

Intellectual and Developmental Disabilities

Factors Influencing Parents' Decisions to Create a Business for Their Adult Child with Intellectual Disability

--Manuscript Draft--

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Abstract:	Obtaining and maintaining work can be a challenge for many individuals with intellectual disability (ID) and parents can play an integral role in supporting their child to secure employment. The purpose of this qualitative research study was to understand factors that influence parents' decisions to create a business for their adult child with ID. Nine parents were identified through purposeful and snowball sampling. Parents participated in individual interviews and data were analyzed using thematic analysis. Our findings suggest that school experiences, expectations for work, presence of specialized support, and encouragement and suggestions from others influenced parents' decisions to create a business. In light of the findings, we discuss how parents' previous experiences and responsiveness influenced the creation of the business.

November 18, 2022

Editors, *Intellectual and Developmental Disabilities*

Dear Dr. Shalock,

Thank you for the opportunity to submit a revised draft of the manuscript “Factors Influencing Parents’ Decisions to Create a Business for Their Adult Child with Intellectual Disability” for publication in *Intellectual and Developmental Disabilities*. We appreciate the comments from reviewers and their dedication to helping us make the manuscript stronger. We have incorporated almost all the suggestions made by reviewers. Changes to the manuscript are made in track changes. Please see the table below for a point-by-point response to each reviewers’ comments and concerns.

Feedback	Authors’ Response
<p>Reviewer 1: While the study was clear that it specifically addressed factors that influenced parents' decisions to create a business, a little more context about the nature of the business, the impact of that decision on families, and perspectives on individual outcomes would strengthen the story. For example, more detail about the businesses including locations (e.g. home-based, studio, community business, or other), the economic success of the businesses would be useful.</p>	<p>Appreciate your suggestions with the intention of helping us strengthen the story.</p> <p>We have labored over the decision of how much information to include about each business (e.g., the nature of the business). To protect the anonymity of participants, we could not report the nature of each business as some are so specialized that even providing the nature of the business would have revealed the identity of the parent and individual with ID. General information about the nature of several businesses can be found at the end of p. 6 and the beginning of p. 7.</p> <p>We agree that adding information related to the impact of the decision to pursue small business creation could strengthen the story, however, we feel as though we would need to add a research question to address this suggestion. After careful consideration, we have decided not to make this edit because it does not align with the current research question, and it would significantly add to the length of the paper.</p> <p>We have added information to the last paragraph on p. 6 that provides additional detail about the business locations.</p>
<p>Reviewer 1: From an outcomes perspective, it is clear that individual preference for the tasks</p>	<p>Thank you for your suggestions! Interestingly, no parent discussed regrets</p>

<p>was central to the decision to pursue self-employment, but work brings other personal benefits such as social interaction. Were there any regrets about missed opportunities or goals that were not met if another path had been viable? For example, some self-employment outcomes are home based and offer limited opportunity for community engagement or the development of extended relationships, and it would be useful to know if the outcome was ever perceived as a necessary compromise or if it was uniformly perceived as the best possible outcome.</p>	<p>about their decision to create a business for their child with ID. Several parents felt as though their child experienced <i>more</i> opportunities to engage with their community through the creation of the business. Because the interview questions were heavily focused on the factors that influenced the decision to create the business, we do not have sufficient information to state whether parents had regrets about missed opportunities or goals that were not met if another path had been viable. We have add information to clarify that many parents believed that it was the best possible outcome for their child on p. 22 on lines 3-4.</p>
<p>Reviewer 1: It is striking that a significant factor in parents' decision was systems failures, and these concerns mirror other research on individual and family experiences with the transition process. The author(s) found that "every parent described some type of misalignment between their expectations for their child's engagement in work and the options available post-school." In the discussion more attention to the role of systems failures would be useful. At least some parents described school experiences as valuable and strength-based learning experiences, but the failure of the system to support the transition to long term employment became an overriding catalyst. This raises questions about the design of school and transition services and the capacity of adult systems. To what extent was the parents' decision largely driven by system failures versus a preference for self-employment and the opportunities it provided?</p>	<p>What an important call-out – appreciate the attention to our paper and the suggestion to add this information in the discussion. We have added a paragraph in the discussion section (see pp. 22-23) related to the systemic challenges faced by parents in this study and have connected that information to previous literature.</p> <p>The final question posed in this comment is such an intriguing one! We have added several sentences in the implications for research (see p. 25) to address this topic and provide an additional line of inquiry for readers (and us) to consider!</p>
<p>Reviewer 2: First, it would be helpful to readers if the authors could more fully describe the semi-structured interview approach and the questions developed.</p>	<p>Appreciate the suggestion! Additional information has been added to the section titled Semi-Structured Interview Protocol. Information has been added to clarify why a semi-structured interview approach was selected for this study.</p>

<p>Reviewer 2: Second, some presentation about the nature of the businesses created is needed.</p>	<p>Thank you for the suggestion. We have labored over the decision of how much information to include about each business (e.g., the nature of the business). To protect the anonymity of participants, we could not report the nature of each business as some are so specialized that even providing the nature of the business would have revealed the identity of the parent and individual with ID. General information about the nature of several businesses can be found at the end of p. 6 and the beginning of p. 7.</p>
<p>Reviewer 2: Third, it would be useful to know the roles of the individuals with disabilities in these businesses, as well as the roles of any others working in these endeavors.</p>	<p>Thank you for the suggestion. Reflecting on the study now, we recognize the value of asking a question or two about the role of the individuals with ID in the business. We did not include questions in our demographic questionnaire or interview protocol that specifically pertained to the roles of the individuals with ID for whom the business was created.</p> <p>Information related to the roles of others working in these businesses has been added to pp. 6-7.</p>
<p>Reviewer 2: Fourth, some information about outcomes is needed, in terms of hours worked in these businesses and the earnings of the individuals with disabilities.</p>	<p>We appreciate the suggestions about including information about outcomes. There is information related to the number of hours the parents and individuals with ID worked at the business on p. 6 (lines 6-7 and 17 respectively).</p> <p>After careful consideration, we have decided not to make any edits related to outcome data of the individuals with ID. The questions posed in our demographic questionnaire and interview protocol aligned with the research question that was focused on understanding the factors that influenced parents' decisions to create a business. We did not ask parents to provide specific information related to the earnings of the individuals with ID as we felt it did not contribute information that was pertinent in answering the research question.</p>

FACTORS INFLUENCING BUSINESS CREATION

Factors Influencing Parents' Decisions to Create a Business for Their Adult Child with Intellectual Disability

FACTORS INFLUENCING BUSINESS CREATION

1

Abstract

Obtaining and maintaining work can be a challenge for many individuals with intellectual disability (ID) and parents can play an integral role in supporting their child to secure employment. The purpose of this qualitative research study was to understand factors that influence parents' decisions to create a business for their adult child with ID. Nine parents were identified through purposeful and snowball sampling. Parents participated in individual interviews and data were analyzed using thematic analysis. Our findings suggest that school experiences, expectations for work, presence of specialized support, and encouragement and suggestions from others influenced parents' decisions to create a business. In light of the findings, we discuss how parents' previous experiences and responsiveness influenced the creation of the business.

Keywords: self-employment, small business creation, intellectual disability, parents

Work is an integral component of adult life in the United States (U.S.). Unfortunately, not all individuals are equally successful at obtaining work. According to the U.S. Bureau of Labor Statistics (2021), only 19.1% of individuals with disabilities are employed compared to 63.7% of individuals without disabilities. Furthermore, adults with intellectual disability (ID) face lower employment rates than individuals with less significant disabilities (Hiersteiner & Butterworth, 2018). Though a variety of work options exist for individuals with ID, one option that is relatively under-explored is self-employment (i.e., working for oneself). Self-employment may be an advantageous work option for individuals who are not easily matched with other types of employment (Ouimette & Rammler, 2017; Wehman, 1999).

One way to achieve self-employment is through the creation of a small business (Ouimette & Rammler, 2017). Though the definition of a small business varies by industry, generally, a small business is a privately owned, independent company that employs a relatively small number of people, if it employs others at all (United States Census Bureau, 2021; United States Small Business Administration [U.S. SBA], 2016). In 2021, the U.S. SBA of Advocacy estimated that there were 32.5 million small businesses in the U.S.. Interestingly, individuals with disabilities are about twice as likely to start a small business as individuals without disabilities (U.S. Bureau of Labor Statistics, 2021).

Many small businesses are created with the help and support of other people such as family and friends (Caldwell et al., 2020+9; U.S. SBA, 2021). For individuals with ID, family members may play an especially important role in assisting individuals with ID to obtain and maintain employment (Blustein et al., 2016; Henninger & Lounds Taylor, 2014). In fact, a large body of research suggests parents and family members may influence the type of work their family member with ID pursues and the location of that work (e.g., integrated community

setting, sheltered workshop; see Blustein et al., 2016; Carter et al., 2018; Dague, 2012; Francis et al., 2014; Gilson et al., 2018; Migliore et al., 2008; Timmons et al., 2011).

Despite evidence suggesting the strong influence families can have on employment decisions for individuals with ID, we were unable to find prior research that investigated parent and family involvement in decisions surrounding business creation. Two qualitative research studies, however, have explored self-employment from the perspective of the business owner with ID. Hagner and Davis (2002) sought to broadly describe the employment experiences of individuals with ID who are self-employed while Caldwell et al. (2020) examined what motivated individuals with ID to become an entrepreneur. Although these studies did not specifically investigate family involvement in decisions about starting a small business, they provide insights into potential factors that led to the creation of a business for the individuals with ID.

Findings from Caldwell et al. (2020) and Hagner and Davis (2002) suggest four factors contributed to the creation of a small business. One factor was dissatisfaction with prior or existing employment options (Caldwell et al., 2020; Hagner & Davies, 2002). Though several business owners with ID were able to obtain employment prior to the creation of their business, they expressed a lack of alignment between their personal values, areas of interest, and the jobs that were available to them. Additionally, individuals with ID did not feel that their previous jobs were aligned with their existing skills and strengths. A second factor was that business owners with ID saw business creation as an opportunity to highlight their skills, interests, and strengths (Caldwell et al., 2020; Hagner & Davies, 2002). Being motivated to start a business or having a passion for a specific social mission further influenced business owners with ID to create their own small business. A third factor was the absence of employment options (Caldwell et al.,

2020; Hagner & Davies, 2002). Business owners with ID spoke about difficulty finding flexible work settings that would allow them to work at their own pace (Caldwell et al., 2020). The fourth factor related to the inaccessibility of vocational rehabilitation services. Challenges obtaining and maintaining partnerships with vocational rehabilitation providers discouraged business owners with ID from seeking vocational rehabilitation services (Hagner & Davies, 2002).

Although individuals with ID have identified several factors that contributed to their decision to create a business (Caldwell et al., 2020; Hagner & Davies, 2002), research has yet to focus on the factors parents consider when deciding whether to create a business for their adult child with ID. It is important to understand these factors because parent expectations are a strong predictor of employment and parents can play a pivotal role in supporting their child with ID to reach their employment goals (e.g., Doren et al., 2012; Henninger & Lounds Taylor, 2014, Rowe et al., 2015; Mazzotti et al., 2021). Moreover, the creation of a small business is one of many pathways to work for adults with ID, but the area of small business creation for this population is relatively unexplored. Additional research is needed to understand the factors that cause parents to forgo other types of employment and instead create a business for their child. The purpose of this study therefore was to investigate the following question: what factors influence parents' decisions to create a business for their adult child with ID?

Method

Participants

The participants were parents of children with disabilities. Criteria for selection in the study included having (a) a child aged 18 or older with ID, (b) experience creating a business for the child, and (c) extensive knowledge of the child's previous and current employment. For

purposes of this study, a business was defined as an establishment that produced a product or service that was sold to others.

Several methods were used to identify information rich cases. These included recruitment of a parent known by the researchers to have developed a business for her child (i.e., a key informant), using business cards collected at a conference from business owners with ID, and searching the Internet. These methods resulted in five participants (i.e., the key informant, one individual from a business card, and three individuals from the Internet). Participants were encouraged to forward information about the study to others. One participant forwarded the flyer to a national organization focused on employment for adults with ID. A second participant posted the flyer to a Facebook group for business owners with ID. These methods yielded four additional participants, resulting in a total sample size of nine parents.

For purposes of maintaining the anonymity of each participant, their child with ID, and the business, participant data are presented as group data. Participants included seven mothers and two fathers who were an average of 62.2 yrs old (range: 49 - 73 yrs). All parents in this study identified as White, and most participants ($n = 8$) were married. Six parents held a master's degree and the remaining parents held either a doctoral degree ($n = 1$), bachelor's degree ($n = 1$), or associate degree ($n = 1$). All parents reported that they were actively involved in their local community in some capacity (e.g., creating sports teams for their child with ID, organizing political fundraisers, advocating for their child within the school and adult services system).

All parents interviewed were involved in their adult child's business in some capacity. Four parents were employed by the business either part-time ($n = 2$) or full-time ($n = 2$), four parents were retired and not employed by the business, and one parent worked full-time outside of the business. Prior to the creation of the business, parents indicated they were

employed as a teacher ($n = 4$) or direct service provider ($n = 2$), were self-employed ($n = 2$), or worked for a disability agency in their state ($n = 1$). Regardless of prior employment, every parent helped their child manage the financial aspects of the business, order supplies, and advertise and promote the business. Many parents ($n = 8$) interfaced with customers and several parents ($n = 7$) also supervised the work of individuals involved in the business, including their child or other employees with and without disabilities. Parents spent an average of between 23.8 and 31.7 hrs per week (range: 3 - 60 hrs/week) assisting with different business activities and indicated that weekly hours were dependent on whether they were attending an event outside of business hours (e.g., sale, craft fair, art exhibition).

Parents also provided descriptive information about their adult child with ID. The adults with ID were an average of 31.4 yrs old (range: 25 - 41 yrs). Five were male and four were female. Most of the adults with ID were White ($n = 8$) and one parent selected “other” regarding her child’s race/ethnicity. Eight of the adults with ID primarily communicated verbally and one individual primarily used gestures. Furthermore, most adults with ID ($n = 7$) needed “moderate supports” to perform daily tasks and activities with the remaining adults needing “extensive supports” ($n = 1$) or “very little support” ($n = 1$). Within the context of the business, adults with ID worked between 15.1 and 24.1 hrs each week (range: 6 - 60 hrs/week). Like parents, weekly hours fluctuated depending on the business activities in which adults with ID were involved.

Parents also provided information about their child’s business. On average, businesses had been operating for 6.17 yrs (range: 2 - 16 yrs) and parents indicated they had been involved in the business since its inception. Businesses were located in nine different states across the U.S. and most ($n = 6$) were in suburban areas. The remainder were in urban ($n = 2$) or rural ($n = 1$) communities. Five businesses were home-based, operating out of the home that the parent and

individual with ID shared. The remaining businesses either operated out of a store front (n = 2) or operated at a location separate from their home but did not sell products directly to the public from this location (n = 2). Many of the businesses (n = 8) created a product that was sold to others (e.g., original artwork, crafts, candles, clothing). Only one business provided a service to its customers (i.e., cleaning).

Semi-Structured Interview Protocol

A semi-structured interview protocol was developed based upon existing literature about factors influencing parents' decisions when selecting employment for their child with ID (e.g., Carter et al., 2018; Francis et al., 2014). A semi-structured approach was selected to ensure that each participant was presented with the same questions while allowing the researcher the flexibility to ask follow-up questions and probes when needed. During the development of the protocol, the authors met frequently to r-revising and refining interview questions and to ensure the questions in the protocol answered the research question. Additionally, two experts in the areas of ID, families, and employment reviewed the protocol and offered additional suggestions to enhance the content. The updated protocol was piloted with a parent of a child with ID who did not qualify for the study and then further refined. The final protocol consisted of 8 interview questions that addressed factors influencing parents' decisions to create a business for their child with ID.

Data Collection

The first author collected data in the Spring of 2021. Following receipt of Institutional Review Board (IRB) approval and informed consent from all participants, parents completed an online questionnaire. The purpose of the questionnaire was to gather demographic information, identify potential interview dates, and determine the preferred method of interview (i.e., Zoom or

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telephone). Interviews were audio recorded and ranged in length from 65 to 102 min ($M = 81$ min). The first author took handwritten structured notes during interviews to record time stamps of particularly intriguing information and to generate additional probes, as needed. Immediately following each interview, the first author listened to the recording to verify the completeness and audio quality. Structured notes were de-identified and typed into a Word document. All interview data, including audio files and interview notes, were uploaded to a password protected, secure website. After ensuring successful upload of the files, local recordings were deleted, and any handwritten notes were destroyed.

Data Analysis

The first author transcribed the interviews verbatim and created a summary of each participant's interview based on several readings of the transcript. Each summary provided a two to four-page synopsis of the information discussed during the interview. Participants received a copy of their interview summary via email for member checking. During member checks, participants were asked to review the interview summary for accuracy and confirm, revise, or remove information as appropriate. All nine participants confirmed the accuracy of the summary without need for revision.

Once member checks were completed, the research team used thematic analysis to inductively develop codes, categories, and themes across the dataset (Maxwell, 2013). The first author and two research assistants (RAs) began by openly assigning codes to phrases and short sections of each transcript. After independently coding one transcript, they met to discuss the codes and refine code descriptions. The first author developed an initial codebook based on the codes discussed and sent the codebook to the RAs to use to code the next transcript. This process (i.e., independent coding, collaboratively discussing and refining codes, and updating and

disseminating the codebook) was repeated as each interview transcript was coded. A preliminary codebook was established after all transcripts were coded once. The codebook was shared with the second author who challenged the clarity of the codes, potential biases, and perceptions of emerging categories (Brantlinger et al., 2005).

After clarifying several codes, the first author and RAs engaged in a second round of coding to test the preliminary codebook. The first author and RAs used the same process (i.e., independent coding, collaboratively discussing and refining codes, and updating and disseminating the codebook) to recode all nine interviews. The first author and RAs then examined each unit of data associated with each code to verify that it aligned with the code's description. After verifying alignment of the data within each code, the first author and RAs collapsed, group, and nested sets of codes into larger categories. The first author and RAs collaboratively identified relationships and patterns amongst the data to develop the larger categories. After several meetings, the first author, RAs, and second author reached consensus about categories. The first and second authors then began to develop themes in a similar fashion. The first author collapsed, grouped, and nested various categories to identify emergent themes that cut across categories. After several iterative discussions about themes specific to the research question, the first and second authors reached consensus on themes and theme descriptions. Once consensus was reached, the first author updated the codebook to reflect the final themes.

Trustworthiness and Credibility

The authors used multiple methods to ensure trustworthiness and credibility during the development and implementation of this study (Brantlinger et al., 2005; Maxwell, 2013). First, participants were screened and selected based on specific criteria. These criteria were developed

in an effort to include participants who would provide the greatest insights about the proposed research question. Additionally, participants were asked to complete member checks to verify the accuracy of the researcher's interpretations and clarify misinterpretations. Furthermore, the first author met regularly with the RAs and second author to engage in discussions about the data. These discussions contributed to the development of rich descriptions that may facilitate particularizability for readers (Brantlinger et al., 2005).

Positionality

Both authors are White, female, and currently affiliated with a university department of special education. Each author has direct experience preparing students with significant disabilities to transition from school to work. It is their belief that work is an important part of adult life and that all people can work if given the right supports. They have particular interest in understanding and improving post-school work outcomes for individuals with significant disabilities.

Findings

The findings from this study suggest several factors influence parents' decisions to create a business for their son or daughter with ID. Four themes emerged, including school experiences, expectations for work, presence of specialized support needs, and suggestions and encouragement from others. All names used in this section are pseudonyms for the parent participants and their adult child with ID.

School Experiences

Several parents in this study expressed that their child's school experiences had a profound impact on their decision to create the business. These school experiences, both negative and positive, seemed to help parents develop a more refined idea about work for their child. One

area of dissatisfaction stemmed from the type of work experiences the school provided. Though parents acknowledged that their child benefitted from work experiences (e.g., learning new skills, sampling a variety of jobs, identifying interests), they expressed concern that these experiences did not lead to long-term employment. The work experiences offered through the school were part of the school's program and used solely as an opportunity for students to gain skills. As Olivia stated: "You could have [a job] for ... the semester or even a year, but once you left school ... the job wasn't yours, the job belonged to the school." Linda spoke about her daughter's experience stating, "the idea is not that you learn a job and then you get a job [at that location after high school]. ... Ever." Despite receiving training, support, and becoming fluent in several jobs that they enjoyed, Olivia's and Linda's daughters never had the opportunity to continue to work in those jobs upon graduation.

In addition to parents' frustration that work experiences did not lead to long-term employment, parents felt as though their child's work preparation activities were ineffective at preparing their child for work after high school. Parents indicated that their child's work experiences provided broad, generalizable skill instruction (e.g., how to wipe a table, empty the garbage, or sweep a floor) rather than individualized activities to support the attainment of a job. Erin stated that her son's transition program focused on "independent [living] skills. ... Not employment skills, independent [living] skills." Erin's son, Jack, was taught how to ride the bus, shop and cook, as well as clean during his transition program. While Erin acknowledged that these skills were important and meaningful, she felt that Jack's experiences did not actually prepare him for work. Similarly, Tamara, spoke extensively about how her son's IEP team had "no plan" for providing work experiences once he reached age 16. Tamara went on to say: "What was he going to do? And no one [on the team] had any ideas. ... What were they going to

do for job readiness skills? I couldn't take it." Tamara felt that school staff should have been capable of developing a comprehensive transition plan that prepared her son, Justin, for work after high school.

Moreover, parents reported feeling like they were left with very little guidance from the schools about how to navigate the adult service system when their child transitioned from high school. Despite having positive experiences with their child's educational team throughout high school, Chris and Jim both expressed that their sons experienced the "21-year-old cliff" when they graduated. Chris spoke about how "the school district kinda washes their hands [of you and] says, 'Okay, you're done'" when your child ages out of high school. From Chris' experience, the district did not seem to have much knowledge of the adult service agencies in his state, nor did district professionals understand how to navigate the adult service system. Similarly, Jim described the difference between his perception of school and post-school by noting that "When you're in school, everything is right in front of you. Once you're done, boy ... it's the wild, wild west."

Frustration with work experiences and activities as well as dissatisfaction with assistance navigating adult service systems seemed to prompt parents to start thinking and planning differently for their child's transition from school. For Linda and Olivia, this meant cultivating and nurturing pre-existing hobbies to prepare their child for work. Both Linda and Olivia decided to formalize activities related to their daughters' hobby (e.g., create a set schedule, start taking and fulfilling orders, seek out job coach supports). In providing additional structure and formality, both parents realized that they could create a business with very little additional effort. Erin and Tamara's negative school experiences served as a catalyst to develop additional programming to support their child's acquisition of work skills. Erin decided to transition her

child early from high school and Tamara supplied her son's educational team with supplemental work activities. Through these additional activities, Erin and Tamara found their child enjoyed a particular type of work and required a very specific work environment, leading to the decision to create the business. Finally, Jim and Chris, former entrepreneurs themselves, started to think creatively about how they could help their sons achieve work after experiencing so many obstacles accessing adult services. Both fathers acknowledged that they may not have created a business for their son if school personnel had helped them navigate the world of adult services.

While many parents spoke about dissatisfaction with their child's school experiences, several also spoke about positive school experiences that influenced their decision to create a business. For Beth and Tamara, seeing their child successfully participate in functional, meaningful, and individualized curriculum had a profound impact. It shifted their perspective about what work could look like for their child. For example, Beth's daughter, Anna, formed a particular affinity for fiber work while participating in a weaving class during her transition program. Observing this interest, Beth knew weaving and fiber work "was something that excited [Anna] and [something] that she enjoyed doing, so that's how ... we really came upon that idea [for the business]." Similarly, Tamara's son, Justin, successfully participated in a school-based enterprise during middle school. His participation was the first time Tamara saw her son complete meaningful work activities in a setting that he enjoyed. According to Tamara, the school-based enterprise "planted the seed" that Justin could meaningfully engage in work through the creation of a business.

Beth and Tamara also spoke about how school personnel facilitated these positive school experiences that influenced the decision to create the business. Beth stated that the educational team was deeply focused on identifying and nurturing her daughter's strengths and gifts. She

went on to say that had the educational team not taken a strengths-based approach, they would not have found Anna's interest in fiber work or created the business. Beth stated, "This was really a pivotal experience for her and us...and you know, I think she might have wound up in an institution, honestly ... if we didn't have this experience of success with her." After Tamara provided several structured task boxes to her son's educational team, the team's staff members helped her son, Justin, complete the work activities in each task box, identified an activity he preferred, and taught him how to complete that activity with increasing independence. Subsequently, school staff helped Justin develop his business, think of the business' name, create the logo, and begin marketing and selling his products.

Expectations for Work

Every parent in this study described some type of misalignment between their expectations for their child's engagement in work and the options available post-school. Several parents spoke about how the options offered were rooted in low expectations and did not reflect their child's potential. Overwhelmingly, parents in this study expressed that they wanted their child to be happy and feel fulfilled. In order for their son or daughter to be happy, work needed to be more than just a job – parents wanted their child to have an interest in their work, feel a sense of purpose and pride, and have ongoing opportunities to learn and grow.

Parents assessed a variety of post-school programs and work options with their child; however, none found a match between what was available and what their child wanted to do. Three parents (Linda, Jim, and Heather) were told that their child would have the most success in a sheltered work setting or day program. Parents stated these options were "of no interest" to their child and subsequently ~~they~~ were not considered a viable post-school work option. Linda went on to explain that even if her daughter, Ashley, was able to find supported employment, she

“didn’t want to do...what a lot of people with disabilities do—wipe tables ... she wouldn’t be a greeter...[Ashley’s] dreams were definitely cooking, cooking, cooking. ... And that, that’s really what led us down this path [to create a business].” Rather than continually sacrificing their child’s interests and fitting a “square peg [into a] round hole,” parents decided to create a business that enabled their child to engage in preferred activities, not otherwise available through post-school work and non-work options. Heather talked about this process: “So it’s like, where does your child lead you? The programs we looked at, you know ~~... [were not]~~ [my daughter, Hope,] would’ve been miserable. ... We were just kind of following her lead.”

In addition to wanting work that aligned with their child’s interests, parents also expressed the desire for work to foster a sense of purpose and pride for their child. For many parents, the available work options did not meet these expectations. For instance, Beth stated that her daughter, Anna, was unable to find jobs that “fed her soul.” Though Anna had jobs prior to the decision to create the business (at a restaurant and retail store), Anna was unable to find a job in the community that married her passions and cultivated a sense of pride. Similarly, Linda’s decision to create a business for her daughter, Ashley, was based on the desire to provide work that would give Ashley “a reason to get out of bed.” Despite enrolling her daughter in a day program several days a week to provide daily structure, Linda stated that “it just wasn’t, um, motivating ... you know, she would go ... and would have some fun, but it wasn’t purposeful.”

Parents also revealed that they wanted their child to have the opportunity to learn and grow through work. Several parents highlighted that they wanted their child to have opportunities to grow socially, expand their repertoire of work skills, and advance within their jobs. Though some parents stated that they simply wanted work to provide their child "something to do," more often, parents highlighted that they wanted their child to have opportunities to

showcase their talents and improve their work skills. Erin spoke about how her son held several jobs prior to creation of the business, many of which involved discrete and repetitive tasks, like crushing cardboard. Even though Erin expressed that her son, Jack, seemed to enjoy these jobs, she stated, “there’s nothing created from it ... he has so much more, he’s so talented, and I don’t want to waste his talents.” Another parent, Julie, who prioritized experiential learning, saw the creation of a business as a way to expand her son’s work skills. Prior to deciding to create the business, Julie’s son, Sai, worked at a local restaurant. Despite working his way up from busboy to host and having a customized serving job, a series of new managers relegated Sai’s work responsibilities to wrapping silverware in napkins in the back of the restaurant. Julie created the business, in part, so that Sai could continue to learn and grow through the process of starting a business. Julie wanted Sai to “see what was involved as far as ordering, making the product, doing the listings ... on social media, you know, all that stuff that’s involved.”

Parents’ decisions to create their child’s business were directly influenced by the misalignment between the available work options and their expectations of work for their child. Though most parents sought out work opportunities for their child prior to deciding to create a business, they were unable to find work options that matched their child’s interests. Many parents also explained their child had a pre-existing idea or vision about what they wanted to do for work. When parents were unable to find a work option that aligned with their child’s vision, they decided to build that option by creating a business. Similarly, parents’ decisions to create a business were influenced by challenges finding work that met their expectations and perceptions of what their child’s work would involve. Parents spoke about how their child had opportunities to participate in activities that filled their day, but many parents were seeking more than just a time-filler. Parents wanted their child to feel a sense of pride and accomplishment through their

work and have continued opportunities to learn and grow. While some parents indicated that their child was able to attend a day program or had a job prior to their decision to create the business, none of these options met parents' expectations for work quite like creating a business.

Presence of Specialized Support Needs

Several parents identified that their child's specialized support needs influenced their decision to create the business. These parents expressed their child's support needs significantly limited the number and type of post-school options available to their child. Some parents were deterred from pursuing supported employment, and others struggled to find sheltered workshop or day programs that would serve their child. Parents identified two distinct categories of specialized support needs, including behavioral support needs and medical support needs.

Parents indicated that their child's behavioral support needs impeded their child's ability to maintain long-term employment or significantly limited work options available to their child. Some parents expressed that their child was able to participate in supported employment for brief periods of time but struggled to stay employed. Parents shared that their child had difficulty following directions, had challenges completing work tasks with appropriate quality, and struggled to display appropriate social skills (e.g., talking too much, distracting coworkers) even when on-the-job supports were present. Because of the incongruence between behavior and work environment, the child was either fired from their position or placed in a different work setting. Rather than hoping their child would find the right work environment, parents decided to construct that environment through the creation of a business. In doing so, parents could meet their child's behavioral support needs and provide a long-term work option for their child.

One parent specifically expressed that her child's challenging behavior made it difficult for her child to find work. Tamara stated that while "some people have, uh, hung up clothes at a

clothing store, [my son, Justin] doesn't like tags. He would take off the tags, and then if [his behavior was interrupted], he got frustrated [and] he would get physical." Justin would also remove the labels from cans and unplug cords from computers and walls, which eliminated job opportunities in grocery stores and office buildings. Because of his behavioral support needs, Tamara felt that Justin would not be able to find work through supported employment. Determined to ensure that Justin was able to work after he graduated from high school, Tamara continued the activities that his educational team started. In her words, she needed to create and continue the business, or else they "would have still been looking for something" for Justin to do.

In addition to behavioral support needs, parents also spoke about how their child's medical support needs limited post-school work options and influenced the decision to create a business. Generally, parents whose child had medical support needs created a business so that their child could maintain work while also having the flexibility to work unconventional hours or take days off as dictated by their medical conditions. One parent, Erin, recalled that despite her son finding several jobs through supported employment, he was unable to maintain those jobs because he "used to get sick quite often" and needed a great deal of time off. Erin went on to say:

You can't have a job, a traditional job, and [get sick]. ... And then you say, 'Well, I'm better now, can I please have these two hours, well, well, we already gave those two hours away, because, you know, you've been sick'

Heather and Linda also struggled to find post-school work or programs that would accommodate their daughter's medical needs. Each parent sought support from their local day program providers with limited success. Heather and a helpful staff member at a day program contacted 12 different post-school programs hoping that one could provide a full-time on-site certified medical technician to administer emergency seizure medication, if needed. Each program

consulted with their lawyers, but no program was able to provide the services that Heather's daughter required. With no other acceptable alternatives, Heather decided to create a business to ensure her daughter, Hope, would have the proper medical care while working out of their home.

Similarly, Linda contacted her local vocational rehabilitation agency to find post-school work for her daughter, Ashley. After conducting a short assessment, the vocational rehabilitation counselor told Linda that Ashley was "unemployable" due to her fluctuating medical needs and suggested that Linda enroll Ashley in a day program. Having no other post-school options at the time, Linda enrolled Ashley in the program but shared that she did not want Ashley to stay at the program just because it was the only option. Linda went on to say, "I think [her dad and I] both had bigger aspirations for her...because we've been pushing her her whole life." As a result, Linda and her husband decided to create a business with a work environment that could accommodate Ashley's medical needs so Ashley could achieve her dream of becoming a chef.

Suggestions and Encouragement from Others

One final finding revealed that suggestions and encouragement from others (i.e., neighbors, family friends, or therapists) illuminated potential business ideas for parents and influenced their decision to create a business. Chris spoke about how his neighbor was aware that he was attempting to find employment for his son and suggested that he look at a cleaning business in a neighboring town. This business had been created to employ individuals with disabilities. Chris paid for the cleaning service and was inspired to create a similar business for his son and his business partner's son. Chris reported that he "told [his business] partner, 'We can do this, you know... it's, it's not brain surgery.'" Additionally, seemingly simple suggestions from trusted individuals gave parents the idea to turn preexisting hobbies into a business. After Erin's son, Jack, experienced a series of traumatic events, Jack seemed to find comfort in

drawing, painting, and playing music. One of her son's behavioral therapists happened to notice Jack's artwork after a therapy session and told Erin that he should sell his artwork. Erin always believed that Jack was a talented artist, but because of the therapist's suggestion, Erin felt that Jack's skills were "known beyond his mother." As a result, she began to think about how she could showcase her son's artistic abilities. In conjunction with Jack requiring a flexible work environment, she decided that starting a business would be the best way to meet Jack's needs.

Parents also identified that support from their local community prompted them to think about how their child's preexisting hobby could become a more formal business opportunity. For example, Olivia recalled the positive support she received from community members and how it facilitated a shift in thinking about her daughter's hobby. At their first sale, Olivia and her daughter, Megan, brought over 200 pieces of product and sold out midway through the sale. Olivia shared the following reflection about this day stating, "It was an eye-opener for me. ... I think that it was a possibility that, that it would become a little vocation for her... I had thought about it as a hobby ... but I hadn't really thought about it as, um, a vocation." Heather had a more nuanced experience with members of her local art community. She spoke about how her daughter's art was selected for art shows through a blind review process and won several awards. Heather shared that her daughter, Hope, "could have been producing things that nobody has any interest in ... She could have been loving what she's doing, and probably we would nurture that ... but would probably not build a business around it." The fact that Hope's art was recognized as quality, could sell, and had commercial interest from important members of the art community gave Heather the confidence to create a business involving Hope's interest and talents in art.

Discussion

The purpose of this study was to understand the factors that influence parents' decisions to create a business for their adult child with ID. The four themes that emerged centered on school experiences, expectations for work, presence of specialized support needs, and suggestions and encouragement from others.

Across these themes, it was evident that parents acted as a conduit for their child's post-school success and that they were reflexive and responsive to their child's work desires. Parents in this study were well-equipped to support their child's post-school work dreams. Well before ideas to create a business occurred, parents had experience creating, developing, and organizing systems to improve their child's lives. For example, when parents believed their child was not receiving a free and appropriate public education, they advocated for change within their child's school programming. One parent even went so far as providing home-school instruction when she felt that the school could not ~~provide~~offer what her child needed. Outside of the school building, parents created and coached disability-focused sports teams and served as disability advocates in their state. Each parent, in essence, ~~served as a conduit for~~helped facilitate their child's success. Given this history, parents were in a unique but not unfamiliar position to continue to create, develop, and improve work outcomes for their child with ID.

In addition to having previous advocacy experiences, all parents in the study had high expectations for their child's work. Consistent with previous research, parent and family expectations are a strong predictor of employment success for individuals with ID (Carter et al., 2012; Doren et al., 2012; Nord et al., 2018). Additionally, parents and family members can serve as strong role models by sharing their values and expectations for work (Timmons et al., 2011). In this study, parents expected that their child was going to work after graduating from high school; however, many of them were not satisfied with the work options provided to their child

with ID. Despite facing systemic challenges to find work that was suitable for their child, parents continued to believe that employment was of value and, as a result, ended up turning to business creation to help their child achieve it.

~~Interestingly, parent dissatisfaction was not derived from a desire for the individual with ID to work in inclusive environments. Parents were dissatisfied with available work and non-work options because they did not align with their child's strengths or interests. It is important to recognize that the systemic challenges faced by parents in this study are not novel. It is well-documented that the transition from school to post-school life for individuals with ID and their families can be difficult (Neece et al., 2009; Newman et al., 2011; Simonsen & Neubert, 2013).~~

Despite federal legislation designed to improve systems that support transition and employment for individuals with disabilities (e.g., Individuals with Disabilities Education Act, 2004; Workforce Innovation and Opportunity Act, 2014), several parents in this study believed that their school and/or adult service agencies were ill equipped or unwilling to provide this support. Parents in this particular study, however, were not deterred by these systemic challenges. Instead, each parent played an integral role in establishing positive work outcomes for their child with ID through the creation of a business.

~~Furthermore, parents wanted more for their child than just the achievement of acquiring a job.~~

Previous research has recognized that parents and family members can have a powerful role in supporting individuals to achieve goals related to work (Blustein et al., 2018; Carter et al., 2016; Doren et al., 2012; Francis et al., 2014; Gilson et al., 2018; Henninger & Lounds Taylor, 2014). This study provides further evidence to support this body of literature, demonstrating that parents were integral in assisting their child with ID to achieve viable and sustainable work. Every parent in this study demonstrated skills related to perseverance, problem solving, and the

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ability to think creatively. When parents felt that the school or adult service systems were unable to provide a path to meaningful employment for their child, they began to devise alternative employment options and ultimately created a small business. Alternatively, some parents in this study had positive experiences with school providers. These positive school experiences directly contributed to the creation of the business, demonstrating that schools can play a pivotal role in the development of a smooth transition from school to post-school work for individuals with ID. ~~In addition, parents in this study worked with school providers to create meaningful transition activities, sought out supports from adult services providers, and acted as a conduit to create viable, successful work for their adult child with ID.~~

Beyond creating a viable work environment in which their child felt successful, parents also expressed that, above all else, they wanted their adult child with ID to live a happy and fulfilling life. Many parents seemed to believe one way to achieve this goal was to listen to their child about what they wanted to do for work. The parents interviewed for this study seemed to be acutely aware of their child's desires for work and their work goals. Several parents spoke about how their child "led" them down the path of business creation and that they wanted to create work opportunities that would allow their child to feel a sense of purpose, fulfillment, and enjoyment. For some parents, this involved validating their child's ideas about work and creating a business centered around their child's interests. For other parents, this involved watching their child enjoy a specific activity and creating work that involved the activity.

Regardless of the way the adult with ID communicated their work preferences, each parent was receptive and motivated to create a work option that met their child's needs and supported their goals. A strong body of literature demonstrates that self-determination is a predictor for improved post-school outcomes for students with disabilities (see Mazzotti et al.,

2016; Test et al., 2009). All of the adults with ID in this study had the opportunity to make choices and express their desires about what they wanted to do for work. They also had a parent who was willing to listen to, and advocate for, their wishes and desires. Research also emphasizes the importance of exposure to a variety of activities in and out of school so that individuals with ID can determine their work preferences (see Inge et al., 2017). The adults with ID in this study seemed to have a variety of experiences that allowed them to form ideas about what they enjoyed doing, which became the foundation for many of the businesses.

Limitations

Several limitations should be considered when reviewing the findings of this study. First, the participants in this study were fairly homogenous. All parents identified as White; all parents were actively involved in their respective disability communities; and most businesses were located in a suburban community. Factors influencing the decision to create a business may be different for parents who do not identify as White, live in rural or urban communities, and are less connected to their local disability community. A further limitation involves the support needs of the individuals with ID for which the businesses were created. Only one parent in the study indicated that her child required “extensive supports” to perform daily activities. Though this parent identified several factors that were congruent with other parents in the study, the majority of the findings are related to parents who have an adult child with moderate ID. Factors influencing parents’ decisions to create a business may differ from parents who have a child with more significant support needs. Additionally, parents indicated that their businesses had been in operation for an average of 6.14 years at the time of the study. Because parents described factors that influenced their decision to create a business several years after they started the business, it is possible that parents may not have spoken about the full breadth of factors that influenced their

decision. Finally, because we used interviews to obtain a deeper understanding of the factors that influenced parents' decisions to create a business for their child with ID, the number of participants involved in the study is limited. As such, the findings should be evaluated carefully to determine their transferability.

Implications for Research

This study examined the factors that influenced parents' decisions to create a business for their adult child with ID. ~~In order to~~To better understand these factors and others that may exist, we recommend replication of this study with a more diverse sample of participants, particularly focusing on including parents who do not identify as White and parents from urban and rural areas. ~~Furthermore, the voices of parents of children with ID who have extensive and/or specialized support needs is particularly needed as these parents may cite factors unique to this population.~~ Parents in this study also cited that schools and adult service systems were unable to support the long-term employment goals of their child with ID; however, this study did not examine the extent to which the design of school and transition services impact long-term employment outcomes for individuals with ID. Nor did the study investigate the impact of this decisions on the individuals with ID and their families. Future research is needed to better understand how specific system design may support (or hinder) long-term employment outcomes for individuals with ID.

~~_____ and parents who are not as actively involved in their disability communities. This research should also focus on parents from both urban and rural areas in order to understand if and how urbanicity influences parents' decisions to create a business for their child with ID. Furthermore, the voices of parents of children with ID who have extensive and/or specialized support needs is particularly needed as these parents may cite factors unique to this population.~~

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An important direction for future research is understanding the process through which parents achieve a viable and long-lasting business for their child with ID. This research might explore how parents create a business, including the steps they take, the supports (e.g., economic, personal) that facilitate development, the barriers (e.g., limited business knowledge, time, space) they encounter, and the strategies they find most successful in overcoming these barriers. Understanding the processes parents use to create and sustain a business for their child with ID may yield guidance for other families who are considering business creation for their child. Research is also needed to understand how individuals with ID participate in their business. Parents in this study indicated that they spent more time participating in activities related to the business than their adult child, which was surprising given that each business was created specifically for the child with ID. Investigating how individuals with ID participate in their business may illuminate differences that exist for individuals with different support needs and the types of training parents may need to maximize participation by the individual with ID.

Implications for Practice

Findings from this study suggest that school personnel can influence the development of businesses for students with ID in several ways. Most strikingly, parents described that they created a business because they believed the work experiences their child had while in school would not lead to long-term employment. With very few viable alternatives or support from the adult service system, parents turned to business creation to provide work activities for their child. This finding suggests that school personnel may need to examine their practices related to providing work experiences for students with ID. Instead of reserving existing work experience sites for use by students enrolled in the transition program, school personnel must be prepared to allow students to maintain their jobs upon graduation, especially if the students are successful

and satisfied with the work experience. Furthermore, if students are not finding success within existing work experiences offered by the school, additional work experience sites are needed to ensure all students are employed in a job of their choice at the time they exit school.

Additionally, findings reveal that positive school experiences influenced parents' decisions to create a business for their adult child with ID. Parents reported that school team members maintained open lines of communication about their child's work experiences. Information gained and shared by the school team allowed parents to better understand their child's work interests and abilities. For some parents, information about their child's strengths and interests in a work activity became the foundation for their business. School teams have an important responsibility to share information about student progress with parents. Through ongoing discussion and collaboration, parents, the individual with ID, and the school team can share information about existing employment options as well as small business creation. Sharing information about business creation may help parents to consider self-employment as a post-school work option for their child. If business creation is appropriate, the transition plan can be updated so that the student receives support to create the business while still enrolled in school.

Findings from this study also identified that dissatisfaction with post-school work options as well as the behavioral and medical needs of the individuals with ID contributed to parents' decisions to create a business for their child. Several individuals with ID were able to attain employment through supported employment, but ultimately left their positions because they were not well-matched with their job (e.g., the job was not of interest, the job did not support behavioral needs). This study highlights the importance of person-centered planning for individuals with ID as they pursue work. Special education teachers and adult service providers must examine the needs, skills, interests, and strengths of an individual and maintain high

expectations when providing work options to individuals with ID and their families. Moreover, several parents indicated that their child had very specific ideas about what they wanted to do for work (e.g., cooking). Though not a novel recommendation, this study provides further evidence that individuals with ID must be involved (and listened to) when planning for the transition from school to work and as their interests related to work evolve throughout their lifespan.

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