). This recurring finding punctuates the importance of asking good questions and avoiding assumptions. Employment practices that are person-centered must involve soliciting the values and preferences of individuals and their families when determining which experiences and outcomes to pursue (Parent-Johnson et al., 2020). Although we affirm that the voices of those with IDD on these issues should be most prominent, the perspectives of their parents also warrant careful consideration.

Limitations and Future Research

Several limitations to this study suggest areas for future research. First, although our sample is quite large for a qualitative study, the perspectives of 55 participants from a single state cannot fully represent the views of hundreds of thousands of parents across the United States whose daughters and sons with IDD are working age. Parents whose backgrounds (e.g., race/ethnicity, language, culture, socioeconomic status), experiences (e.g., family configurations, employment history), and locales (e.g., urbanicity, regions, countries) differ from our sample may articulate their views and preferences regarding employment in different ways. We encourage other researchers to pose similar questions to a broader spectrum of families. Likewise, we encourage future studies to explore whether the views of parents vary based on the characteristics of their family members with IDD, including disability-related factors.

Second, our study focused on the views of parents. This decision was driven by our overarching project’s charge of developing a parent-focused employment intervention. Although each brings essential insights to the topic of employment, the voices of individuals with IDD remain the most important to hear (cf., Gilson et al., 2022). Family voices can augment, but should never supersede, those of adults with IDD. Future studies should examine how the views and preferences of individuals with IDD converge or diverge from those of their family members. Involving individuals with IDD in this research will require adopting creative ways of inviting the perspectives of individuals with complex communication challenges or who experience significant cognitive impairments (Beail & Williams, 2014; Hollomotz, 2018).

Third, we did not gather detailed information from parents about the characteristics of their family member's jobs. The types of benefits that employees accrue are certainly influenced by the nature of their work, the duration of employment, and other contextual factors. Future studies should examine whether and how different jobs impact the stories individuals with disabilities and parents share about the reasons they prioritize employment over other options.

Implications for Practice

Findings from this study have several implications for practice. First, we found that work matters to families for a myriad of reasons. Although income and independence often receive emphasis when advocating for employment, other benefits may resonate as much or more with parents. Among parents who are reluctant to pursue integrated employment with their family members with IDD (see Carter et al., 2018), it may help to also emphasize the additional ways work can impact their child by promoting self-sufficiency, relationships, self-worth, purpose, community engagement, growth, and joy. In other words, broadening the case for the value of work might serve to bring more parents into this pursuit.

Second, our findings—combined with other studies addressing the perspectives of individuals with IDD—suggest that agencies, providers, schools, and researchers should strive to capture more than employment rates (i.e., the percentage of individuals who are employed) or basic job features (e.g., pay, hours, benefits). The attainment of meaningful work (cf., Lysova et al., 2019) must also be characterized by the qualitative features of a job that matter most to individuals with IDD and their families. This study highlights some of those possible features. We encourage greater reflection on both the objective and subjective features of community employment within both research and practice.

Third, this study provided insights into what parents considered to be “meaningful work” for their family members with IDD. However, the question of what constitutes a good job for a particular person must always be answered individually—one person at a time. We encourage practitioners to listen carefully to the answers that individuals with disabilities and their parents give when asked about why work matters and the types of jobs that would work best for them. Such listening should be followed close behind by active efforts to arrange the opportunities, instruction, and supports that lead in the direction of their responses.

Summary

Promoting integrated employment for individuals with IDD has been an enduring, yet still elusive, outcome of policy and practice for more than 50 years (Wehman et al., 2018). Parents remain critical champions and collaborators in this longstanding pursuit of meaningful work. We identified a range of reasons they valued employment for their family members with IDD, including self-sufficiency, relationships, self-worth, purpose, engagement, growth, and well-being. Likewise, parents detailed a number of key job features that they considered to be important to their family member’s satisfaction in the workplace. Such findings emphasize the importance of asking families for their perspectives and preferences in this area. Moreover, they should encourage agency leaders and researchers to consider how they capture the objective and subjective dimensions of employment for individuals with IDD.

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Figure 1. *Parent views on why they value employment for their family member with IDD, ordered from most (top) to least (bottom) emphasized.*

Figure 2. *Parent views regarding important features of work for their family member with IDD, ordered from most (top) to least (bottom) emphasized.*