

## Inclusion

### “A life that feeds her soul.” Caregivers’ Perspectives of Their Youth with Significant Support Needs Transition to Employment.

--Manuscript Draft--

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<b>Corresponding Author:</b>	Richard A. Price, Ph.D. Purdue University West Lafayette, IN UNITED STATES
<b>First Author:</b>	Richard A. Price, Ph.D.
<b>Order of Authors:</b>	Richard A. Price, Ph.D. Hannah R. Brenner, Ph.D. Nikki Donnelly, MA Chak Li, MA
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<b>Abstract:</b>	Caregiver expectations regarding their youths with disabilities post-school life significantly predict their engagement in employment. However, limited research examines the link between caregivers' expectations and their youths with more significant support needs. Thus, understanding caregivers' views on the potential employment of their youth with significant disabilities is crucial. Within this study, we examine the expectations of five caregivers of their transition-aged youth's post-school lives, focusing on employment. Two main themes emerged: Caregiver Expectations and Factors Influencing Expectations. Sub-themes Family Dynamics, Caregiver Dynamics, Supports for Youth with Significant Support Needs, Resources and Support for Caregivers, Previous Work Experiences, Value of Work, and Fear. The findings from this study can be used to guide future research in further understanding the impact of caregiver expectations for youth with significant support needs. Additionally, this information can inform practitioners in effectively supporting caregivers in supporting their youth with significant support needs in life after school.

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**Abstract**

Caregiver expectations regarding their youths with disabilities post-school life significantly predict their engagement in employment. However, limited research examines the link between caregivers' expectations and their youths with more significant support needs. Thus, understanding caregivers' views on the potential employment of their youth with significant disabilities is crucial. Within this study, we examine the expectations of five caregivers of their transition-aged youth's post-school lives, focusing on employment. Two main themes emerged: *Caregiver Expectations* and *Factors Influencing Expectations*. Sub-themes include *Family Dynamics*, *Caregiver Dynamics*, *Supports for Youth with Significant Support Needs*, *Resources and Support for Caregivers*, *Previous Work Experiences*, *Value of Work*, and *Fear*. The findings from this study can be used to guide future research in further understanding the impact of caregiver expectations for youth with significant support needs. Additionally, this information can inform practitioners in effectively supporting caregivers in supporting their youths with significant support needs in life after school.

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The transition from school to adulthood is a complex process for youth with disabilities. Adolescents aging out of the school system and losing access to special education services under the Individuals with Disabilities Education Act (IDEA, 2004) face many barriers when transitioning into postsecondary education, employment, or adult living situations. Researchers have indicated that students with disabilities fare far worse in meeting their postsecondary outcomes when compared to their peers without disabilities (Newman et al., 2011; Taylor et al., 2021). Focusing on a more subset group of youth with disabilities, those with significant support needs (i.e., those who require supports in multiple areas of their life, those with multiple disabilities, autism spectrum disorder, intellectual and developmental disabilities, and those who qualify for their states alternate assessment), face additional challenges and meet their employment postsecondary outcomes at even lower rates (Alsaeed et al., 2023; Giangreco et al., 2018; Winsor et al., 2021).

To address employment disparities and to better equip students for the transition to adult life, federal law mandates the provision of transition services for students with disabilities beginning no later than age 16 (IDEA, 2004). This includes individualized, results-oriented planning and services to support students in meeting their postsecondary goals. These elements comprise students' transition plans, which are assessed yearly and included in their individualized education programs (IEPs). The goals, activities, and supports written into students' transition plans are meant to influence their activities after exiting the school system. However, additional factors may impact students' post-school experiences beyond the scope of special education law, policy, or practice.

One such factor is the expectations of students' caregivers, which has been cited as a significant predictor for students' engagement in employment after leaving high school (Mazzotti et al., 2021; Wehman et al., 2015). The expectations and aspirations that caregivers hold for their adolescents with disabilities have been described as "the most powerful force in changing [their] transition outcomes" (Carter, 2015, p. 1). As evident from findings by Wehman and colleagues (2015), youth with disabilities whose caregivers had higher expectations for their lives after high school were more likely to enter the workforce and obtain competitive employment. It is possible that the impact of caregivers' expectations may be even greater for their youth with significant support needs because of the increased nature of caregivers' involvement in the lives of their adolescents.

### **Caregivers' Perspectives**

Caregivers' perspectives towards employment remain one of the most important influences that may impact the career outcomes of youth with significant support needs, even after accounting for potential discrepancies in how these perspectives and expectations are measured. Caregiver expectations of postsecondary job attainment for their youth often become self-fulfilling and strongly associated with their actual postsecondary outcomes (Carter et al., 2012). However, caregivers' expectations do not always align with those of their youth with significant support needs. For instance, when asked about potential challenges to employment, caregivers were far more likely than their youth to cite potential limitations and concerns related to their disability (Schuster et al., 2003).

Many factors may influence the development of caregivers' expectations. For example, the perceived daily living skills of youth with significant support needs are an essential predictor of caregivers' employment expectations (Qian et al., 2020). Additionally, studies have shown

that caregivers with a college degree are more likely to expect their child to go to college even when other factors at the student, family, and school levels were controlled (Qian et al., 2020). This could be explained by increased access to resources and information related to postsecondary education options, which is correlated with more educated, higher-income households (Shattuck et al., 2011).

Research also demonstrates that specific actions by school teams may influence caregiver perspectives and expectations. In reviewing the available literature on the relationship between caregiver expectations and postschool employment outcomes, two major themes emerged regarding factors that may impact caregiver perspectives: (a) easing caregivers' fears of the unknown, and (b) support for job search and maintenance (Simonsen & Neubert, 2012; Southward & Kyzar, 2017; Wehman et al., 2015). Southward and Kyzar (2017) noted that caregivers may be concerned for the safety of their child within the workplace, which can be eased by having educators facilitate paid, integrated work experiences while they are still in high school. These work experiences, occurring under the supervision of school personnel, may increase caregivers' comfort level with the thought of their adolescent in the workplace. Further, Simonsen and Neubert (2012) remarked that student participation in paid work experiences allows caregivers to observe their children's success within integrated employment settings, which may ease their concerns. Suppose school teams can ease some of the caregivers' concerns about their adolescents' involvement in employment settings. In that case, caregivers may be more likely to work towards facilitating post-school work experiences for their adolescents.

This is noteworthy given that the support provided by families, impacts post-high school paid employment opportunities (Simonsen & Neubert, 2012; Southward & Kyzar, 2017; Wehman et al., 2015). Southward and Kyzar (2017) discussed that families play an essential role

in assisting youth with significant support needs to gain and maintain employment post-high school. This can be through practical support in a job search and general career advice for work aspirations. These supportive actions are often related to caregivers' expectations for their youth. According to Wehman et al. (2015), when caregivers have greater expectations for their children, they offer more chances and support to be self-sufficient. There is a connection between expectations and caregiver support actions; therefore, school teams must educate families in the transition planning process to empower their youth as they enter post-school environments (Simonsen & Neubert, 2012).

Most recently, Carter and colleagues (2023) interviewed 55 parents of individuals with intellectual and developmental disabilities about their perspectives on meaningful work. Parents reported that they value work for their youth and what employment can provide them, including financial independence, a sense of purpose or pride, and community and belonging (Carter et al., 2023). Parents in this study seemed to look beyond just the financial impact of employment, focusing on how work can enhance various other aspects of the lives of their youth with intellectual and developmental disabilities (Carter et al., 2023).

Research that includes caregivers of youth with significant support needs is valuable as this population's characteristics and needs are often far different than those of individuals with less significant support needs (e.g., physical disabilities or learning disabilities). Because of the additional challenges youth with significant support needs may face in entering the workforce, and the potential for caregivers to be increasingly involved in their lives, further exploring the perspectives and aspirations of these caregivers is integral to understanding and improving their youth's postsecondary outcomes. Investigating how caregivers may have developed these perspectives and expectations for their youth is also essential. Therefore, we have chosen to

focus on this population to further contribute to this body of work in better understanding caregiver involvement and potential impact on their youth with significant support needs post-school outcomes.

### **Theoretical Framework**

Recent research highlights the impact of caregivers' expectations of their youth with significant support needs and the value they place on work. This previous work has noted that these expectations impact caregivers' actions (e.g., opportunities afforded to their youth). Therefore, as a research team, we thought including Expectancy-Value Theory (EVT) would be a necessary guide in developing our study (Eccles et al., 1983). In EVT, caregiver expectations of their children are explained to directly impact their growth in terms of self-perception/identity and self-efficacy (Eccles et al., 1983; Eccles et al., 1989; Wigfield & Eccles, 1992, 2000). Expectancies are beliefs a person has about the prospect of someone else's success with a particular behavior or environment, such as caregivers' expectations or beliefs in the success of their youth with significant support needs in employment settings. According to EVT, the more the family values certain life domains and activities (which are classified as achievement domains, including academics or work) and the more the expectations/beliefs they have about their child's success in these areas, the more frequently they will provide or encourage opportunities for their child to engage in behaviors/activities within those domains (Eccles, 1992; Eccles et al., 1983; Wigfield & Eccles, 1992, 2000). Eccles and colleagues (1992/2000) go on to explain that opportunities to engage in various activities or environments (e.g., work) are directly afforded to children based on the expectations and values placed upon them by their caregivers (Eccles & Midgley, 1989; Wigfield & Eccles, 1992, 2000). Generally, caregivers provide many opportunities for their children to engage with specific experiences. Therefore, based on EVT,

the experiences afforded to a child, along with the feedback received by the family regarding those experiences, directly impact the development of the child's belief systems and self-efficacy.

Utilizing EVT to conceptualize research regarding caregiver expectations of their youth with disabilities has yet to be conducted. By contributing to this literature in using theory to ground this work, EVT allowed us to examine a previously explored topic more thoroughly and in a more contemporary way. EVT presents a framework for how caregivers' expectations may shape and influence the beliefs and experiences of their youth with significant support needs and, subsequently, their career development.

Ultimately, the present study sought to answer the following research questions:

1. What are caregivers' expectations regarding the postsecondary employment outcomes of their youth with significant support needs?
2. What factors may influence the development of caregivers' expectations?

### **Method**

The first four authors completed this project as part of a class assignment in the first year of their Ph.D. program in an introductory qualitative course. We were the primary researchers in conducting the study and analyzing data, and we will be referred to as *the research team* from here on out. We want to acknowledge this because the conceptualization and execution of this project, therefore, was completed before more recent research on caregiver expectations (e.g., Carter et al., 2023). There are limitations in the scope of our project, such as our smaller than typical sample size along with similar method execution and analysis from previous studies (more details about our limitations in the discussion section). Nevertheless, as a team, we felt that the stories of these families deserved to be shared. We state this because we caution readers to keep this in mind while exploring our data collection, analysis, and discussion sections.



## **Participants**

Using our personal and professional connections, participants were recruited through a snowball sampling method (Patton, 2015). Participants were recruited from multiple regions within the United States. This choice was made in an attempt to acquire data from a broad range of participants across the United States who may have diverse experiences that could impact the expectations of their youth. Before recruitment, we obtained Institutional Review Board approval from our university. Then, emails were sent to special education teachers within our networks, requesting they forward information about our study to families they felt met our eligibility criteria. We also directly sent recruitment emails to families within our personal and professional networks that we knew would meet inclusion criteria.

Interested participants completed an online consent form and a screening survey via our university's Webtools platform. Participants must have been proficient in English and have been the caregiver or guardian of an adolescent who met all of the following criteria: (a) between the age of 14 –21; (b) had an IEP classification of intellectual disability, autism spectrum disorder, or multiple disabilities; (c) qualified for their school's alternate assessment; and (d) was enrolled in the public school system at the secondary education level at the time of the interview.

Ultimately, five caregivers participated in the study, four of whom identified as female and one of whom identified as male. Participants also identified as Hispanic/Latinx, Black or African American, White or Caucasian, and Other. The disabilities of the children of these five caregivers varied amongst intellectual and developmental disability, autism spectrum disorder, and multiple disabilities.

## **Design and Procedures**

As a research team, we conducted semi-structured interviews and thematically analyzed them to explore caregivers' expectations regarding the postsecondary employment outcomes of their youth with significant support needs. We conducted semi-structured interviews as they allowed us to ask genuinely open-ended questions that allowed interviewees to respond in ways that most accurately reflected their perspectives (Patton, 2015; Tracy, 2020). In completing the thematic analysis, we followed the six steps outlined by Richards and Hemphill (2018) called Collaborative Qualitative Analysis (CQA).

### ***Interview***

Semi-structured interviews were conducted using an interview protocol developed by the research team, based on previous research, our previous experience working with youth with disabilities and their caregivers, EVT, and with support from the professor instructing our course. Once created, the protocol was pilot-tested with experts in special education and family members/caregivers. Experts consisted of former special education teachers who, at the time of the study, were pursuing their doctorate in special education, and family members/caregivers consisted of those with children with significant support needs who were over the age of 21. After revisions from pilot testing, we ultimately created a protocol that included 14 questions asked across three sections: *Section 1, questions to build rapport with caregivers; Section 2, questions regarding caregiver expectations regarding their youth's post-school employment; and Section 3, questions regarding the experiences of their youth in preparing them for life after high school.* Participants were interviewed by one of the first four authors, with whom they had no personal or professional connection. All interviews were conducted via Zoom and lasted between 60-90 minutes. See supplementary materials for a copy of the interview protocol used. After conducting each interview, they were transcribed, de-identified, and given pseudonyms, and then

audio files were deleted. Transcripts were then saved to a password protected storage system through our university.

### *Analysis*

In analyzing the data, we followed the six steps of CQA (Richards & Hemphill, 2018). This method of analysis was chosen as it was the method of analysis taught to us by our instructor, an author of CQA, and due to the structured approach of the analysis, which made completing it more systematic. Additionally, due to the structure of our team, CQA allowed us to enhance trustworthiness and rigor by integrating multiple researchers' perspectives, as well as utilizing various sources (e.g., EVT and previous research) to interpret data, engaging in both inductive and deductive coding (Richard & Hemphill, 2018). A deductive approach was used to develop our research questions, interview protocol, and identify themes driven by previous research and EVT. Inductively, we looked for ways that the data provided by our participants may have challenged or supported previous findings and EVT (Patton, 2015; Richards & Hemphill, 2018).

Following CQA, we first met to plan and organize the study (i.e., establishing questions, making decisions around the theory we would use for analysis, and how data would be collected and analyzed). Second, once data was collected, we engaged in both open (i.e., identifying patterns within the data, creating categories and subcategories of data) and axial coding (i.e., making connections between these patterns related to the research questions). Through this step, each researcher read through all transcripts two to three times, making notes related to the research questions. Next, we individually read through all transcripts an additional one to two times to generate codes in the form of words and phrases that represented what we found within the data, making connections between those codes. After, we met as a group to combine our

codes into a preliminary codebook, step four. Within this step, we each individually tested the preliminary codebook and would meet frequently (i.e., after reading and coding each transcript) to discuss our coding and resolve any discrepancies. Fifth, once there was a consensus on the final codebook, no new information was found, and all discrepancies were resolved, we individually applied it a final time to all the data collected. Lastly, step six involved reviewing our coding, generating themes, and ultimately writing the manuscript (Richards & Hemphill, 2018).

### ***Trustworthiness***

We employed various methods to increase the rigor of the study. First, we utilized an analysis journal to document each step of the research process and establish a reliable way to check our own biases within the research process. This journal also served as an audit trail for the study. Second, we utilized a step-by-step process, as outlined in the description of collaborative qualitative analysis, to conduct the analysis. Third, analyst triangulation occurred to control for analysis drift, ensuring that the interpretation of the data derived from the interviews was consistent and agreed upon across researchers. Within this process, we sought out areas of disagreement to ensure critical analysis of the data acquired. Lastly, another form of triangulation occurred with the use of EVT to influence the development of the questions asked in the interview protocols and during data analysis (Patton, 2015).

### **Findings**

Two main themes were identified in answering our research questions: Theme 1, *Caregiver Expectations*, was used to address research question 1; Theme 2, *Factors Influencing Expectations*, was used to address research question 2.

#### **Theme 1: Caregivers Expectations**

Caregivers expressed expectations of their youth regarding work in two distinct ways: expecting or not expecting employment. One caregiver, Tony, responded to whether he expected his son to work after high school with, "No, I don't see him [working]." Other caregivers, like Carol, did express expectations of work:

I think she thinks that she will stay at home and watch videos and FaceTime with friends and, you know, that kind of thing. And I think she doesn't get at all that, in fact, there will be, uh, some kind of employment or some kind of something that's, you know, provide structure and, you know, you're not just going to get to do whatever you want to do all day long every day.

Regardless of their expectations regarding work, all caregivers expressed how they wanted their youth to have a meaningful and purposeful life and presented opportunities for independence. However, caregivers differed in how they felt work contributed to a 'meaningful life.' For instance, caregivers who did not expect their child to work instead focused on expectations of independence related to daily living or functional skills. For example, Tony expressed how he wants his son to be independent with hygiene skills.

Routine of, of, of brushing your teeth and combing your hair, putting on deodorant and those kinds of things, I think those are the biggest...to me, those are like the big deal...I think just him learning how to manage himself take care of themselves.

In comparison, other caregivers, such as Natasha, who expressed expectations of work, described that work was part of a meaningful life:

So, I think not just, you know, the social aspect and keeping her busy, keeping her engaged, doing something versus sitting at home, watching her videos, you know, that's super important. Just, you know, I can't have her home 24/7, you know, it's seven days a

week...Obviously I'm not looking full-time employment. I'd be happy...if we could have year-round part-time employment, I'd be happy. That's great.

Not only was work described as part of a meaningful life for some, but caregivers expanded on what they felt work would mean for their youth. Wanda discussed that employment for her son could be a customized experience centered around his strengths and interests.

I dunno, he's really good at, like I said, coloring, drawing. Um, I dunno...for me, ideally...If he could like get into like graphic designing, um, that kind of stuff, like make the movies and stuff like that. I think he, that would help him because I mean, he can work like three or four computers at the same time...So he's very tech savvy.

Regardless of whether some caregivers did not expect work for their youth, at this moment, they stated that they did not have a loss of hope for what the future could look like. Tony remarked, "...maybe someday, you know, we're not, we don't ever lose hope, but that's kind of where he's at [now]."

## **Theme 2: Factors Influencing Caregiver Expectations**

We found that caregivers expressed these expectations for their youth with significant support needs through narrative accounts of their personal experiences, current challenges, and future aspirations. Expectations were manifestations of caregivers' actions and decisions regarding their youth's education, personal life, independent living, and employment. Caregivers discussed their personal lives, family dynamics, community support, and hopes and fears for their youth after high school, all of which seemed to play a significant role in shaping their expectations regarding work.

### ***Sub-Theme 1: Family Dynamics***

Caregivers uniquely described their family units. Some caregivers we spoke to were single, with a very supportive extended family, while others had a marital partner with immediate family support. Other characteristics of the family unit were having only one child (i.e., their youth with a significant support need), and having multiple children with and without disabilities. Each family's various dynamics could have influenced how caregivers saw the future of their youth after high school, specifically regarding work.

For example, Natasha explained: "Just myself and my son and my daughter...Both of them were adopted. Both of them have Down syndrome..." She then goes on to explain how her oldest child works and lives independently, "My son worked from the time he's been 14, he had a job, um, without a job coach..." Natasha then said that she expected her youngest child to work as well. The experiences of her oldest child might have positively impacted the value and expectation she placed on work for her youngest child.

In contrast, Tony described having three children, of which only one had a disability, the oldest. During his interview, he expressed how his two youngest children were looking at colleges, getting jobs, and planning to have full careers, something he did not see for the future of his youth with a disability. Tony did not expect his son with a significant support need to work, but he did for his other children, both of which did not have a disability. The experiences of his children without disabilities potentially negatively impacted how Tony expected work for his son with a disability, possibly due to the stark comparisons he witnessed between their experiences and needs.

Another example of the link between family dynamics and expectations after high school was discussed with Carol. As a single caregiver, Carol expressed that her divorce may have negatively impacted her daughter. She talked about how it has been difficult for her daughter to

understand the divorce. She thought that providing her daughter with opportunities to engage in work and exposing her to various aspects of life might help her be better informed and understand all aspects of life so that she would be best prepared to make her own decisions.

I mean, so like this whole divorce, she can't [understand], you know, well, who can, but, you know, it's really hard for her because things aren't black or white, she doesn't know what to do with it. And so I think it's so important for her to have some of these [work] experiences, the things that help you, that it's not just 'I'm thinking about what this job might actually be', but I'm, I'm actually doing it and saying, 'Oh, do I like this or not?'

### ***Sub-Theme 2: Caregiver Dynamics***

In addition to distinct family units, each caregiver was unique in describing their life. For example, caregivers gave detailed accounts of their past and present jobs, which may have influenced their expectations for their youth. For instance, Carol had the opportunity to quit her job and be a stay-at-home caregiver. This allowed Carol space to provide opportunities to support her daughter, which may have influenced her to expect her daughter to work after high school:

And I think that's what's well, I know that's, what's so hard for families in this universe is that, you know, if you're able to get your kid, the things they need, it consumes your life. Right. I mean, just, it just does. And we were so fortunate, and I stopped working when she was born and that's been my life for the last 17 and a half years.

Related, current or past positions in educational systems seemed to be associated with caregivers' expectations for their youth. One caregiver, Natasha, expected her youth to work. She shared that she had worked with students with disabilities for decades before raising her children. "I was an intervention specialist for 33 years and I said, I still think transition is the worst [and]



should be the most, probably the most important part of the IEP." Conversely, Tony, who is currently a special education teacher and his school's transition to work coordinator, did not expect his youth to work after high school. He stated, "I'm the work coordinator for the school district...And, um, and I told my wife, I said, I don't ever see him having one of those jobs..."

### ***Sub-Theme 3: Supports for Youth with Significant Support Needs***

Caregivers' perceptions of their youth with significant support needs and their abilities seemed to play a role in forming their expectations for their adult experiences. For instance, Wanda, who expected her son to work after high school, discussed the extensive supports they need. However, when discussing these supports and accommodations, she discussed how they could be provided in a workplace setting to enable his success.

So he has...visuals on like, um, you know, follow instructions, be respectful, um, mute when you're not speaking, You know, those are the little reminders that he needs. Um, I don't know if you know, somebody would be willing to, to kind of, you know, have this kind of stuff for him. And if there's a job in general, that would, you know, benefit...benefit from it. If that makes sense. I think those supports sound really... are all really reasonable and could definitely be implemented in like future settings.

Caregivers highlighted the potential for their youth to gain independence, develop new skills, and contribute to their community through paid employment. On the other hand, some caregivers, when discussing the support needs of their youth, believed that their employment options would be more limited or they would be unlikely to become employed at all:

I don't think he could be a Walmart greeter. I don't think he could stand in front of Walmart and greet because he gets distracted and he zones off. So, he wouldn't even be able to hand people that sticker in front of the, he would be like, zoned off... (Tony).

*Sub-Theme 4: Resources and Support for Caregivers*

One potential factor that was consistently raised amongst caregivers was the availability and quality of the resources and support that caregivers had access to. For example, supportive school staff was frequently discussed. Some caregivers reported challenges in securing appropriate services for their youth in their home districts. These challenges often involved significant effort on the part of the caregivers to advocate for their youth's needs. For instance, Wanda described a lack of communication between school professionals in how they were supporting and educating her son, "Um, and [the teachers] did not answer back, but it's work that I feel is, you know, they're not pushing him...he needs to be challenged a little bit more, a little bit more." Another caregiver, Tony, even expressed that his son didn't even have a transition plan, "We, we don't really have a transition plan. I know that he can stay in school until he is 22 with the county." These instances showcase how school supports, or the lack thereof, may contribute to their expectations of their youths' futures.

In contrast, some caregivers reported having very positive experiences with the schools. These caregivers described instances of collaboration and effective communication between themselves and the educators supporting their youth, facilitating their youth's preparation for work. These positive experiences highlight the positive influence that school staff can have on caregivers' expectations by reinforcing the idea that their youth can work. For example, Hope explained:

I think it was like a team effort. I said, "Hey guys, I wanna do this. I want him to get prepared for this... I said, 'I want him to be prepared to be able to go out in the work world.' And it was like they just jumped on. Ok, we're gonna, you know we're gonna do little things like this. We're gonna start interviewing him. We're gonna have him answer

interview questions. We'll set them up in the cafeteria. We're gonna, you know, just little things it was. I think it was a joint effort.

We also found that caregivers had connections outside the school system that may have influenced their expectations of their youth. For instance, some caregivers, like Carol, discussed having personal connections to support them and their youth in achieving needed services or a potential job. These personal connections likely played a significant role in shaping caregivers' expectations and beliefs about the potential for their youth to succeed at work.

...luckily for us, my husband has, he's an architect and he was the assistant building commissioner for ten years, and he's very connected. And so, I mean, that's how, honestly that's how she's got an aid at school. He made a phone call because if we waited for her to do the right thing, it never would have happened...Or maybe it's elitist or whatever, you know, if you're connected, you can get something and if you're not dream on, right.

#### ***Sub-Theme 5: Work Experiences***

Another factor discussed and associated with work expectations was the experiences with work that youth already had. Caregivers who stated that they expected their youth to work after high school also described their youth as having some work experience already, such as school-based jobs, summer work programs, or involvement in family businesses. Carol discussed her daughter's experience in an office setting.

And, you know, she likes helping in the office and sorting the mail and those kinds of things and so I think, 'Oh, there, there are lots of ways that could translate into something.' She could work in a law office. She could work in whatever, you know?

Another example is Hope's description of her son's work experiences, such as his school-based work experiences. This suggests that the presence of work experience could have played a crucial role in shaping caregivers' expectations for their youths' future employment.

He had little jobs at the school where he's working café, making coffee, taking orders delivering orders. He also had small jobs where he was in charge of collecting our recyclable items. He's been a gardener. He's done a lot of small things, but he really enjoys those things and so his teachers are now working with him on interviewing skills and you know how to ask questions and all of those things, so I think he's gonna be. I think they're preparing him as much as they can with the limited staff that they have.

In contrast, there was also an association between caregivers and youth without work experience who did not expect them to engage in work after high school. For example, Tony described that his son has not had any work experience to date, in school or otherwise, and he did not expect him to work after graduation.

#### ***Sub-Theme 6: Value of Work***

The value of work was reflected in how caregivers talked about their engagement in work and how they perceived work for their youth. Caregivers and their families had differing views of the value of work and what work could and should be in one's life. This seemed to be associated with their expectation of whether their youth would participate in postsecondary employment. While some caregivers emphasized work's integral role in one's life, others discussed other aspects of life that they felt were more important than being employed. For example, Tony, when talking about what he expected for his son after high school, did not mention work; instead, he stated how he valued his son's happiness and dreamed for him to be

able to work on the skills needed to be as independent as possible and to establish a meaningful routine.

You just want him to be in a place consistently, like where he has his routine. He gets some, some challenging things and it builds some successes. You know, I think for him and he's going to be, uh, we're all supposed to be lifelong learners, whatever that's supposed to mean, but he is always going to be a lifelong learner.

Conversely, some caregivers mentioned that work was essential. They valued the benefits that work could espouse, expressing that work was just as important as any other activity for their youth to establish a meaningful life. Wanda shared, "He helps out around the house. It's something that's very expected of him." Another caregiver, Carol, stated:

...the value employment can bring from having a job. And yeah, I think it's going to be everything because it's gonna, you know, it's for so many people, it's gonna end up framing your social life and for her, because it's such a big, she's so social...And so where she works in the atmosphere is going to be so important for her because I mean, it does for all of us that colors everything, whether or not you're realizing when you're unhappy at work, you're just miserable all the time. Because it's work. Not because, you know, you don't love your spouse or whatever, it's because you're spending so much time in this area that's dragging you down.

### ***Sub-Theme 7: Fear***

We found that fear was a common emotion among caregivers. Caregivers expressed anxiety due to the uncertain futures of their youth after high school, as well as the challenges and risks their youth may face in the adult world. For instance, Carol expressed all the unknowns of life after high school and how the everyday world is not designed to include individuals with

disabilities. Carol shared barriers that could get in the way of her daughter having a successful life after high school.

I think I'm just going to say, I think, and I don't know whether or not I'm typical, but the whole thing about transitioning out of high school is really terrifying...And, you know, so there's constantly that advocate, but you know, there's always the next step and it's already laid out. Then there's sort of laws like, you just don't pull your kid out of school. So you know, your kid's going to school and that's what you do...And knowing that at 20, that ends, and then it's the whole wide world is terrifying more than energizing because they just, the world isn't tailored for her and her needs. You have an IEP document that says so then you have people who are hopefully [preparing them] ...And it's really terrifying.

This fear appeared to fuel caregivers' desire to provide a meaningful life for their youth, which led some caregivers to expect work, as Carol did. Conversely, Tony, who did not expect work, also shared the fear of the unknown he had for his son that he had no idea of what the future held; however, he was more concerned that his son would have a happy and meaningful life than for him ever to work. Overall, fear of the future seemed also to be associated with caregivers' expectations of their youth in terms of expecting work.

### **Discussion**

Research has determined that caregiver expectations significantly contribute to their youths with disabilities' post-school work experiences and success (Carter et al., 2012; Carter et al., 2023; Mazzotti et al., 2021; Wehman et al., 2015). Additionally, researchers have begun to explore further how these expectations come to be (Carter et al., 2023; Shattuck et al., 2011; Qian et al., 2020). As important as this work is, continued work needs to be done in exploring

this topic to understand best not only what caregivers' expectations are and how they are developed but also how they impact the experiences afforded to their youth with disabilities and their overall post-school outcomes. As such, we aimed to conduct this study to contribute to this further understanding. What we found is that it is complex.

All the caregivers in our study wanted their youth to have a meaningful life, which may or may not have included work. This information further confirms previous research (e.g., Carter et al., 2023). Similar to earlier work, we also found how caregiver expectations may be associated with the opportunities provided to their youth (Carter et al., 2023; Eccles et al., 1983; Wehman et al., 2015). We decided to focus on this idea more, bringing a novel aspect to this work by including EVT. In analyzing our data through the lens of EVT, it would appear that caregivers' expectations, in some cases, may impact the opportunities afforded to their youth. Caregivers' value and expectation of work for their youth were associated with a higher value and expectation that their youth would then succeed in obtaining work. This was associated with caregivers providing or advocating for work opportunities in and outside of a school context. Conversely, caregivers who did not expect work for their youth did not have as much value for work and discussed not providing or advocating for those types of opportunities. Consistent with EVT, we started to uncover that the values and expectations of these caregivers may be highly associated with the experiences provided to their youth regarding their future. Further, we found information supporting the idea that caregivers' expectations regarding their youth's postsecondary life, specifically regarding employment, might impact the opportunities they provide to prepare them for life after school (Eccles et al., 1983).

We cannot make direct correlations between the factors we have identified and the expectations of the caregivers we interviewed, nor generalize our findings to make predictions

about other caregivers. It would be egregious for us to state that due to a caregiver's demographics and specific expectations for their youth, we can now predict the expectations of all other caregivers with similar demographics. Nonetheless, the information we found highlights how life experiences can influence expectations and how those expectations may influence the experiences afforded to their youth with significant support needs. For instance, both Tony and Natasha worked in the field of special education. This alone does not indicate the career expectations of their youth; both wanted a life of meaning for them, but Natasha expected work, whereas Tony did not. Their roles in the field of special education, coupled with other life events, may have played a role in formulating expectations for their youth. Tony discussed the immense support his son needed; this, coupled with his son having never engaged in work experiences, as well as the comparisons between his children without disabilities, crafted a recipe for him not to expect employment for his son with a disability. On the other hand, Natasha, who also discussed the extensive supports her daughter needs, coupled with her daughter engaging in work experiences and having two youths with significant support needs, led her to expect work for her daughter.

The example of Natasha and Tony illustrates the distinctive nature and complexities of caregivers' experiences and expectations for their youth's postsecondary life. We posit that one life event/experience does not have the weight to influence a specific expectation and outcome; instead, it is the sum of all its parts. Therefore, it is vital to understand this to support caregivers and their youth in having the most successful life after school. What we have found can influence future practice and research on how special educators and other related service providers work with caregivers and provide them with the resources and support needed.

### **Implications for Practice**



Several implications can be gathered from the findings in our study for special educators and other practitioners supporting caregivers and their youth. It is well understood that the expectations and support of caregivers gravely impact the postsecondary opportunities and success of youth, especially regarding employment (Simonsen & Neubert, 2012; Southward & Kyzar, 2017; Wehman et al., 2015). Therefore, practitioners can utilize this information to support better the caregivers they are working with. By having a holistic understanding of caregivers' expectations, the reasons for those expectations, and the impact of those expectations on youth, they can better support caregivers to support their children. Practitioners should also take the time to get to know caregivers, their family unit, and their goals and expectations. Knowledge and understanding of caregivers on a deeper level may help practitioners better educate and support caregivers or provide opportunities to their youth that can positively impact their post-school outcomes. Understanding caregiver expectations and how they can potentially affect the experiences caregivers afford to their youth could encourage practitioners to support caregivers in providing diverse work experiences. These experiences may include engaging in work at school or the community or having additional 'work' responsibilities at home to reinforce the high expectations that should be given to youth. This also sets the occasion for both caregivers and practitioners to be provided with similar opportunities or experiences, which could promote generalization.

Additionally, we noted in our findings that caregivers feared what the future held for their youth. This aligns with previous research indicating that fear and other life events can impact caregivers' expectations of their youth and participation in their career development (Simonsen & Neubert, 2012; Southward & Kyzar, 2017; Wehman et al., 2015). Knowing this, practitioners should cultivate experiences that reduce caregivers' fears of the unknown and demonstrate

students' ability to succeed in a work environment. If caregivers witness students' successes, they may also provide their youth with more responsibilities at home. Facilitating opportunities for caregivers to see the success and achievement of their youth may aid in easing their fears.

Finally, forging early connections between caregivers and their youth and adult service agencies may help reduce these fears of the future by ensuring that their youth have access to the support they need after they exit the school system.

### **Limitations and Future Research**

This project comes with many limitations that are important to acknowledge. First, our sampling method and the number of participants recruited is a significant limitation. By only sampling through our personal and professional networks, a potential bias could have occurred by recruiting participants with strong ties to individuals in higher education settings. This could have also impacted the experiences of the caregivers we sampled. Additionally, this lends to the fact that we did not meet saturation. As stated, this project was completed as a class project, and we chose to turn this into a manuscript as we felt strongly that the stories of these caregivers deserved to be shared. Nevertheless, this data is only representative of these five families.

Second, we only gained the expectations and experiences of one individual in the youths' life.

Future research should examine the expectations of multiple caregivers or other family members, such as siblings, and discuss the similarities and differences these expectations could have on the postsecondary success of their family members. Third, we did not utilize participant strategies to increase the trustworthiness of our findings. Future research should examine the inclusion of participants in the research process, for instance, through member checking. Lastly, we only included caregivers' thoughts; their youth's goals and ambitions were not examined. Future

research should incorporate the expectations and perspectives of caregivers and those of their youth, analyzing how these might align with or diverge from those of their caregivers.

### **Conclusion**

We provide a glimpse into the complex nature of caregivers' experiences and expectations of their youth with significant support needs in postsecondary life. Our analysis of caregiver expectations of their youth adds to the emergent literature on this topic, further documenting the importance of this research and the need for its continuation. This information should not be interpreted as *we must ensure all caregivers do \_\_\_\_\_ for their youth to have a successful life after school*. That is unrealistic, and if anything, the data we collected showcase how life is messy and not the same across people, all of which makes it beautiful. Understanding this and taking the time to know their caregivers, special educators, and other related service providers can build a rapport and gather information to support them best as they work with them to support their youth in having a successful and meaningful life post-school.

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