

HOUSEHOLD TASKS AND PARENT EXPECTATIONS FOR EMPLOYMENT

BY

KIMBERLY A. PATTON

DISSERTATION

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Doctoral Committee:

Professor Stacy Dymond, Co-Chair  
Associate Professor Meghan Burke, Co-Chair  
Professor Emerita Adelle Renzaglia  
Professor David Strauser  
Assistant Professor Kim W. Fisher, Illinois State University

## **Abstract**

Research has found that transition-aged youth (i.e., ages 14-21) with severe disabilities who engage in household tasks have increased odds of employment after exiting school. Moreover, the odds of youth being employed increase when parents expected that their children would have paying jobs after high school. However, research has not identified the extent that youth with severe disabilities, including intellectual disability (ID), participate in household tasks and how their participation relates to parent expectations for employment. This cross-sectional survey study had two primary purposes. It sought to determine the extent that parents reported their transition-aged youth with intellectual disability participated in household tasks and the level of support their youth required to participate in tasks. Additionally, this study aimed to examine the relation between youth involvement in household tasks and parent expectations for postschool employment. Parents of 118 transition-aged youth with intellectual disability from 28 states participated in the study. Descriptive statistics revealed that youth with intellectual disability had low overall levels of participation in household tasks and often required assistance to participate in tasks. A significant, positive relation was found between increased youth household task participation and high parent expectations for employment. Additionally, correlates of youth household task participation were identified. Specifically, youth with profound ID (versus youth with mild and moderate ID) were significantly less likely to participate in household tasks. Youth with increased engagement in community-based activities and previous paid employment experiences had increased participation in household tasks. Implications for research and practice research are discussed based on the study's findings.

*To Chris, Reese, Charlie, & Owen*

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## CHAPTER 1

### Introduction

Most adolescents and young adults desire future careers that match their interests and will allow them to financially support themselves, provide good benefits, and offer opportunities for advancement (Porfeli & Mortimer, 2010). Additionally, employment can provide purpose and meaning in an individual's life by promoting independence and self-confidence, fostering new social relationships and friendships, and contributing to local communities or society through their work (Lee & Carter, 2012). Most individuals with disabilities have the same desires for meaningful employment as individuals without disabilities. However, individuals with disabilities have continually struggled to obtain and maintain employment after exiting school. Employment data have consistently and historically shown that individuals with disabilities are employed at a much lower rate than individuals without disabilities (Bureau of Labor Statistics, 2018). As a way to address dismal employment outcomes, transition planning was mandated in the Individuals with Disabilities Education Act (IDEA) beginning in 1990. Transition planning involves creating individualized plans for students to set and achieve postschool goals. Families play integral roles in transition planning by partnering with schools to develop plans for future employment outcomes based on students' desires and interests. Parental involvement in transition planning has also been identified as a predictor of postschool employment success (Mazzotti et al., 2016; Test et al., 2009).

In addition to parents being active members of the transition team, researchers have also found that parent expectations for employment are predictive of future employment for individuals with disabilities (Carter et al., 2012; Doren et al., 2012). Specifically, individuals whose families expect postschool employment outcomes are more likely to be employed than



individuals whose families do not expect postschool employment as an outcome. This research highlights the importance of family involvement in transition planning and developing ways to promote high parent expectations for employment. A potential way to increase parent expectations regarding postschool employment involves parents engaging youth in tasks at home (Doren et al., 2012, Wehman et al., 2015). Participation in household tasks has been associated with increased odds of employment for youth with severe disabilities (Carter et al., 2012, Wehman et al., 2015); however, household task participation is an under-explored area for students with severe disabilities likely because household tasks are typically determined by parents outside of school.

The purpose of this study was to determine the extent that parents reported their transition-aged children with intellectual disability were engaging in various household tasks and the level of support their children needed to engage in household tasks. Additionally, this study sought to examine the relation between youth involvement in household tasks and parent expectations for postschool employment. An overview is provided of the transition from school to work for students with disabilities, including a description of transition and employment services, and a brief description of predictors of postschool employment identified in the literature. A review of the literature focused on two primary areas: (a) parent expectations of employment and factors related to parent expectations, and (b) youth involvement in household tasks and factors related to youth involvement in household tasks. Gaps in the literature were identified. To address the gaps, a cross-sectional survey was conducted with parents (e.g., legal parent, biological parent, step-parent) of transition-aged youth (i.e. youth between the ages of 14-22) with intellectual disability who lived at home with a parent.

## **Definition of Terms**

Key terminology are defined below as they relate to this study.

**Transition-aged youth with disabilities.** Individuals between the ages of 14-22 who have a disability defined by IDEA and have a need for special education services.

**Intellectual disability.** A disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18 (American Association on Intellectual Developmental Disabilities, 2019).

**Severe disabilities.** While there is no universal definition, severe disabilities typically refer to individuals with the most extensive and complex support needs. Students with severe disabilities frequently have a disability label of intellectual disability, autism, and/or multiple disabilities and are eligible for participation in their state's alternate assessment.

**Household tasks.** Participation in tasks that are done regularly at home. For this study, 34 common household tasks (Dunn, 2004) were included in the definition of household tasks (see Appendix I, question 22-55 for a complete list).

**Integrated employment.** Integrated community-based work which is not funded by agencies solely for individuals with disabilities. Integrated employment provides opportunities for interactions with individuals without disabilities through a proportionate ratio of employees with and without disabilities (Inge et al., 2017).

**Segregated employment.** Segregated, facility-based employment, such as employment in sheltered workshops. Typically, sheltered workshops pay sub-minimum wage and only or primarily employ individuals with disabilities (Winsor et al., 2017).

## CHAPTER 2

### Literature Review

Upon completion of high school or college, most individuals desire to find meaningful work that will provide them with the financial means to acquire resources essential to making autonomous life decisions and living as independently as possible. Although individuals with disabilities are not an exception to this desire, finding meaningful paid employment in community settings is often elusive for them as they exit the school system (Carter et al., 2012; Carter et al., 2014; Test et al., 2009). For example, data from the last 10 years indicate that individuals with disabilities were employed at an average rate of 18.3% compared to 64.9% for individuals without disabilities (Bureau of Labor Statistics, 2018).

Even more disparaging, data from the National Longitudinal Transition Study-2 (NLTS2) suggest that individuals with severe disabilities (i.e., intellectual disability, autism, and multiple disabilities) were employed at significantly lower rates (37.2% - 39.2%) one year after exiting school than individuals with less significant disabilities (i.e., learning disabilities, speech and hearing impairments, and other health impairments) who were employed at rates of 64.4% - 67.7% (Newman et al., 2011). Additionally, data from the National Core Indicators (NCI Adult Consumer Survey Final Report, 2014-2015), suggest that while 21% of individuals with severe disabilities ages 21 and older served by state developmental disabilities agencies had paid jobs, only 5% had jobs in integrated community settings. The remaining 16% had paid jobs in segregated facility-based settings such as sheltered workshops which typically include piecemeal work and subminimum wages. Further, 49% of individuals with severe disabilities participated in *unpaid* facility-based activities such as day programs (i.e., non-work programs). More recent

NCI reports have not provided updated figures about employment specific to individuals with severe disabilities, thus these data are the most recent available.

### **Transition from School to Work**

As exhibited by the poor employment outcomes for individuals with disabilities, the transition from school to work for individuals with disabilities is not a simple process; it involves shifting from a familiar entitlement system (i.e., the school) to an unfamiliar and complex eligibility-based adult service delivery system (Cooney, 2002; Hanley-Maxwell et al., 1995). To promote seamless transitions from school to adult services, school and adult service providers need to coordinate with students with disabilities and their families to create transition plans that outline specific services and supports students will receive to meet their postschool goals for employment, as well as, education, and community living (Oertle & Trach, 2007). Federal initiatives focused on improving employment outcomes for individuals with disabilities have been established to provide guidance for school and adult service professionals in preparing students for the transition from school to employment in the areas of transition services and employment services.

### **Transition Services**

Transition services include services designed to assist students with disabilities in meeting transition goals for postschool outcomes related to employment, independent living, and post-secondary education. A mandate to include transition services for students with disabilities by their sixteenth birthday was first established in 1990 as part of the reauthorization of the Individuals with Disabilities Education Act (IDEA) as a way to address poor postschool outcomes. Since 1990, the transition mandate has been expanded with the 1997 and 2004 reauthorizations of IDEA. The transition mandate specifies that transition services are a

coordinated set of activities “focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation” (IDEA, 20 U.S.C. 1401 § 602.34, 2004). IDEA also requires collaboration among agencies (e.g., local education agency [LEA], vocational rehabilitation [VR]) as part of transition planning.

In addition to IDEA, the Rehabilitation Act, which was amended by Title IV of the Workforce Innovation and Opportunity Act (WIOA) in 2014, also includes provisions for incorporating transition services for students with disabilities by providing a continuum of services designed to assist students in achieving integrated employment outcomes. While VR services are eligibility based, the Rehabilitation Act references that all students with disabilities in a secondary or post-secondary education program between the ages of 16-21 (unless states have elected a lower minimum age or a higher maximum age) are considered eligible to receive pre-employment transition services. WIOA requires VR agencies to set aside at least 15% of their federal funds to provide pre-employment services to students with disabilities. Pre-employment services are designed to help students identify their career interests through services such as: (a) job exploration counseling, (b) work-based learning experiences, (c) workplace readiness training, (d) counseling on post-secondary education and training programs, and (e) self-advocacy instruction. If students require additional VR transition services beyond pre-employment services, they are required to apply and be determined eligible to develop an individualized plan for employment (IPE). While students can apply for additional employment services at any point after turning 16 (or sooner if states have elected a lower minimum age),

ideally, they will apply before exiting school to avoid a disruption in services. The Rehabilitation Act, like IDEA, requires coordinated and collaborative efforts between VR agencies and schools through a formal interagency agreement to facilitate an effective delivery of transition-related services for students with disabilities as they transition from school to work.

## **Employment Services**

One of the primary goals of effective transition services is to assist students to obtain post-school employment. Schools work with state VR agencies to determine the extent and type of employment services needed for individual students prior to students exiting school.

Employment services support students to work in either integrated or segregated settings.

**Integrated employment.** Competitive integrated employment refers to community-based work which is not funded by agencies solely for individuals with disabilities and provides opportunities for interactions with individuals without disabilities through a proportionate ratio of employees with and without disabilities (Inge et al., 2017). Competitive integrated employment outcomes for individuals with severe disabilities are typically facilitated through the following integrated employment options: (a) supported employment, (b) customized employment, and (c) self-employment (Inge et al., 2017; Wehman et al., 2018).

According to WIOA, supported employment involves placing individuals with the most significant disabilities in competitive integrated jobs and providing ongoing support to achieve an individual's employment outcome as written in their individual plan for employment. Supported employment services can be provided individually or in a group setting. While consideration is taken to ensure that the job is a good match for individuals' strengths and interests, supported employment rejects the philosophy that individuals need to master prerequisite skills to be initially placed in a competitive integrated job; rather individuals receive

support and training in real work settings (Wehman et al., 2018). Supported employment is an on-going support that may be required for the entirety of an individual's employment, although the intensity of the support being provided will likely fade as an individual builds his or her competency for the job (Brooke, et al., 2018; Inge et al., 2017; Wehman et al., 2018). Supported employment has been found to be an effective VR service option for assisting individuals with significant disabilities with achieving positive postschool employment outcomes (Howlin, 2013; Wehman et al., 2014).

A second integrated employment service is customized employment. Customized employment is an extension of supported employment and is also focused on competitive integrated employment for individuals with the most significant disabilities (WIOA, 2014). Customized employment is differentiated from other types of supported employment in that it is specifically designed to customize job responsibilities beyond what jobs typically require in the labor market. This customization process is done to meet the needs, strengths, and desires of the individual with a significant disability as well as the business needs of the employer. It is carried out through flexible strategies such as,

(A) job exploration by the individual; (B) working with an employer to facilitate placement including (i) customizing a job description based on current employer needs or on previously unidentified and unmet employer needs; (ii) developing a set of job duties, a work schedule and job arrangement, and specifics of supervision (including performance evaluation and review), and determining a job location; (iii) representation by a professional chosen by the individual, or self-representation of the individual, in working with an employer to facilitate placement; and (iv) providing services and supports at the job location (WIOA, 29 U.S.C. 3101 § 404.7, 2014).

Customized employment services are ongoing, but likely will be more intensive in the beginning and then fade to include natural supports (e.g., support from other employees), and less frequent support from VR agency staff (Wehman et al., 2018). There is limited research documenting the effectiveness of customized employment, but the limited research has found positive results in individuals with significant disabilities achieving positive employment outcomes (Citron et al., 2008; Wehman et al., 2016).

Another option for attaining integrated employment can include self-employment where individuals with severe disabilities receive customized on-going supports to effectively run a business that is based on their hobbies and/or strengths. Self-employment may also be an option when other employment opportunities in the community are lacking (Inge et al., 2017). Self-employment often involves a variety of services and supports that VR agencies provide or coordinate with different agencies, organizations, and family members including: (a) financial assistance from family, government loans and grants, and community organizations; (b) personal support and services from Social Security and other agencies; and (c) business related assistance from attorneys, business mentors, accountants, marketing professionals, and computer and technology consultants (Yamamoto et al., 2011). Oftentimes, individuals are expected to contribute personally or find external funding prior to VR agencies contributing their own funds for startup costs (Arnold & Seekins, 2002). There is minimal research on the outcomes of self-employment for individuals with severe disabilities, but there are data showing that people with disabilities report being self-employed at a higher rate (12.2% compared to 7.8%) than the general population (Arnold & Seekins, 2002).

**Segregated employment.** On the other side of the employment continuum are segregated, facility-based services, such as sheltered workshops. Typically, sheltered workshops



pay sub-minimum wage and only or primarily employ individuals with disabilities (Winsor et al., 2017). Research has found that while individuals with disabilities desire integrated employment, (Migliore et al., 2007; Timmons et al., 2011), the majority of adults with severe disabilities are either unemployed or served in facility-based settings such as sheltered workshops (Carter et al., 2018; Nord et al., 2018; Winsor et al., 2017). Employment in segregated settings such as sheltered workshops occurs at a 3:1 ratio compared to employment in integrated settings for individuals with severe disabilities (Certo et al., 2008; Migliore et al., 2008). Additionally, Simonsen and Nuebert (2012) found that the majority (57.1%,  $n = 338$ ) of transitioning youth with intellectual and developmental disabilities in their study were engaged in sheltered or non-work activities 18 months after exiting school. Employment in sheltered workshops rarely leads to integrated employment. In fact, the transition rate for individuals moving from sheltered to integrated work is between less than one and five percent (Hoffman, 2013). Due to low employment rates and low earnings in jobs such as those in sheltered workshops, adults with severe disabilities are three times more likely to be in poverty than their peers without disabilities (Certo et al., 2008). Regardless of these statistics, there are parents and individuals with severe disabilities who prefer work in sheltered workshops and often cite safety, transportation, and/or scheduling concerns as reasons to continue work in sheltered workshops (Carter et al, 2018; Migliore et al., 2008).

### **Predictors of Postschool Employment**

As a way to address dismal employment statistics for individuals with disabilities, researchers have sought to identify in-school predictors of post-school employment. In 2009, Test and colleagues conducted a systematic review of correlational studies focused on identifying relations between predictor and outcome variables to secondary transition predictors

of postschool success. Their inclusionary criteria included multiple components including a 13-item checklist for correlational research to assess the quality of evidence. The checklist was based on criteria for quality indicators for correlational research developed by Thompson et al. (2005). For the articles that met the quality indicator criteria ( $n = 22$ ), the researchers determined the level of evidence (i.e., potential, moderate, emerging) based on specific criteria from the Institute for Education Sciences (IES).

The results of Test and colleagues' (2009) systematic review yielded the identification of 16 in-school predictor categories that correlated with postschool employment: career awareness, community experiences, exit exam requirements/high school diploma status, inclusion in general education, interagency collaboration, occupational courses, paid work experience, parental involvement, program of study, self-advocacy/self-determination, self-care/independent living, social skills, student support, transition program, vocational education, and work study. Four predictors had moderate levels of evidence (i.e., inclusion in general education, paid employment/work experience, vocational education, work study). The remaining 12 predictor categories had potential levels of evidence.

In an effort to extend the predictor work done by Test et al., (2009), Mazzotti et al. (2016) systematically reviewed articles published from 2009 to 2014 that conducted secondary analyses of the National Longitudinal Transition Study—2 (NLTS2) and met the quality indicators for correlational research. In their review, Mazzotti and colleagues identified 11 articles that met the inclusionary criteria and found evidence to support nine of the existing predictors identified by Test et al. (2009): career awareness, exit exam/high school diploma status, inclusion in general education, paid employment/work experience, parent involvement, self-care/independent living skills, social skills, vocational education, and work study. The level

of evidence (i.e., moderate, potential) did not change with the addition of the supporting evidence for these predictors. In addition to providing support for existing predictors, Mazzotti et al. also identified four new predictors of postschool employment for students with disabilities: parent expectations, youth autonomy, goal setting, and travel skills. Three of the four new predictors (i.e., parent expectations, youth autonomy, and travel skills) had potential levels of evidence, while goal setting was found to have an emerging level of evidence.

In all the studies reviewed by Test et al. (2009) and Mazzotti et al. (2016), only one study (Carter et al., 2012) specifically disaggregated data to focus on individuals with severe disabilities. Carter et al. (2012) used NLTS2 data to determine predictors of postschool employment for individuals with severe disabilities two years after exiting school. They found that community-based paid employment in high school was the strongest predictor of successful postschool employment. Moreover, the odds of students being employed increased fivefold when parents expected that their child would have a paying job after high school. Increased participation in household tasks during adolescence, higher social skills, and higher levels of independent self-care skills were also associated with increased odds of postschool employment.

Although social skills and self-care skills are frequently taught at school, household tasks are typically determined by parents outside of school. The area of household tasks has received limited investigation in the literature. To better understand how involvement in household tasks can predict future employment for youth with severe disabilities, it is important to investigate this area more extensively. To determine that involvement in household tasks was a predictor of employment for youth with severe disabilities, Carter and colleagues (2012) used a four-item scale that asked parents to report the frequency with which they believed their child with severe disabilities engaged in the following tasks: (a) fixes his or her own breakfast, (b) does laundry,

(c) cleans his or her own room, and (d) picks up a few things from the store. Scores ranged from 1 = *never*, 2 = *sometimes*, 3 = *usually*, and 4 = *always* for each item; summed scores in the 4-8 range were considered low, and were compared with scores in the moderate to high range (9-16).

When considering all of the potential household tasks a person may have, this scale is limited in scope and may not be representative of other household tasks individuals have that may also be helpful when pursuing employment outcomes. Carter and colleagues (2012) did not describe the process they used to develop the items on the scale, nor did they describe how or why the four activities were selected as opposed to other activities. Furthermore, while this scale does reference how often a student does these activities, it does not ask about the level of support students receive to complete the tasks. For example, some students may require only a visual task analysis to complete steps for doing the laundry, while other students may require physical assistance to complete most steps for doing laundry. The importance families place on the specific tasks asked about in the household tasks scale may also differ among families (e.g., some families may not prioritize making breakfast because the student eats breakfast at school). Additionally, parents were also not asked about their expectations for involving their children in household tasks, nor how their children were instructed on how to do chores in the home and how parents were involved in the instruction. While this scale does provide some information about an individual's participation in household tasks, it is likely that parents of young adults with severe disabilities have different expectations for their children's involvement in household tasks, which may impact the different tasks individuals engage in and the levels of support individuals require to engage in various household tasks and chores.

## **Parents' Expectations for Postschool Employment**

Parent expectations for postschool employment have been found to be a significant predictor of employment for individuals with severe disabilities (Carter et al., 2012), yet few studies have investigated parents' expectations for postschool employment for individuals with severe disabilities. From the limited available literature, it has been determined that the majority of parents desire community-integrated employment outcomes for their children with severe disabilities (Blacher et al., 2010; Blustein et al., 2016; Ivey, 2004; Kramer & Blacher, 2001; McNair & Rusch, 1990; Migliore et al., 2007). In contrast, Grigal and Neubert (2004) found that a majority of parents of young adults with severe disabilities desired segregated sheltered workshops over supported employment or other community employment outcomes.

Research has also found that parents' desires for postschool employment often do not align with the employment outcomes they expect for their sons and daughters with severe disabilities. While parents often desire or value community integrated employment outcomes, they often expect their children will work in segregated settings or have non-work outcomes (e.g., day activity centers, volunteer work) (Blustein et al., 2016; Ivey, 2004; Kramer & Blacher, 2001; McNair & Rusch, 1990). Additionally, some parents do not expect their young adult children will partake in any kind of work after exiting school (Blacher et al., 2010; Doren et al., 2012; Grigal & Neubert, 2004; Kraember & Blacher, 2001; McNair & Rusch, 1990).

### **Factors Related to Parent Expectations**

Research has identified a variety of factors that can influence parent expectations for employment including: (a) type of disability (Blacher et al., 2010; Blustein et al., 2016; Doren, et al., 2012; Grigal & Nuebert, 2004; Wagner et al., 2007); (b) past work-related experiences (Blustein et al. 2016; Migliore et al., 2007); (c) availability of adult services (Hanley-Maxwell et

al., 1995; Timmons et al., 2004); (d) minority status (Doren et al., 2012); and (e) socioeconomic status (Doren et al., 2012). While many factors are associated with parent expectations for employment, research suggests that parent expectations are malleable (Bozick et al., 2010; Doren et al., 2012). Parent expectations can potentially be elevated through schools providing supports to parents such as ensuring parents' understanding of work-related skills and behaviors that can be addressed both in the school and home environments, showing documented progress of students learning work-related skills through data collection (e.g., data sheets, videos, testimonials), and providing information about integrated employment resources and opportunities in the community (Blustein et al., 2016; Carter et al., 2010; Wehman et al., 2015).

**Type of disability.** Parent expectations for postschool employment have been found to be influenced by the type of disability and whether the disability is classified as high-incidence or low-incidence. Higher parent expectations for employment outcomes are associated with individuals with high-incidence disabilities such as learning disabilities, other health impairments, and speech and language disorders in comparison with low-incidence disabilities (e.g., intellectual disability, autism, multiple disabilities) (Blacher et al., 2010; Blustein et al., 2016; Doren et al., 2012; Grigal & Nuebert, 2004; Wagner et al., 2007). Studies that focused on specific disability types (e.g., intellectual disability, autism, Down Syndrome, cerebral palsy) found that higher parent expectations for employment were associated with youth with autism (Blustein et al., 2016), Down syndrome (Blacher et al., 2010), higher functional abilities, (Blustein et al., 2016) and better health (Blacher et al., 2010). Blacher et al. found that parents of individuals with cerebral palsy who had moderate to severe intellectual disability had lower expectations for employment than parents of children with Down syndrome or parents of children with autism. In contrast, Migliore et al. (2007) whose survey included parents of young

adults with varying levels of intellectual disability found that the severity of an individual's disability did not factor into parent expectations for employment.

**Past work-related experiences.** Individuals with disabilities who had previous work-related experiences in the community, as well as, at home and in the school, also tended to have parents and families with higher expectations for employment (Blustein et al., 2016; Migliore et al., 2007). Previous community work experiences included paid or unpaid after school, weekend, or summer jobs; home experiences included helping with chores, helping with money management, and conferring with parents about future employment goals; and school experiences included participation in job training at school, taking vocational classes, and learning about different careers and professions (Blustein et al., 2016).

**Availability of adult services.** An additional factor that may influence parent expectations for employment is the availability of post-school services (Hanley Maxwell et al., 1995; Timmons et al., 2004). Higher parent expectations for employment outcomes were associated with increased availability of adult services, while lower parent expectations were associated with a lack of adult services.

**Minority status.** Doren et al. (2012) found that parents of minority adolescents had significantly lower expectations for employment outcomes than parents of non-minority adolescents. While 93% of non-minority parents thought their child would definitely have a job, only 79% of minority parents thought their child would definitely have a job.

**Socioeconomic status.** Parent expectations for employment outcomes were found to be significantly lower for adolescents from lower income backgrounds than adolescents from higher income backgrounds (Doren et al., 2012). Similar to minority status, Doren and colleagues found

that 94% of parents with higher socioeconomic status expected their child would definitely have a job compared to 76% of parents with lower socioeconomic status.

### **Research Methods Used to Determine Parent Expectations and Factors**

Studies that have identified parent expectations for employment and factors associated with parent expectations have primarily used quantitative survey methods (Blacher et al., 2010; Blustein et al., 2016; Doren et al., 2012; Grigal & Nuebert, 2004; Ivey, 2004; Kramer & Blacher, 2001; McNair & Rusch, 1990; Migliore et al., 2007; Wagner et al., 2007). Generally, surveys were generated using a mixture of pre-existing measures and created measures to determine parent expectations for employment and factors associated with parent expectations. Two studies analyzed NLTS2 data to make determinations about parent expectations and associated factors (Doren et al., 2012; Wagner et al., 2007). Additionally, two studies conducted qualitative analyses through the use of in-depth interviews (Hanley-Maxwell et al., 1995), and a combination of focus groups and case-studies (Timmons et al., 2004).

The majority of studies used purposive sampling to recruit parent participants (Blacher et al., 2010; Blustein et al., 2016; Grigal & Nuebert, 2004; Hanley-Maxwell et al., 1995; Ivey, 2004; Kraemer & Blacher, 2001; McNair & Rusch, 1990; Migliore et al., 2007; Timmons et al., 2004). Parents were typically recruited through the following methods: (a) contacting various disability- and family-focused organizations within specific states (Blustein et al., 2016; Ivey, 2004; McNair & Rush, 1990; Timmons et al., 2004), (b) having regional centers in specific states that provide case management services send invitations to parents with young adult children with severe disabilities (Blacher et al., 2010; Kraemer & Blacher, 2001; Migliore et al., 2007), and (c) recruiting school districts to invite parents of students with disabilities (Grigal & Nuebert, 2004; Hanley-Maxwell et al., 1995). Two studies (Doren et al., 2012; Wagner et al., 2007) used



nationally representative NLTS2 parent data which is sorted by disability category, but includes individuals with all disability types.

The studies in this review included parents whose children were between the ages of birth to adulthood and included parents whose children had a variety of disabilities. Specifically, five studies focused on involving parents of adolescents and young adults between the ages of 14-26 (Blacher et al., 2010; Grigal & Neubert, 2004; Hanley-Maxwell et al., 1995; Kraemer & Blacher, 2001; McNair & Rusch, 1990). Additionally, two studies included parents of children from birth to age 22 (Blustein et al., 2016, Ivey, 2004), while one study included parents of adults (Migliore et al., 2007). Children of the parent participants were identified as having the following types of disabilities: (a) severe disabilities (Blacher et al., 2010; Hanley-Maxwell et al., 1995; Kraemer & Blacher, 2001; McNair & Rusch, 1990), (b) high and low incidence disabilities (Grigal & Neubert, 2004), (c) autism spectrum disorder (Ivey, 2004), (d) intellectual disabilities (Migliore et al., 2007), and (e) various disabilities (Blustein et al., 2016; Doren et al., 2012; & Wagner et al., 2007).

Studies used a variety of methods to determine the expectations and preferences of parents regarding postschool employment outcomes for their young adult children with severe disabilities. Five studies asked parents to use a likert-type scale to rate forced-choice statements about employment outcomes that parents expected or thought likely for their children with severe disabilities after exiting school (Blacher, et al. 2010; Blustein et al., 2016; Doren et al., 2012; Ivey, 2004; Wagner et al., 2007). Additionally, four studies asked parents to evaluate the importance of employment outcomes for their sons and daughters in addition to evaluating the employment outcomes parents expected (Blustein et al., 2016; Kraemer & Blacher, 2001, Ivey, 2004; McNair & Rusch, 1990). For example, Blustein et al. (2016) asked parents of children

with intellectual and developmental disabilities (IDD) to use a 4-point scale to determine the importance and the likelihood of four possible employment outcomes including full-time community employment, part-time community employment, full-time employment in a sheltered workshop, and part-time employment in a sheltered workshop. To determine factors associated with parent expectations, studies used a variety of previously developed scales and demographic questions (e.g., disability status, minority status, socioeconomic status) and then conducted statistical analyses (e.g., regression analyses, *t*-tests, chi-square analyses) to determine if factors were associated with parent expectations for employment.

### **Gaps in the Literature**

While research has investigated parent expectations for employment for young adults with severe disabilities, researchers have examined this topic with varying levels of depth. Some studies have simply asked parents a “yes” or “no” question about whether or not they think their child will have a paid job in the future. Whereas other studies have examined parent expectations with more depth by using methods such as likert-type scales to determine the extent parents think it is likely their child will have a paid job in the future, and/or parent preferences for employment. Additionally, some studies that investigated parent expectations did not examine factors that were associated with parent expectations, so it is possible that there are additional factors that could be associated with parent expectations for employment. While all of the studies in the review included transition-aged youth with severe disabilities in their samples, many of the samples also included both younger and older individuals with and without severe disabilities. Therefore, it is difficult to determine if the parent expectations and factors associated with those expectations are representative of parent expectations for transition-aged youth with severe disabilities. Moreover, only two of the studies have been conducted in the last 10 years, and it is

possible that parent expectations for employment outcomes may have changed as technology and access to information has become more prevalent. To have a better understanding of parent expectations for employment, it is important that researchers investigate additional factors that are associated with parent expectations for employment, in addition to investigating the types of employment parents expect or value for their children with severe disabilities.

### **Household Tasks**

Literature suggests that a potential way to raise parent expectations regarding employment outcomes involves providing information and resources to parents to work with their child on skills related to employment outside of school (Doren et al., 2012; Wehman et al., 2015). Predictor research indicates that individuals with severe disabilities who engage in household tasks have higher odds of successful employment outcomes after exiting school than individuals who do not engage in household tasks (Carter et al., 2012). Therefore, by involving adolescent and young adult children with severe disabilities in household tasks, parents may not only be helping their children gain skills that will help them reach their employment goals, but also potentially raising their own expectations for their child's employment. The following section reviews 13 total studies that have investigated: (a) parent expectations for household tasks, and (b) factors associated with household task participation for youth.

#### **Parent Expectations for Household Tasks**

In general, families expect that children will engage in various household tasks. The age at which children begin having these tasks is dependent on unique family and child characteristics (Bowes et al., 2001; Dunn et al., 2009). Parents also generally assume responsibility for teaching their children how to participate in household tasks (typically by modeling) with children gradually taking on some level of responsibility for tasks over time

(Dunn et al., 2009). While the age children begin taking on household tasks may differ within families, most families expect that children entering adolescence will engage in household tasks (Bowes et al., 2001). Whether this expectation is also true for parents of adolescents and older children with severe disabilities is unclear given that no studies have directly investigated parent expectations for household tasks for youth of any age with severe disabilities.

The limited extant literature that has investigated parent expectations for household tasks has focused primarily on youth with physical disabilities such as cerebral palsy and spina bifida who have average to above average intelligence, and youth described as having high-functioning autism. This literature has found that when compared to parents of children without disabilities, parents of children with physical disabilities and high-functioning autism have lower expectations for their children's involvement in household tasks (Amaral et al., 2014; Dunn et al., 2009; Dunn & Gardner, 2013; Egilson et al., 2017; Luther, 2001; Reynolds et al., 2011). Of the six studies that examined parent expectations for household tasks, only two included parent expectations about transition-aged youth (Egilson et al., 2017; Luther, 2001), while the other four included parent expectations for younger children between the ages of 6-14. Given the findings from these studies, it seems likely that parents of transition-aged youth with severe disabilities may have lower expectations for their sons' and daughters' involvement in household tasks than parents of children who do not have severe disabilities.

### **Factors Related to Youth Household Participation**

While there were limited studies that focused specifically on parent expectations for youth engagement in household tasks, 12 studies were identified that have addressed family and youth characteristics that influence children's participation in household tasks. Although these studies may not address parent expectations specifically, the factors identified in these studies

provide ideas about factors that likely influence parents' expectations for their children's participation in tasks at home (e.g., child gender, family size, parent education levels), as it is likely that all youth involvement in household tasks is due in part to parent expectations (Blair, 1992).

The research on youth participation in household tasks has primarily focused on youth with average to above average intelligence, and has not focused on youth with intellectual disabilities. Two studies were identified that investigated factors related to household task participation and also included children (ages 5-13) with severe disabilities (Little et al., 2014; McManus et al., 2008). However, no studies were identified that included household task participation for transition-aged youth with intellectual or severe disabilities. Due to the small amount of literature focused on identifying factors of household task participation for youth with intellectual or severe disabilities, the literature in this section was expanded to include factors associated with the participation in household tasks by youth with physical disabilities with average to above average intelligence, high functioning autism, and youth without disabilities. Although transition-aged youth with intellectual or severe disabilities are likely to have differences that are not represented by this literature, it is also likely that some of these factors may influence parent expectations for household tasks regardless of disability status. Moreover, literature focused on household tasks for youth without disabilities can provide information about factors influencing household tasks for youth at a general level to see differences not associated with disability status.

Research has determined both youth characteristics and family characteristics that influence youth household task participation. A primary youth characteristic that seems to have the strongest evidence associated with youth participation in household tasks is a youth's

disability, type, and severity. This section will describe the youth and family characteristics that researchers have investigated to determine the relation between the characteristics and youth household tasks.

**Youth characteristics.** Researchers investigated the following characteristics of youth to determine their association with involvement in household tasks: (a) disability, type, and severity (Amaral et al., 2014; Blum et al., 1991; Dunn et al., 2009; Dunn & Gardner, 2013; Egilson et al., 2017; Little et al., 2014; McManus et al., 2008; Reynolds et al., 2011), (b) child gender (Cheal, 2003; Dunn et al., 2009; Gager et al., 2009; Little et al., 2014; Reynolds et al., 2011), (c) child age (Amaral et al., 2014; Dunn et al., 2009; Dunn & Gardner 2013; Gager et al., 2009; Klein et al., 2009; Little et al., 2014), and (d) child's activity participation (Gager et al., 2009). Youth factors and their associations with involvement in household tasks are described in this section.

***Disability, type, and severity.*** The presence of a disability was found to be impactful in terms of the participation of youth in household tasks; youth with disabilities were found to participate in fewer or less household tasks than youth without disabilities (Amaral et al., 2014; Blum et al., 1991; Egilson et al., 2017; Little et al., 2014; Reynolds et al., 2011). One study addressed how disability type is associated with youth engagement in household tasks and found that children with cerebral palsy had greater engagement in household tasks than children of the same-age with Down syndrome (Amaral et al., 2014). In addition to having a disability, the severity of a disability was also found to be a factor in household task participation for youth. Youth with more severe disabilities had lower levels of household task participation than youth with less severe disabilities (Little et al., 2014; McManus et al., 2008). In contrast, two studies found that youth with ADHD and youth with physical disabilities did not differ significantly from their peers without disabilities in terms of the number of household tasks they performed,

but in both studies youth with disabilities did require significantly greater assistance to perform household tasks than their typically developing peers (Dunn et al., 2009; Dunn & Gardner, 2013).

***Child gender.*** Female gender was strongly associated with children's participation in household tasks in four studies (Cheal, 2003; Gager et al., 2009; Little et al., 2014). Gager et al. (2009) noted that while girls spend more time participating in household tasks than their male peers, the difference between groups is smaller than found in previous studies. To that end, two studies found no significant differences between male or female gender and children's participation in household tasks (Dunn et al., 2009; Reynolds et al., 2011).

***Child age.*** Studies have determined that younger children typically engage in fewer household tasks than older children (Amaral et al., 2014; Dunn et al., 2009; Dunn & Gardner, 2013; Gager et al., 2009; Klein et al., 2009; Little et al., 2014). Additionally, child age was found to be associated with the types of tasks children engaged in; younger children engaged more often in self-care types of tasks (e.g., making one's bed, cleaning one's room), whereas older children had higher involvement in family-care types of tasks (e.g., doing the dishes, cleaning common areas) (Amaral et al., 2014; Dunn et al., 2009). Furthermore, studies found that younger children required significantly more assistance to perform household tasks than older children (Amaral et al., 2014; Dunn & Gardner, 2013).

***Child's activity participation.*** Gager et al. (2009) was the only study that examined the relation between children's activity participation (i.e. paid employment, extracurricular activities) and children's involvement in household tasks. While they anticipated that increased youth activity involvement in either extra-curricular or paid employment would be associated with decreased involvement in household tasks, they found the opposite. Youth with paid

employment and/or involvement in extracurricular activities had increased levels of household task involvement compared to their same-age peers who were not involved in extracurricular activities or did not have paid jobs. Notably, Gager and colleagues study only included youth without disabilities.

**Family characteristics.** The family characteristics researchers examined to determine associations with household responsibility engagement by youth included: (a) family size (Cheal, 2003; Dunn et al., 2009; Gager et al., 2009), (b) parent education levels (Dunn et al., 2009; Gager et al., 2009; Little et al., 2014), (c) parent work status (Cheal, 2003; Dunn et al., 2009; Gager et al., 2009), (d) parent stress level (Dunn et al., 2009; Gager et al., 2009), (e) parent-child interactions (Blair, 1992; Cheal, 2003), (f) the value of family routines (Dunn et al., 2009), (g) family structure (Dunn et al., 2009; Gager et al., 2009), and (h) family income (Blair, 1992). This section describes these family factors and associations with youth involvement in household tasks.

**Family size.** The number of children in a home was found to be significantly associated with youth participation in household tasks in two studies that focused on children without disabilities (Cheal, 2003; Gager et al., 2009). Both studies, which focused on children without disabilities, found that having more children in the family was associated with increased participation in household tasks for youth. In contrast, Dunn et al. (2009) whose study included comparing children with and without ADHD, found that number of children in the home did not have a significant effect on the involvement of youth in household tasks.

**Parent education levels.** In two studies, the level of education achieved by parents did not have a significant impact on the participation level of their children in household tasks (Dunn et al., 2009; Little et al., 2014). In a third study, Gager et al. (2009) found that youth whose



parents attended college had decreased participation in household tasks when compared to youth whose parents had lower levels of education.

***Parent work status.*** Only one study (Gager et al., 2009) found a small but significant effect for fathers' work status; increased time fathers spent working was associated with increased participation by youth in household tasks. Two studies diverged from these findings and found no relation between parent work status and children's participation in household tasks (Cheal, 2003; Dunn et al., 2009).

***Parent stress level.*** Higher levels of parental stress were associated with children spending increased time in household tasks (Dunn et al., 2009; Gager et al., 2009) and with children requiring increased levels of assistance when engaging in household tasks (Dunn et al., 2009).

***Parent-child interactions.*** The two studies that investigated associations between parent-child interactions and youth participation in household tasks found conflicting results. Blair (1992) found high levels of supportive parent-child interactions were associated with lower levels of child participation in household tasks and low levels of supportive parent-child interactions were associated with increased child participation in household tasks. In contrast, Cheal (2003) found that positive parent-child interactions were associated with an increase in household task participation for youth.

***Value of family routines.*** The value parents place on family routines (i.e., daily activities including household tasks) was investigated by one study (Dunn et al., 2009) and was found to have a significant positive association on youth participation in household tasks. Families who placed high importance on having established daily routines tended to have children who

engaged more frequently in household tasks than children whose parents placed less importance on family routines.

***Family structure.*** Family structure, which refers to the composition of the family (e.g., biological mother and father, single parent, adoptive parents) was not significantly associated with youth household task participation (Dunn et al., 2009; Gager et al., 2009).

***Family income.*** Only one study examined the association between family income and youth participation in household tasks and found that it was not a significant association (Blair, 1992).

### **Research Methods Used to Determine Parent Expectations and Factors**

To investigate parent expectations and factors associated with youth participation in household tasks, researchers have predominantly used quantitative measures including cross-sectional surveys (Amaral et al. 2014; Blair, 1992; Blum et al., 1991; Cheal, 2003; Dunn et al., 2009; Dunn & Gardner, 2013; Egilson et al., 2017; Gager et al., 2009; Little et al., 2014; McManus et al., 2008; Reynolds et al., 2011). The majority of these survey studies used purposive sampling techniques to recruit specific participants from a specific location (Amaral et al., 2014; Blum et al., 1991; Dunn et al., 2009; Dunn & Gardner, 2013; Little et al., 2014; McManus et al., 2008; Reynolds et al., 2011). Parents were typically recruited through the following methods: (a) contacting various disability- and family-focused organizations within or across specific states or countries (Amaral et al., 2014; Dunn et al., 2009; Dunn & Gardner, 2013; Little et al., 2014; Reynolds et al., 2011), (b) identifying potential student participants through school districts and local camps (Blum et al., 1991), or (c) a combination of recruiting participants through parent organizations and school districts (McManus et al., 2008). Three

studies (Blair, 1992; Cheal, 2003; Gager et al., 2009) used data collected from nationally representative samples; Cheal's study is nationally representative of Canada.

Almost all of the studies in this review included parents as the participants; one study was conducted with youth with physical disabilities between the ages of 12-22 as the participants (Blum et al., 1991). Four studies in the review were conducted outside of the United States including Brazil (Amaral et al., 2014), Canada, (Cheal, 2003), Iceland, (Egilson et al., 2017), and Ireland (McManus et al., 2008). Given the limited studies that have researched household tasks for youth, and the similar nature of household tasks in other countries, these studies were included in the review. In addition to the quantitative cross-sectional studies in this review, two studies used qualitative methods. One study included a mixture of video ethnography, scan sampling, and interviews (Klein et al., 2009) and the other used focus groups (Luther, 2001). Both qualitative studies used purposeful sampling techniques to recruit participants.

To determine parent expectations for household tasks, five of the six studies used existing survey measures. Three of the six studies that investigated parent expectations used the *Children Helping Out: Responsibilities, Expectations, and Supports* (CHORES) measure (Amaral et al., 2014; Dunn et al., 2009; Dunn & Gardner, 2013), which is a 34-item parent-report survey with Likert-scale responses. As part of this measure, parents were asked to determine the extent their children were expected to participate in various household tasks, as well as rate the importance they placed on their child's participation for each household responsibility. Two other studies used existing measures including the *Participation and Environment Measure for Children and Youth* (PEMC-CY: Egilson et al., 2017) and the *Child Behavior Checklist* (CBCL: Reynolds et al., 2011). These measures asked parents to report about various chores and household tasks in which they expected their children to participate (Egilson et al., 2017; Reynolds et al., 2011).

The final study that examined parent expectations used mixed methods including parent focus groups and a survey created by the authors (Luther, 2001). Through focus group interviews, parents were asked to discuss household tasks their children engaged in and what parents perceived was the impact of having children engage in household tasks.

Factors for youth participation in household tasks were determined primarily through cross-sectional survey studies; 11 of the 12 studies that identified factors were survey studies (Amaral et al., 2014; Blair, 1992, Blum et al., 1991; Cheal, 2003; Dunn et al, 2009; Dunn & Gardner, 2013; Egilson et al., 2017; Gager et al., 2009; Little et al., 2014; McManus et al., 2008; Reynolds et al., 2011). To determine factors, the survey studies used a variety of existing measures and demographic questions. Statistical analyses to determine relations between factors and youth participation in household tasks included: (a) correlation analysis (Amaral et al., 2014; Cheal, 2003; Dunn et al., 2009), (b) regression analyses (Blair, 1992; Cheal, 2003; Gager et al., 2009; Little et al., 2014; McManus et al., 2008), (c) descriptive statistics (Blum et al., 1991), (d) independent *t* tests (Dunn & Gardner, 2013), (e) chi-square tests (Egilson et al., 2017; McManus et al., 2008), and (f) a multivariate analysis of covariance (MANCOVA; Reynolds et al., 2011). Only one study (Klein et al., 2009) used qualitative methods involving ethnography and scan sampling along with interviews of parents and youth to make determinations about factors associated with youth participation in household tasks.

### **Gaps in the Literature**

The current literature on household tasks is limited in that there are no studies that have directly investigated the involvement of or parent expectations for transition-aged youth with severe disabilities in household tasks. More broadly, there are no studies about transition-aged youth with intellectual disability and household tasks. Much of the existing research in this area

has investigated the household tasks of youth between the ages of 5 and 14. Additionally, research on household tasks has primarily focused on youth without disabilities or on youth with physical disabilities who have average to above average intelligence or youth with high-functioning autism. While the findings of these studies can inform hypotheses about parent expectations and factors for participation in household tasks for young adults with severe disabilities, it is important to include parents of transition-aged individuals with intellectual disabilities in this research as it is likely there may be additional factors that influence young adults' participation in various household tasks. Because youth with intellectual disabilities require greater assistance with activities of daily living (Bouck, 2010), it may be that they also require assistance to participate in household tasks. Additionally, it is important to determine if parent expectations for their children's involvement in household tasks is associated with the level of intellectual disability. Notably, individuals with intellectual disabilities comprised 6.8% of the student population (United States Department of Education, 2019). In comparison, individuals with severe disabilities are typically defined as individuals who take alternate state assessments reflecting only 1% of the student population (Every Student Succeeds Act, 2015). Thus, for this exploratory study, it is helpful to draw from the larger sample of youth with intellectual disability. In this way, the relation between the severity of the disability and household task participation can be explored in a bigger sample (Little et al., 2014 McManus et al. 2008).

### **Statement of the Problem**

Even after 30-plus years of transition-related research and initiatives and a focus of federal legislation on improving employment outcomes for individuals with severe disabilities, the employment rate for individuals with severe disabilities in integrated settings is still

abysmally low (Bureau of Labor Statistics, 2018). Fortunately, existing research has been able to identify predictors of employment that can help teachers, parents, and adult service providers determine opportunities and skills that are likely to assist students with disabilities in obtaining integrated employment outcomes (Mazzotti et al., 2016; Test et al., 2009). However, only one predictor study (Carter et al., 2012) has specifically focused on identifying predictors of employment for young adults with severe disabilities. Carter and colleagues determined that parent expectations for employment and student involvement in household tasks for individuals with severe disabilities were both found to be significant predictors of postschool employment.

Research has investigated parent expectations for employment outcomes, household tasks, and factors associated with parent expectations. Current research indicates that while parents often desire community-based integrated employment outcomes for their young adult children with severe disabilities, they tend to have lower expectations that community-based integrated employment is a realistic outcome (Blustein et al., 2016; Ivey, 2004; Kramer & Blacher, 2001; McNair & Rusch, 1990). Research focused on household tasks has determined that parents of children with disabilities tend to have lower expectations for their child's participation in household tasks than parents of children without disabilities (Amaral et al., 2014; Dunn et al., 2009; Dunn & Gardner, 2013; Egilson et al., 2017; Luther, 2001; Reynolds et al., 2011). Various factors have been found to be associated with parent expectations for employment and child involvement in household tasks. However, studies have not investigated the relation between the involvement of youth with severe disabilities in household tasks and parent expectations for employment outcomes. Wehman et al. (2015) reminds us that "parental expectations are modifiable" (p. 332), and that schools should take an active role in helping parents "become aware of the impact their expectations could have on their child's goals and

decisions and to provide supports to encourage parents to hold higher expectations” (p. 332). A potential means to increasing parent expectations for employment outcomes includes educating parents about developmentally appropriate employment-related activities that they can involve their children in activities such as household tasks (Blustein et al., 2016; Wehman et al., 2015). By determining if there is a relation between parent expectations for household tasks and parent expectations for employment outcomes for individuals with intellectual disabilities we will have a better understanding in the field about the connection between household tasks and parent expectations for employment.

## CHAPTER 3

### Method

The purpose of this study was twofold. It sought to determine the extent parents reported their transition-aged children with intellectual disability were engaging in various household tasks and the level of support their children needed to engage in household tasks. Additionally, this study sought to examine the relation between youth involvement in household tasks and parent expectations for postschool employment.

### Research Questions

This study sought to answer the following research questions

1. To what extent do parents report that their transition-aged children with intellectual disability participate in household tasks and with what level of support?
2. What are parent expectations for postschool employment for their transition-aged children with intellectual disability?
3. What is the relation between youth involvement in household tasks and parent expectations for postschool employment for transition-aged youth with intellectual disability?
4. What youth and family characteristics correlate with youth participation in household tasks?

### Hypotheses

**Research question 1.** Based on prior research, I hypothesized that parents would report that their transition-aged children with intellectual disability would have minimal participation in household tasks and require high levels of support to participate in household tasks (Amaral et



al., 2014; Blum et al., 1991; Dunn et al., 2009; Dunn & Gardner, 2013; Egilson et al., 2017; Little et al., 2014; Luther, 2001; McManus et al., 2008; Reynolds et al., 2011).

**Research question 2.** I hypothesized that a majority of parents of transition-aged youth with intellectual disability would expect segregated work outcomes or non-work outcomes for postschool employment (Blacher et al., 2010; Blustein et al., 2016; Doren et al., 2012; Ivey, 2004; Kramer & Blacher, 2001; McNair & Rusch, 1990).

**Research question 3.** I hypothesized that parents who reported their children had greater household tasks would also have higher expectations for postschool employment, and parents who reported less household tasks would have lower expectations for postschool employment. This hypothesis aligns with findings from one prior study (Carter et al., 2012).

**Research question 4.** I hypothesized that the following youth characteristics would positively correlate with youth involvement in household tasks, youth with less significant disabilities (Amaral et al., 2014; Blum et al., 1991; Egilson et al., 2017; Little et al., 2014; McManus et al., 2008; Reynolds et al., 2011); youth with female gender (Cheal, 2003; Gager et al., 2009; Little et al., 2014); older youth (Amaral et al., 2014; Dunn et al., 2009; Dunn & Gardner, 2013; Gager et al., 2009; Klein et al., 2009; Little et al., 2014); and youth with greater activity participation (i.e., paid employment, school and community-based extracurricular activities; Gager et al., 2009). Additionally, I hypothesized that the following family characteristics would positively correlate with youth involvement in household tasks, greater family size (Cheal, 2003; Gager et al., 2009) and families with parents who spent more time working (Gager et al., 2009).

## **Research Design**

A cross-sectional survey design was used for this study. Specifically, a web-based questionnaire was used to collect responses from participants. The questionnaire was designed with REDCap, an accessible online software program which hosted the questionnaire. REDCap meets the physical safeguard component of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Paper copies of the questionnaire were available upon request.

## **Participants**

The targeted participants for this study consisted of legal parents of transition-aged youth (between the ages of 14 to 22) with intellectual disability who lived in their parents' or step parents' home. If interested individuals did not have a child between the ages of 14 and 22, they were excluded from the study because they were not engaged in transition planning. Interested individuals who had a child between the ages of 14 and 22 who lived outside the parents' or step parents' home were excluded as they would not be able to report on the child's household tasks. Transition-aged youth were targeted because these youth are typically working on independent living skills which may include household tasks and preparing for the transition to employment.

## **Power Analysis**

An a priori power analysis was completed using G\*Power to calculate the needed sample size to ensure a statistically significant result would occur if the alternate hypothesis was true (Howell, 2010). The power analysis relied on traditional assumptions (i.e., alpha = .05, power = .80) and included 10 potential independent variables in the linear regression. To achieve a small effect size of 0.15, the minimum sample size needed was 118 participants.

## **Recruitment**

Participants were recruited through 67 Parent Training and Information Centers (PTIs), The Arc of the United States, and 41 state chapters of The Arc. Recruitment was a multi-step process. Initially, participants were recruited through the PTIs across the continental U.S.; every state has at least one PTI, with some states having multiple PTIs. The PTIs were chosen for recruitment because they are located in every state and provide free information and training to parents of youth with disabilities between birth and 26, and provide access to a diverse sample of parents across the country. To increase the sample size, The Arc of the United States and state chapters of The Arc were also used for recruitment. The Arc is a national organization which promotes the rights of individuals with intellectual and developmental disabilities and their families. Like the PTIs, The Arc provides access to a diverse sample of parents across the country.

### **Instrument Development**

The Transition and Household Tasks Survey (i.e., the name of this questionnaire) was designed specifically for this study using primarily existing measures (see Appendix H for the questionnaire). To establish content validity, expert reviews were conducted with five university professors with expertise in individuals with severe disabilities, families, and employment. These experts provided feedback about the content of the instrument in addition to providing feedback about wording, clarity of questions and responses, and question order to improve the overall quality of the survey instrument.

After incorporating the experts' suggestions into the questionnaire, cognitive interviews were then conducted with two parents of transition-aged youth with intellectual disability to determine the clarity of the questionnaire questions and potential responses. During the cognitive interviews, respondents were asked to review the questionnaire question by question with the

researcher and talk aloud to describe their thoughts as they were answering the questions (Groves et al., 2009; Presser et al., 2004). They were asked if any questions seemed unclear or if any potential responses were missing. Respondents were also asked about the format of the questionnaire to ensure it was easily followed. After the cognitive interviews were completed, the questionnaire was revised to incorporate specific feedback to increase clarity and understanding. Specifically, wording was added in the descriptions of the Household Tasks section and the Vocational Expectations sections to make clear what types of questions were to be asked in each of those sections.

The online questionnaire was tested numerous times by the first author and two graduate students to determine whether the questionnaire worked as planned. The graduate students completed the questionnaire using various response options to ensure that all branching logic and carry forward response options worked correctly. The graduate students provided specific feedback about the format of the questionnaire and clarity of the questions. One change was made based on feedback from graduate students to the formatting of the Vocational Index question to include the definition of sheltered vocational setting in a note within the question. As a final test, two parents of transition-aged youth with intellectual disability piloted the online questionnaire and provided feedback to ensure that the questions were clear and all possible response options were included. No additional concerns were raised. After piloting, the questionnaire was posted online through REDCap. Once the Dissertation Committee approved the survey study, the questionnaire link was activated online. The online questionnaire was open for four months. Participants could also request a hard copy of the questionnaire to complete and return by mail. Contact information for hard copy requests was located on the participant recruitment form (see Appendix A, B, & C).

The survey instrument included 95-items including 13 parent demographic questions, and eight youth demographic questions. Additionally, the questionnaire included “yes” or “no” questions about youth participation in 34 household tasks, as well as a 7-point likert-type scale to determine the level of support youth need to participate in each task. Four questions were asked about parent expectations for post-school employment. Specifically, two questions included a 4-point likert-type scale to determine parent expectations of paid employment and expectations of their youth ever having a paid job. One question asked parents to choose a realistic employment outcome for their youth from a choice of ten possible outcomes, and one question asked parents to indicate the type of job they expected their youth would have after exiting school. Finally, two open-ended questions were included to allow participants to provide additional information about their children’s household task participation.

**Survey items for research question 1.** The Children Helping Out: Responsibilities, Expectations, and Supports (CHORES: Dunn, 2004) measure was used to determine the extent that parents reported their transition-aged youth with disabilities participated in household tasks and the assistance they required to perform household tasks. The 34-item CHORES measure includes a performance scale in which parents are asked to give a yes-no response regarding if their child performs household tasks. The CHORES measure also includes an assistance scale that is formatted as a 7-point Likert scale wherein parents report the level of assistance their child needs to perform the task (*0 = child is not expected to perform task, 1 = child cannot perform task, 2 = child performs task with a lot of help, 3 = child performs task with some help, 4 = child performs task with supervision, 5 = child performs task given verbal cue, and 6 = child performs task on own initiative more than 50% of the time*). The CHORES measure was adapted slightly for this study. Adaptations included changing the wording of the first household task listed from

“cleans up after own *play*” to “cleans up after own *activities*” due to the older age of the youth participants in this study. Additionally, branching logic was used for each item in the CHORES measure for the online format. For each household task in the CHORES measure, if participants selected “yes” their child performed the task, they were presented with five assistance options from the Likert scale (2-6 above). If participants selected “no” their child did not perform the task, they were presented with two assistance options from the Likert scale (0-1 above). An example of how the branching logic was presented in the online-version of the questionnaire is included in Appendix I.

The CHORES measure has two subscales including self-care household tasks and family care household tasks. Self-care tasks include tasks the child does primarily for him/herself (e.g., makes self a hot meal, picks up own bedroom); family care tasks include tasks that affect other members of the family (e.g., cleans bathroom, feeds pet). For this study, the whole scale (i.e., the sum of the subscales) was used because all types of household tasks were relevant to the research questions. Notably, the whole scale has been used in previous studies (Amaral et al., 2014; Dunn et al., 2009). The Cronbach’s alpha for the whole CHORES scale was .96, indicating high reliability (Dunn, 2004). The CHORES measure, while initially developed for parents of children with and without disabilities ages 6-11 with average to above average intelligence (Dunn, 2004), has expanded in recent studies to include children between the ages of 6-14 and included children with cerebral palsy and Down syndrome who had average intelligence quotient composite scores in the “lower extreme” range (i.e. scores of 69 or less) on the Kaufman brief intelligence test (Amaral et al., 2014), and children with attention deficit hyperactivity disorder (Dunn, et al., 2009).

**Survey items for research question 2.** To address research question two, the Vocational Index (Taylor & Seltzer, 2012) was adapted to include ten employment outcome categories, coded on a scale of 1-9, with one being the least independent outcome and nine being the most independent. In its original form, the Vocational Index includes education and employment outcomes. For the purpose of this study, the scale was adapted to include only employment outcomes. The employment outcomes included were

- (9) Community employment *without* supports greater than 10 hours a week (no time spent in sheltered settings)
- (8) Community employment *without* supports for 10 hours a week or less (no time spent in sheltered settings)
- (7) Community employment *with* supports greater than 10 hours a week (no time spent in sheltered settings)
- (6) Community employment *with* supports for 10 hours a week or less week (no time spent in sheltered settings)
- (5) Sheltered vocational setting (e.g., sheltered workshop or adult day center) and employment in the community greater than 10 hours a week
- (4) Sheltered vocational setting and volunteering in the community greater than 10 hours a week
- (4) Sheltered vocational setting greater than 10 hours a week (with no community employment/volunteering)
- (3) Sheltered vocational setting for 10 hours a week or less
- (2) Volunteering with no other vocational activities
- (1) No vocational activities

The scale was developed and tested using a longitudinal sample of adolescents and adults with autism spectrum disorder that spanned 12 years and six data collection periods.

**Survey items for research question 3.** No additional items were needed to address research question 3 as the data from research question one and research question two were used to answer research question three.

**Survey items for research question 4–Dependent variable.** The dependent variable was the responses to the whole scale CHORES measure.

**Survey items for research question 4–Independent variables.** The independent variables included demographic questions and established measures related to youth and family characteristics. These variables were chosen based on the literature review in Chapter 2.

***Youth characteristics.*** The measures addressing youth characteristics included: (a) the overall level of the youth’s intellectual disability, (b) activity participation of youth, (c) the youth’s age, and (d) the youth’s gender.

***Overall level of youth’s intellectual disability.*** A question was created that asked participants to describe the overall level of the youth’s intellectual disability based on the levels of support in the Supports Intensity Scale (Thompson et al., 2004). Specifically for this study, participants were provided levels of intellectual disability that included the type of supports their children required: (a) mild (intermittent supports [support is rarely needed]), (b) moderate (limited supports [support is sometimes needed]), (c) severe (extensive supports [support is often needed]), and (d) profound (pervasive supports [support is always needed]).

***Activity participation of youth.*** Participants were asked if their child was involved in any school-based and community-based activities in the last year. Additionally, participants were asked if their child ever had paid employment outside of the home.



*Youth's age.* Participants were asked to provide their child's current age.

*Youth's gender.* Participants provided the gender of their youth.

***Family characteristics.*** Measures related to family characteristics included: (a) the number of children and adults living in the household, and (b) the number of hours that parents spent working each week.

*The number of individuals living in the household.* A question was created to determine how many individuals were currently living in the household based on similar questions in prior studies (e.g., Cheal, 2003; Gager et al. 2009), which were discussed in Chapter Two.

*The number of hours that parents spent working each week.* Participants were asked to provide the number of hours they spent working each week, and the number of hours their spouse or partner worked each week. These questions were also based on a prior study (i.e., Gager et al., 2009).

**Open-ended questions.** Because of the limited extant research focused on household tasks for transition-aged individuals with intellectual disability, two open-ended questions were created for this study. Specifically, a multi-part question was created to gather additional data for research question four. The first question asked participants to describe why their child either did or did not participate in household tasks, and the second question asked about the challenges of involving their child in household tasks.

## **Procedures**

Recruitment emails were sent to a general email address for each of the 67 PTIs, The Arc of the U.S., and state chapters of The Arc (see Appendix A). Each organization was asked to distribute a recruitment flyer (see Appendix B) to parents on their listservs, social media accounts, website postings, face-to-face events or any other way in which they contact families.

The flyer included language asking parents to forward the flyer to other parents who may be interested in participating but were not affiliated with PTIs or The Arc to reach potential participants outside of PTI and Arc members. Contact information for the researcher was listed on the e-mails and flyers, and interested parents contacted the researcher to indicate their interest in participating in the study and their preferred format for participating (i.e., online or paper questionnaire). If no response was received, a reminder email was sent to each PTI or Arc chapter one week after the initial email was sent. If no response was received after the first reminder, a second reminder email was sent to PTIs and The Arc chapters a week after the second reminder was sent (see Appendix C). All participants were eligible to participate in a drawing for one of 25 \$20 Amazon gift cards upon completing the questionnaire as an incentive to participate.

Potential participants were emailed to provide either a unique URL link to participate online (see Appendix D) or to let them know a paper version had been mailed to the address they provided (see Appendix E). An identity key was created in REDCap using indirect identifiers to keep track of who had and had not completed the questionnaire. If potential participants who requested to participate in the study did not complete the questionnaire within one week of receiving the email with the unique URL code, they were sent an email reminder with the URL code again. If they had not completed the questionnaire within two weeks after the first reminder email, they were emailed a second reminder to participate in the study (see Appendix F). If participants who were mailed a paper questionnaire had not returned it within two weeks after it was sent, they were emailed a reminder email asking them to complete and mail in the questionnaire. If they had not returned the questionnaire within 2 weeks after the first reminder

email, they were sent a second reminder email asking them to please complete and return the questionnaire at their earliest convenience (see Appendix G).

Participants who clicked on the URL were presented with a consent letter (see Appendix I). This letter explained that participation in the study was voluntary and anonymous. It also explained that participants could withdraw their consent to participate at any time by not completing the questionnaire and that they were free to skip any question that they did not wish to answer for any reason. By clicking the “Agree” button, participants agreed that they read the information in the consent form and met the criteria to participate in the study. If they disagreed or chose not to participate, they were given the option of clicking a “Disagree” button, which thanked them for their time. After participants clicked the “Agree” button to provide consent, they were taken to the first page of the questionnaire. Participants were able to print a copy of the consent form for their records. For participants who requested paper copies of the questionnaire, the same consent form was attached to the front of the questionnaire, but participants were told that returning a completed questionnaire served as their consent to participate. Any participants who chose to complete the questionnaire by mail, were also provided a self-addressed stamped envelope to return the questionnaire to the researcher’s university address.

### **Preliminary Data Analysis**

Online data from REDCap were downloaded to SPSS version 26 for analysis. One participant turned in a paper questionnaire for which the data were inputted into SPSS by the first author and verified for accuracy by a trained graduate assistant. All data were stored on University of Illinois’ Box. Preliminary analyses were conducted relative to inter-item relations, missing data, and distribution of responses.

**Analyses of inter-item relations for established measures.** The internal consistency of the established measure used in the questionnaire (i.e., CHORES) was tested using Cronbach's alpha to determine if the scaled measure should be examined separately or as a singular construct. The Cronbach's alpha for the CHORES scale was .91, indicating it had high levels of internal consistency; accordingly, the CHORES scale was examined as a singular construct.

**Analyses of missing data and methods for imputation.** First, the data were examined for missing values in scaled constructs (i.e., CHORES) to determine if the values constituted a pattern. Of the 4,012 total scaled response from the 34-item CHORES scale, there were only eight missing responses (0.19%). These responses were determined to be missing at random after conducting a visual analysis of the responses. Mean values were imputed for missing data following Harrell's (2001) guidelines.

**Analyses of distributions and strategies for handling non-normal distributions.** Both the CHORES scale and the Vocational Index were normally distributed so parametric statistics were conducted.

### **Primary Data Analyses**

The analysis for each research question is listed below. See Table 1 for the data analysis plan including the independent and dependent variables and hypotheses for each question.

**Analysis of research question 1.** Descriptive statistics (e.g., frequencies, means, ranges, standard deviations) were conducted to address research question one. In addition, for the CHORES, mean performance and assistance scores were used to determine the extent that parents reported their transition-aged youth with intellectual disability participated in household tasks. Performance scores were calculated by summing the "yes" and "no" responses for the total CHORES measure. Assistance scores were determined by calculating the Percent of Maximum

Possible (POMP) score as outlined by Dunn and colleagues (2009). The POMP score includes only the expected tasks (i.e., tasks with a rating of 1-6 on the assistance scale) for each youth, which allows a comparison of assistance scores because not all youth were expected to do the same number of household tasks. POMP scores were conducted by first counting the number of expected tasks (i.e., any tasks that did not receive a score of zero). Then, that number was multiplied by the maximum score of 6, which is the maximum possible score youth could earn for each task. The number of expected tasks was then divided by the maximum possible score to calculate the POMP score.

**Analysis of research question 2.** Descriptive statistics (e.g., frequencies, means, ranges, standard deviations) were also conducted to address research question two.

**Analysis of research question 3.** A Pearson correlation was conducted to determine the inter-relations between the independent (i.e., household task participation) and continuous dependent variable (i.e., vocational index). Additionally, ordinal regressions were conducted to determine the relations between the independent variable and ordinal dependent variables (i.e., parent expectations their child will ever have a paid job, parent expectations their child will ever be self-supporting). Prior to conducting the ordinal regressions, the test of parallel lines was conducted to assure the assumption of proportional odds was met. The assumption of proportional odds was met for both regressions, as assessed by a full likelihood ratio test comparing the fit of the proportional odds model to a model with varying location parameters,  $\chi^2(2) = 1.16, p = .560$  (for the dependent variable about parent expectations for their child to have a paid job), and  $\chi^2(2) = .36, p = .835$  (for the dependent variable about parent expectations their child to be self-supporting). Accordingly, the ordinal regressions were conducted.

**Analysis of research question 4.** Univariate statistics (i.e., correlations, ANOVAs, and *t*-tests) were conducted to determine the relations between the independent variables and the dependent variable. Only independent variables that had *p*-values less than 0.25 based on the univariate statistics were included in the final model, as the traditional *p* value of .05 can fail to identify important variables (Cohen et al., 2003). Additionally, a correlation matrix with all of the independent variables was conducted to determine inter-relations between variables. Also, a variable inflation factor (VIF) was conducted. There was no multicollinearity among the independent variables (i.e.,  $r^2$ 's < .6, VIF < 2.5). Therefore, a multiple linear regression was performed which included all of the independent variables with *p* values < 0.25. The final regression model included five variables (i.e., overall level of youth's intellectual disability; activity participation of youth including school activity, community activity, and paid employment; and youth's age). Neither youth's gender nor any family characteristics (i.e., number of children and adults living in the household, number of hours parents spent working each week, race, income level) were included in the final model because the *p* values from the univariate statistics were not less than 0.25. Per the dissertation committee, I also conducted univariate analyses with demographic variables (i.e., income level, race) and household task participation; none of the *p*-values were less than 0.25, so to attain the most parsimonious model, those variables were not included in the regression.

**Analysis of open-ended items for research question 4.** Content analysis (Patton, 2015) was used to analyze each open-ended response. To begin, the first researcher read the responses for the open-ended question repeatedly to become familiar with the data (Tesch, 1990). Next, data were read word by word to develop initial codes (Miles & Huberman, 1994) by highlighting exact words in the responses that appeared to capture key concepts (Hsieh & Shannon, 2005).

This process was done multiple times and the first researcher took notes throughout the process to record thoughts and impressions which went into the development of preliminary codes and definitions. A trained graduate student reviewed the data along with the preliminary codes and definitions to determine if the codes accurately reflected the data. Then, the researchers met multiple times to discuss and refine the codes and definitions until they came to a consensus and created a final codebook for the data for the first open-ended question. The first researcher and the graduate student then used the codebook to independently code the data for the first open-ended question. They met to compare how they individually coded the data and discussed each of the codes until they came to agreement about the coding of each piece of data. The same procedures were used to analyze and code the data from the second open-ended question.

After the data were coded, the codes for each open-ended question were then grouped into larger categories and subcategories by reviewing the codes to determine how the individual codes were related and linked. The first researcher created the initial categories and subcategories and then met with the graduate student multiple times to review the data and discuss the categories created. Discussions about the categories continued until consensus was reached. Then, the researchers organized the categories by frequency and developed definitions for each category and subcategory. These procedures were repeated for the second question.

Prior to reporting the findings for the content analysis for both open-ended responses, the researchers identified exemplars for each code and category from the data. To ensure trustworthiness and credibility of the data and analysis (Brantlinger et al., 2005), a Co-Dissertation Committee Chair reviewed the codes and definitions and challenged the researcher about the meaning of the data as a check to potential researcher biases or misinterpretations.

## CHAPTER 4

### Results

This chapter describes the participants and the results of the analyses for each of the four research questions.

#### Participants

In total, 151 people from across the country requested a link to the survey. In addition, one person requested a paper version of the survey. Of the 152 people who expressed interest in the study, 127 individuals provided online consent and one individual provided consent by completing and mailing the paper version of the survey. Of the 128 participants who provided consent, 118 individuals from 28 states (i.e., AL, CA, CO, CT, FL, GA, ID, IL, IN, KY, MA, ME, MN, MS, NC, NE, NJ, NY, OH, PA, SD, TN, TX, UT, VA, VT, WA, and WI) completed all of the survey questions relative to the research questions; those 118 individuals were included in the data analysis.

The majority of participants was mothers (91.5%,  $n = 108$ ). Further, most participants were married (84.7%,  $n = 100$ ), highly educated (i.e., 44.1% [ $n = 52$ ] were college graduates and 30.5% [ $n = 36$ ] had attended graduate school), and hailed from the Midwest (33.9%,  $n = 40$ ). On average, the transition-aged youth were 18.5 years old ( $SD = 2.2$ , range 14 to 22). The majority of youth was male (64.4%,  $n = 76$ ), and most parents reported that their youth had a moderate intellectual disability (54.2%,  $n = 64$ ). See Table 2 for more descriptive information about the parent participants. See Table 3 for more descriptive information about the transition-aged youth with disabilities.



## **The Extent of Youth Participation in Household Tasks and the Level of Assistance Needed**

On average, participants reported that their children engaged in 16.44 ( $SD = 7.5$ , range 0-33.33) of the 34 household tasks in the CHORES measure. Youth were most likely to participate in self-care tasks: puts own laundry in hamper (90.7%,  $n = 107$ ), cleans up after own activities (89.8%,  $n = 106$ ), and makes self a snack (84.7%,  $n = 100$ ). Youth were least likely to participate in family-care tasks: puts laundry away for family (13.6%,  $n = 16$ ), cares for other family members (11.0%,  $n = 13$ ), and cares for younger siblings (5.9%,  $n = 7$ ). Because it seemed that parents reported their children engaged in more self-care (versus family-care) tasks, paired t-tests were conducted to determine if there was a significant difference in the frequency of such tasks. However, there was no significant difference between the frequency of self-care and family-care tasks, ( $t(118) = 1.307, p = .194$ ). See Table 4.

The average assistance score for youth was 60.9 ( $SD = 23.0$ , range = 11.76-100.0) on a scale of 1-100, with greater scores indicating less assistance was needed. Participants reported the level of assistance required to perform each household task on a likert scale from 1 to 5 with 1 indicating the most amount of assistance (i.e., “with a lot of assistance”), and 5 indicating the least amount of assistance needed (i.e., on own initiative >50% of time). Youth required the least amount of assistance with self-care tasks including organizes own belongings for school ( $M = 4.4, SD = 1.1$ ), puts own laundry in hamper ( $M = 4.4, SD = 1.0$ ), and makes self a snack ( $M = 4.4, SD = 1.1$ ). Youth required the most assistance with family-care tasks including cleans bathroom ( $M = 3.1, SD = 1.4$ ), runs errands ( $M = 3.0, SD = 1.7$ ), and prepares a hot meal for family ( $M = 2.8, SD = 1.7$ ). The self-care tasks were often one-step tasks (e.g., puts own laundry in hamper) or tasks youth likely engaged in daily or frequently (e.g., organizes own belongings for school), whereas family-care tasks often involved multiple steps (e.g., preparing a hot meal,

cleans bathroom) or were tasks youth likely did less frequently. This could explain the differences noted between youth participation in self-care tasks and family-care tasks. See Table 5.

For tasks which youth did not participate in, participants provided one of two reasons: “I do not expect this of my child,” or “Child cannot perform task.” In general, participants reported that their children were less likely to be expected to participate in or could not perform family-care tasks compared to self-care tasks. The tasks that had the highest percentage of participants who reported that they did not expect their youth to do the task included cares for plants (62.7%,  $n = 74$ ), puts laundry away for family (61.9%,  $n = 73$ ), and cares for younger siblings (55.1%,  $n = 65$ ). The following tasks had the highest percentage of participants who reported that their child cannot perform the task prepares a hot meal for family (44.9%,  $n = 53$ ), runs errands (44.9%,  $n = 53$ ), and cares for other family members (37.3%,  $n = 44$ ). See Table 6.

### **Parent Expectations for Employment**

Participants were asked “Which of the following describes your expectations that your child will ever have a paying job?” with the response options “definitely will not,” “probably will not,” “probably will,” and “definitely will.” The majority of participants reported that they expected that their child “probably will” or “definitely will” hold a paying job (73.7%,  $n = 87$ ). The remainder of the participants reported that their child “probably will not” or “definitely will not” hold a paying job (26.3%,  $n = 31$ ).

Participants were also asked “Which of the following describes your expectations that your child will ever be self-supporting?” with the response options “definitely will not,” “probably will not,” “probably will,” and “definitely will.” Most participants reported that their youth “probably will not” or “definitely will not” be self-supporting (80.5%,  $n = 95$ ). While a

smaller percentage of participants reported that their youth “probably will” or “definitely will” be self-supporting (19.5%,  $n = 23$ ).

When asked about their expectations for future employment for their children, the majority of participants (65.3%,  $n = 77$ ) identified some form of community employment. Specifically, the most prevalent expected employment outcome was community employment with supports for greater than 10 hours a week ( $n = 40$ , 33.9%). The least prevalent employment outcomes included sheltered vocational setting greater than 10 hours a week with no community employment or volunteering ( $n = 3$ , 2.5%), and volunteering with no other vocational activities ( $n = 3$ , 2.5%). Eight participants (6.8%) reported that they expected their child would have no vocational activities in the future. See Table 7.

Participants were asked to identify what type of job they expected for their child. “Food service” was the most prevalent job type ( $n = 23$ , 19.5%) while “cashier” was the least prevalent job type ( $n = 2$ , 1.7%). There were 48 participants (40.7%) who reported “other” with respect to job type; these participants wrote open-ended responses to this question. Some of the “other” jobs included working with animals ( $n = 5$ , 4.2%) and working in a grocery store ( $n = 4$ , 3.39%). Many of the “other” responses were “I don’t know” ( $n = 10$ , 8.47%). See Table 8.

### **Relation Between Youth Task Participation and Parent Expectations for Employment**

A Pearson’s correlation was conducted to assess the relation between youth involvement in household tasks (using the CHORES measure) and parent expectations for employment (using the Vocational Index measure). There was a significant, moderate positive correlation between youth involvement in household tasks and parent expectations for employment,  $r(116) = .44$ ,  $p < .001$ .

Additionally, two ordinal regressions were conducted to assess the relation between youth involvement in household tasks (i.e., the CHORES measure) and (a) parent expectations that their child would ever have a paying job, and (b) parent expectations that their child would ever be self-supporting. With respect to having a paying job, the ordinal regression was significant, ( $\chi^2(1) = 36.81, p < .001$ ), indicating that an increase in participation in household tasks was associated with a 17% increase in the odds that parents would expect that their child would ever have a paid job. Regarding parent expectations that their child would ever be self-supporting, the ordinal regression was also significant, ( $\chi^2(1) = 17.23, p < .001$ ), indicating that an increase in participation in household tasks was associated with an 11% increase in the odds that parents would expect that their child would ever be self-supporting.

### **Correlates of Youth Household Task Participation**

Univariate analyses revealed significant relations between three youth factors and participation in household tasks (i.e., the CHORES measure). Household task participation was significantly different for youth with different levels of intellectual disability ( $F(3, 113) = 6.82, p < .001, ES = .13$ ). Specifically, when compared with youth with mild disabilities, youth with profound disabilities had significantly lower participation in household tasks ( $p = .020$ ). Moreover, youth with profound disabilities also had significantly lower participation in household tasks ( $p < .001$ ) when compared to youth with moderate disabilities.

Additionally, greater participation in household tasks was positively associated with youth who participated in community-based activities in the past year ( $t(116) = -2.08, p = .040, ES = .45$ ). There was also a positive association between participation in household tasks and having had a paid employment experience outside the home ( $t(116) = -4.61, p < .001, ES = .88$ ). Two additional independent variables had  $p$ -values below .25: youth participation in school-

based activities ( $t(116) = -1.28, p < .204, ES = .24$ , and youth age ( $r(117) = .17, p = .076$ ); both variables were positively associated with greater participation in household tasks indicating that youth who participated in school-based activities and older youth had greater participation in household tasks. See Table 9.

A multiple linear regression was conducted to determine the extent that youth characteristics (i.e., overall level of youth's intellectual disability; youth activity participation including school participation, community participation, and paid employment experience; youth age) explained the variance in participation in household tasks. The overall model was significant ( $F(7, 109) = 5.68, p < .001$ ) with an  $R^2$  of .27. Three independent variables in the model were significantly correlated with youth household task participation. Specifically, youth with profound disabilities were significantly less likely to participate in household tasks ( $p < .05$ ). Youth who participated in community-based extracurricular activities in the past year had a significant positive correlation with household task participation ( $p < .05$ ). Moreover, youth who had ever had paid employment outside of the home had a significant positive correlation with household task participation ( $p < .01$ ). See Table 10.

The results of the content analysis of the open-ended questions revealed additional insights into parent perceptions of youth and family characteristics which were associated with youth participation in household tasks. Responses from the first question (i.e., "What are the reasons you do (or do not) have your child participate in household tasks?") were divided into two overarching categories: (a) "reasons youth were included", and (b) "reasons youth were not included." A total of 117 of the 118 participants answered the question. Notably, 52 participants provided reasons why they had their child participate in household tasks and 88 participants provided reasons why they did not have their child participate in household tasks. The sum of

these numbers is greater than 118 because 23 participants included reasons why their child does and does not participate in household tasks.

Two categories emerged from the content analysis for reasons participants had their child participate in household tasks: (a) benefits to youth ( $n = 66, 82.5\%$ ), and (b) capitalizing on youth skills ( $n = 14, 17.5\%$ ). Regarding benefits to the youth, participants reported that their youth participated in household tasks because such participation provided an opportunity for the youth to be a contributing member of the family, fostered independence in the youth, and prepared the youth for independent living. With respect to capitalizing on youth skills, participants reported that youth participated in household tasks because youth displayed a willingness to help, youth skills aligned with tasks assigned, and youth engaged in tasks independently. See Table 11 for more information about categories, codes, and exemplars for why youth participated in household tasks.

The analysis of the reasons participants did not have their child participate in household tasks revealed three categories: (a) parent perceptions of youth barriers ( $n = 77, 50.3\%$ ), (b) parent concerns ( $n = 53, 34.6\%$ ), and (c) task barriers ( $n = 23, 15.0\%$ ). Parents perceived youth barriers as youth resisting tasks, having physical limitations, posing safety concerns, and working carelessly. Parent concerns included codes such as difficulties involving youth in tasks, holding low expectations for youth participation, and lacking time to involve youth. Task barriers consisted of tasks not being expected of youth. See Table 12 for more information about categories, codes, and exemplars for why youth did not participate in household tasks.

Participants were also asked to describe the challenges of involving youth in household tasks. A total of 117 of the 118 participants answered the question. The content analysis revealed two categories: (a) parent perceptions of youth challenges ( $n = 185, 78.7\%$ ) and (b) parent

perceptions of their own challenges ( $n = 50, 21.3\%$ ). With respect to parent perceptions of youth challenges, participants reported their child resisted doing tasks, required supervision to participate, and performed tasks carelessly. Parent perceptions of their own challenges included lack of time, and difficulties involving youth in tasks. See Table 13 for more information about categories, codes, and exemplars for challenges of involving youth in household tasks.

## **CHAPTER 5**

### **Discussion**

The purpose of this study was to determine the extent parents reported their transition-aged children with intellectual disability engaged in household tasks and the level of support their children needed to engage in household tasks. Correlates of youth household task participation were also investigated. Additionally, this study sought to examine parent expectations for employment and the relation between youth involvement in household tasks and parent expectations for postschool employment. This chapter discusses the key findings related to (a) frequency and correlates of household task participation, (b) parent expectations for employment, and (c) the relation between household task participation and parent expectations for employment as well as limitations of the study and implications for future research and practice.

#### **Frequency and Correlates of Household Task Participation**

In comparison to other studies that have investigated household task participation, parents reported that transition-aged youth with intellectual disability in the current study had low overall participation in household tasks, participating on average in 48.2% of the tasks in the CHORES measure. Other studies that have used the CHORES measure have found that parents reported younger children (ages 9-11) with attention deficit/hyperactivity disorder (ADHD) participated in an average of 67.4% of tasks compared to 69.4% participation for youth who were typically developing (Dunn et al., 2009). Additionally, Dunn and Gardner (2013) found that children with physical disabilities between the ages of 6 and 14 participated in an average of 64.1% of tasks compared to youth without disabilities who engaged in 73.5% of tasks per parent report. This finding suggests that transition-aged youth with intellectual disability may have low



levels of household task participation in comparison to younger children with ADHD and physical disabilities. A possible explanation for the difference between task participation levels is that prior studies recruited youth with disabilities who had average to above average intelligence, while this study specifically recruited youth with intellectual disability. A previous study of young adults with disabilities found that the presence of intellectual disability was strongly associated with limited participation in activities including household tasks (Braun et al., 2009). It is possible that youth with intellectual disability require additional support and supervision to participate in household tasks than youth with average to above average intelligence. Indeed, in the current study, participants reported on average, youth typically required a moderate amount of support to complete household tasks. Participants also reported in the open-ended responses that one reason they did not involve their children in household tasks was because their children often required supervision. Therefore, it is possible that youth with intellectual disability have low levels of participation in household tasks because of needed additional support.

The current study also identified several correlates of youth participation in household tasks. The final regression model which included youth's level of disability; youth participation in school-based activities, community-based activities, and previous paid employment; and youth age was significant and explained 27% of the variance. Of the variables that were included in the final model, three variables were significant (a) youth's level of disability, (b) youth participation in community-based activities, and (c) previous paid employment. Youth participation in school-based activities and youth age were not significant in the final model.

First, youth with profound intellectual disability were significantly less likely to participate in household tasks than youth with mild or moderate intellectual disability. While

prior research has not investigated the extent that transition-aged youth with profound intellectual disability participated in household tasks compared to youth with mild and moderate intellectual disability, it has compared household task participation of younger children with disabilities to their same age peers without disabilities. Prior research suggests that youth with disabilities participate in household tasks to a lesser extent than their peers without disabilities (Amaral et al., 2014; Blum et al., 1991; Egilson et al., 2017; Little et al., 2014; McManus et al., 2008; Reynolds et al., 2011). For example, Reynolds et al. (2012) found that children between the ages of 6 and 12 with autism spectrum disorder participated in significantly fewer household tasks than same-age youth without disabilities. The current study adds to the literature by suggesting that disability level may be impactful for youth household task participation as youth enter adolescence and adulthood.

Second, youth who participated in community-based activities in the past year were found to have significantly higher levels of participation in household tasks. This finding aligns with one previous study (Gager et al., 2009) which focused on youth without disabilities between the ages of 10 and 18. While youth participation in community-based activities was significantly associated with increased household task participation, youth participation in school-based activities was not significant. Perhaps, this is because participation in community-based activities often involves parents initiating or coordinating activities for their youth due to transportation needs (Trainor et al., 2008). Unlike community-based activities, school-based activities may be initiated or coordinated by the youth or school personnel during school hours without parental involvement. Parents who initiated and coordinated their children's community activities may be more likely to involve their children in activities at home as well, including household tasks.

Finally, increased participation in household tasks was also associated with youth who had paid employment experience outside of the home. Prior research has also found that youth with paid employment are more likely to participate in household tasks (Gager et al., 2009). However, the study by Gager and colleagues did not include youth with disabilities. Thus, this finding adds to the extant literature by suggesting that paid employment is also associated with increased household participation for youth with intellectual disability. There may be many reasons why there was a positive relation between paid employment and household task participation. For example, youth who were involved in paid work experiences may have had parents with higher expectations for employment (Carter et al., 2012, Doren et al., 2012), which may have also increased parent expectations for participation in tasks at home. Additionally, it is likely that some basic work skills (e.g., ability to stay with a task until it is finished, ability to seek help when needed; Ju et al., 2012) are similar to skills used when participating in household tasks and therefore youth may be more likely to engage in tasks that require similar skills at home.

While 27% of the variance in youth household task participation was explained by the final model, the analysis of the open-ended responses can offer some additional insight regarding the unexplained variance. For example, participants described barriers and concerns (e.g., difficulties with youth resisting doing tasks and the amount of time it took for parents to teach and/or assist the youth with the task) which led them to not involve their youth in household tasks. While few studies have investigated barriers to household task participation for youth with disabilities, one study (Law et al., 2007) had a similar finding in that parents reported youth did not participate in household tasks because of the difficulty of involving their child in tasks. Further, youth with intellectual disability often benefit from task analysis instruction wherein

tasks are broken down into smaller steps and provided prompting strategies (e.g., least to most prompts; Domarki & Lyon, 1992). It may be difficult for parents to involve their children in tasks when parents may not have experience breaking down tasks into smaller steps and teaching their children step-by-step with appropriate supports (Blum et al., 1991). Training from practitioners or respite providers may help teach parents strategies for breaking down tasks and help them determine how to provide appropriate prompting strategies to involve their children in household tasks.

### **Parent Expectations for Employment**

The majority of parents expected that their child would have some type of paid community employment, but they did not expect that their child would ever be self-supporting. The finding that parents expect paid community employment differs with some prior research which has found that parents of youth with intellectual disability and other severe disabilities expect sheltered or segregated employment outcomes (Blacher et al., 2010; Ivey, 2004; Kraemer & Blacher, 2001; McNair & Rusch, 1990). However, two more recent studies (Blustein et al., 2016; Doren et al., 2012) have also found that parents of youth with intellectual disability expected paid community employment outcomes.

The difference in parent expectations for employment may be due to whether parents are conveying their realistic expectations for employment or desired expectations. Regarding the former, Kraemer and Blacher (2001) asked parents to choose their ideal work outcome and the outcome they believed to be realistic for their youth with ID. They found that while the majority of parents (i.e., 71%) ideally wanted their youth to work either independently or with individual support in the community, only 26.9% reported that those were realistic outcomes. Instead, they found that the majority of parents (i.e., 59.6%) realistically believed that their youth would have

sheltered workshops or day activity centers as outcomes. In the current study, parents were asked to identify realistic employment outcomes. If parents had been asked about their desired employment outcomes, their responses may have been different. However, it is also possible that with the advances in integrated employment (e.g., supported employment services, customized employment) which assist individuals with severe disabilities in obtaining employment (Howlin, 2013, Wehman et al., 2016), parents are more optimistic about their youths' future employment outcomes.

It may also be important to consider how type of school program influences parent expectations for employment. School programs that adopt a philosophy wherein youth should engage in community employment experiences during school may positively influence parents' expectations for employment. For example, Bluestein and colleagues (2016) found that high parent expectations were associated with teachers who held high expectations for competitive employment. Unfortunately, teachers may have low expectations for youth with intellectual disability. Indeed, Grigal et al. (2011) found that youth with intellectual disability were more likely than youth with other types of disabilities to have transition goals for sheltered employment and less likely to have goals for competitive employment. Thus, it could be that teacher expectations and, more broadly, program philosophy, could impact parent expectations and, accordingly, employment outcomes.

While it is discouraging that the majority of participants did not expect their youth will ever be self-supporting, it is unsurprising given that people with disabilities tend to work fewer hours and earn less than individuals without disabilities (Kruse et al., 2018). Additionally, a prior study (Carter et al., 2012) had similar findings. Specifically, Carter and colleagues found that 81.4% of parents did not expect that their youth would ever be self-supporting. This finding is

important given that parental expectations of their children ever being self-supporting has been associated with positive post-school employment (Carter et al., 2012). Fortunately, prior research also suggests that parent expectations are malleable (Doren et al., 2012). Specifically, parent expectations can change as a result of teacher expectations (Mistery et al., 2009) and parents' own employment outcomes (Bozick et al., 2010). Thus, it is possible to raise parent expectations which, in turn, may facilitate more positive post-school employment outcomes.

### **Relation Between Youth Task Participation and Parent Expectations for Employment**

Youth task participation and parent expectations for employment were found to have a significant, moderate positive correlation indicating that youth with higher levels of task participation had parents with higher expectations for employment outcomes. Consistent with one prior study (Carter et al., 2012), this finding is important because higher parent expectations are associated with positive post-school employment outcomes. However, due to the cross-sectional nature of this study, the direction of this finding is unclear. Indeed, involving youth in more household tasks could increase parent expectations for employment. Conversely, it is also possible that parents with high expectations are more likely to have their youth participate in household tasks.

Additionally, an increase in household task participation was also associated with an increase in the odds that parents would expect their child would ever have a paying job, and that parents would ever expect their child to be self-supporting. Involving youth in household tasks could potentially increase parent expectations for both paid employment outcomes and for their child to be self-supporting. Although prior research has not investigated the relation between household task participation and parent expectations for employment, research has suggested that household task participation is a predictor of post-school employment (Carter et al., 2012). It

is possible that parent expectations may mediate the relation between household task participation and post-school employment.

### **Limitations**

There were several limitations to the current study which should be considered when evaluating its implications. First, participants were not randomly selected for this study. Participants were recruited from national organizations which provided parent assistance for transition-aged youth with intellectual disability. The majority of the sample was comprised of White, highly educated mothers of youth with high socioeconomic status. As such, the generalizability of the study's findings is reduced as the findings may not represent fathers, individuals with less formal education, racial minorities, and individuals with lower socioeconomic backgrounds. The limited generalizability is especially important because individuals with intellectual disability and their families are more likely to live in poverty (Emerson, 2006).

Second, the platform for this study was a web-based survey and recruitment efforts were completed primarily online. Thus, participation from individuals who did not have access to computers or the Internet was likely limited (Wright, 2005). According to the Pew Research Center, individuals with lower income are less likely to have reliable access to the Internet, which indicates that individuals with lower income may be less likely to participate in web-based studies (Anderson & Kumar, 2019). Thus, the generalizability of the findings may be reduced as individuals with lower socioeconomic status may not be proportionately represented in this study.

Third, because national organizations did not report the number of individuals to whom they distributed the recruitment information, the response rate could not be determined for this

study. Therefore, the differences between responders and non-responders is not known. The lack of a response rate indicates a possibility of non-response bias which could mean the results misrepresent the population (Schouten et al., 2009).

Finally, this study did not ask parents to report on how often their child participates in household tasks. Consequently, it is possible that parents could have interpreted the question “Does your child participate in this task?” differently. Some parents may have responded “yes” if their child has ever participated in the task whereas other participants may have responded “yes” only if their child participates in the task frequently.

### **Directions for Future Research**

It is important that future researchers reach a broader and more diverse sample of parents (e.g., families of color) as non-white students (e.g., Black, Hispanic/Latino) make up a majority (i.e. 53.3%) of students ages six to 21 in special education (U.S. Department of Education, 2019). A potential way to increase diverse family participation in research includes having recruitment information and survey instruments written in English with non-technical terms. Also, recruitment information and survey instruments should be available in multiple languages (e.g., Spanish) to accommodate participants whose primary language is not English. According to the National Center for Education Statistics (2020), 10.1% of public school students are English learners with 14.3% receiving special education services. It is also important to identify community and cultural organizations who can disseminate study-related information to diverse families (Haack et al., 2014). While it is difficult to predict how the results of this study may have differed given a more diverse population, previous research suggests that parents’ expectations for employment outcomes are influenced by their cultural backgrounds (Rueda et al., 2005; Kim et al., 2007). For example, Rueda and colleagues found that Latina mothers of



youth with intellectual and developmental disabilities did not identify future employment as a pertinent issue. Instead, the mothers wanted their children's education to focus on increasing independence in skills that would be helpful around the home including self-care skills (Rueda et al., 2005).

Additionally, future research should investigate the number of items (i.e., household tasks) to adequately measure household task participation as a construct. In one of the few studies which addressed household task participation for transition aged-youth with intellectual disability, Carter and colleagues (2012) used only four tasks (i.e., fixes his or her own breakfast, does laundry, cleans his or her own room, and picks up a few things from the store). In comparison, the current study described youth involvement in 34 household tasks. For example, one task from Carter and colleagues' study (i.e., laundry) was broken down into five tasks in the current study (i.e., puts own laundry in hamper, puts away own clean laundry, sorts laundry for family, puts laundry away for family, and runs washer/dryer). Given the limited extant research surrounding household task participation for transition-aged youth with intellectual disability, it is important that future research investigate whether the shorter construct used by Carter and colleagues and the longer CHORES construct used in this study equally measure household task participation.

In the future, longitudinal research should be conducted to determine the direction of the relation between youth task participation and parent expectations for employment. In the current study, a relation was found between youth participation in household tasks and parent expectations for employment. Based on prior research on parent expectations in which a nationally representative longitudinal data set was used (Doren et al., 2012), parents expectations were positively associated with youth's level of autonomy. Doren and colleagues' finding

suggests that parents with high expectations may provide increased opportunities for their youth to engage in activities, such as household tasks, to promote autonomy and independence. In addition, parents with lower expectations may hold a more limited view of their child's abilities and thus limit opportunities in activities that may promote increased autonomy and independence (Doren et al., 2012). Although Doren's study provides some insight into the directionality of the relation between youth task participation and parent expectations for employment, it is important that future longitudinal research investigate autonomy and youth household task participation.

The linear regression conducted in this study only explained 27% of the variance, and while the open-ended responses may shed some light on other potential independent variables, it is possible that there are potential variables associated with household task participation. One such variable may be family attitude toward household tasks, which was not measured in the current study. Because household tasks may look different in every household, it could be that some families do not expect any child—with or without disabilities—to perform household tasks. In one study, Dunn et al. (2009) found that parents who placed higher value on family routines had youth with increased household task participation. By including questions about family attitude towards household tasks and expectations for all children in the family (if the youth with intellectual disability has siblings), the expectations for youth with intellectual disability could be described within the context of expectations for other family members.

### **Implications for Practice**

The current study found that youth who have previous paid employment are more likely to participate in household tasks. Prior research has revealed that previous paid employment, along with teaching skills including independent living skills, are also predictive of positive employment outcomes (Test et al., 2009; Carter et al., 2012). To increase youth participation in

household tasks and engage youth in skills that are predictive of post-school employment, practitioners should engage students in independent living skills at school, when appropriate, and seek paid employment opportunities for youth while they are attending school. Parents and practitioners should work together in these endeavors to ensure that students' strengths, needs, and preferences are taken into consideration when planning for employment opportunities. Practitioners can also seek input from parents about the types of household tasks youth typically engage in at home or tasks in which parents want to involve their youth to determine if there are similar tasks that youth can engage in at school as part of their natural school routines (e.g., picks up areas shared by others, organizes school belongings).

Additionally, parents reported low overall levels of their youths' participation in household tasks. This was especially true for youth with profound intellectual disability. Curricula for transition-aged youth with intellectual disability, specifically youth with severe and profound intellectual disability, often includes functional components which involve teaching independent living skills (Dymond et al., 2018). Independent living skills learned at school will have some crossover with some household tasks. All special educators should be knowledgeable in providing a variety of strategies and supports to advance student learning (Council for Exceptional Children (CEC) Initial Teacher Standards, 2012). As such, special educators can work with parents as they develop individualized strategies and supports for students to learn how to incorporate these same strategies and supports at home in order to increase household task participation.

Furthermore, increased youth household task participation in the current study was associated with higher parent expectations for employment outcomes. Parents holding high expectations for employment has been identified as a significant predictor of employment (Carter

et al., 2012), and research has found that teacher expectations can positively influence parent expectations (Mistry et al., 2009). Thus, it is important that teachers work with parents to foster the development of high expectations for future employment, which in turn may also increase youth participation in household tasks. Teachers can create opportunities for youth through the information they provide to students and families about community employment opportunities as well as inviting representatives from community agencies such as vocational rehabilitation to meetings. However, teachers can also limit future possibilities for students by providing information to students and families that is not promoting successful outcomes such as information about working in sheltered workshops or not inviting community representatives to be part of the transition planning team. In order to assist students to achieve successful employment outcomes and to promote high expectations in parents about employment, teachers need to understand the importance of developing their own high expectations for all of their students and communicating those high expectations to parents and students.

Moreover, given the association between youth involvement in household tasks and parent expectations for employment, teachers and parents may need to discuss the importance of involving children with intellectual disability in household tasks at a young age. Typically, youth without disabilities are engaging in household tasks by age nine (Dunn et al., 2009). Youth with disabilities can often participate with support in many household tasks by age nine as well. Therefore, it is important that special education teachers start having conversations about the benefits of youth involvement in household tasks when youth are in elementary school. By involving children at a younger age in household tasks, youth can develop increased skills related to household tasks, and parents can potentially develop increased expectations for employment earlier on in their child's life.

## **Conclusion**

Individuals with intellectual disability have continually struggled to obtain and maintain paid employment opportunities. Prior research indicates that a potential way to increase postschool employment opportunities for youth with intellectual disability is through participation in household tasks (Carter et al., 2012; Wehman et al., 2015). Additionally, prior research has found that having parents who hold high expectations for employment also increased youth opportunities for postschool employment (Carter et al., 2012). Findings from this study indicate that increased youth household task participation was associated with increased parent expectations for employment. Additionally, youth participation in community-based activities and previous paid employment experiences were associated with increased household task participation. By identifying factors associated with increased household task participation, we can better understand ways to potentially increase youth engagement in household tasks and parent expectations for employment, which ultimately may increase postschool employment opportunities for youth with intellectual disabilities.

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## Tables

Table 1

*Data Analysis Plan*

Research Question	Independent Variable	Dependent Variable	Analyses
1) To what extent do parents report that their transition-aged youth with intellectual disability participate in household tasks and with what level of support?		The extent youth participate in household tasks; level of support required (see Likert scale for questions # 22-55)	Descriptive statistics
2) What are parent expectations for postschool employment for their transition-aged children with intellectual disability?		Expectations for postschool employment outcome (see #'s 56-59 in questionnaire)	Descriptive statistics
3) What is the relation between youth involvement in household tasks and parent expectations for postschool employment for transition-aged youth with intellectual disability?	Whole-scale CHORES measure (see #'s 22-55 in questionnaire)	Parent expectations for employment (See #'s 56-59 in questionnaire)	Correlation, Ordinal regression
4) What youth and family characteristics correlate with student involvement in household tasks?	Youth disability level, youth age, youth community-based activity participation, youth paid employment	Whole-scale CHORES measure (see #'s 22-55)  Open-ended questions (see #'s 56 & 57)	Univariate statistics, correlation matrix, linear regression  Content analysis

Table 2

*Participant Demographics (N = 118)*

Characteristic	<i>n</i>	%
Respondent's role		
Mother	108	91.5
Father	5	4.2
Other	4	3.4
Missing	1	0.8
Respondent's age		
36-40	2	1.7
41-45	9	7.6
46-50	32	37.1
51-55	31	26.3
56-60	28	23.7
61-65	14	11.9
66+	1	0.8
Missing	1	0.8
Respondent's location		
Midwest	40	33.9
West	27	22.9
Northeast	27	22.9
South	24	20.3
Marital status		
Married	100	84.7
Separated/divorced	12	10.2
Not married, but living with partner	2	1.7
Never married	2	1.7
Widowed	2	1.7
Educational background		
Some high school	1	0.8
High school graduate	4	3.4
Some college	25	21.2
College graduate	52	44.1
Graduate school	36	30.5
Annual household income level		
Less than \$15,000	2	1.7
\$15-29,999	5	4.2
\$30-49,999	14	11.9
\$50-69,999	15	12.7

Table 2 (continued).

Characteristic	<i>n</i>	%
\$70-99,999	30	25.4
Over \$100,000	48	40.7
Missing	4	3.4
Ethnicity		
White	95	80.5
Hispanic or Latino	6	5.1
Black or African American	6	5.1
Asian or Asian Indian	2	1.7
American Indian or Alaskan Native	1	0.8
Native Hawaiian or Other Pacific Islander	1	0.8
Other	6	5.1
Respondent's hours worked per week for paid job		
No work	26	22.0
Less than 5 hours	6	5.1
5-10 hours	4	3.4
11-20 hours	10	8.5
21-37 hours	23	19.5
37.5+ hours	49	41.5
Partner's hours worked per week for paid job		
No work	22	18.6
Less than 5 hours	1	0.8
11-20 hours	3	2.5
21-37 hours	7	5.9
37.5+ hours	84	71.2
Missing	1	0.8
Number of children who live in household		
1	52	44.1
2	40	33.9
3	18	15.3
4+	6	5.1
Missing	2	1.7
With whom the child lives		
Both his or her parents	89	74.6
Mother only	13	11.5
Mother and stepfather/stepmother	9	7.4
Other arrangement	4	4.1
Father and stepmother/stepfather	2	1.6
Father only	1	0.8

Table 3

*Youth Demographics*

Characteristic	<i>n</i>	%
Youth gender		
Male	76	64.4
Female	41	34.7
Transgender woman	1	0.8
Additional disabilities (other than ID)		
Autism	63	53.4
Multiple disabilities	26	22.0
Down syndrome	25	21.2
Health condition	21	17.8
Hearing impairment	8	6.8
Cerebral palsy	6	5.1
Blind/vision impairment	6	5.1
Other	31	26.3
Youth's overall level of ID		
Mild (intermittent supports [support is rarely needed])	9	7.6
Moderate (limited supports [support is sometimes needed])	64	54.2
Severe (extensive supports [support is often needed])	30	25.4
Profound (pervasive supports [support is always needed])	14	11.9
Missing	1	0.8
Youth's primary method of communication		
Verbal	99	83.9
Gestures	6	5.1
Communication device	4	3.4
Sign language	3	2.5
Other	6	5.1
Has child participated in any school-based extracurricular activities in the past year		
Yes	61	51.7
No	57	48.3
Has child participated in any community-based extracurricular activities in the past year		
Yes	89	75.4
No	29	24.6
Has child ever had paid employment outside of the home?		
Yes	43	36.4
No	75	63.6

Table 4

*Household Tasks in which Youth Participated*

Household Task	<i>n</i>	%
Puts own laundry in hamper	107	90.7
Cleans up after own activities	106	89.8
Makes self a snack	100	84.7
Picks up own bedroom	88	74.6
Brings in or puts away groceries	88	74.6
Sets or clears the table	83	70.3
Gets the mail or the newspaper	83	70.3
Makes self a cold meal	80	67.8
Puts away own clean laundry	80	67.8
Puts clean clothes away	78	66.1
Dries dishes (unloads dishwasher)	76	64.4
Takes out garbage/ recycling	75	63.6
Makes own bed	74	62.7
Organizes own belongings for school	73	61.9
Picks up area shared by others	72	61.0
Washes dishes (loads dishwasher)	67	56.8
Organizes after-school belongings	65	55.1
Runs washer/dryer	59	50.0
Sweeps or vacuums own room	57	48.3
Sweeps or vacuums home	54	45.8
Feeds pet	54	45.8
Makes self a hot meal	53	44.9
Sorts laundry for family	35	29.7
Cleans bathroom	32	27.1
Takes a phone message	30	25.4
Dusts own room	29	24.6
Prepares a cold meal for family	22	18.6
Dusts the house	22	18.6
Runs errands	22	18.6
Prepares a hot meal for family	19	16.1
Cares for plants	17	14.4
Puts laundry away for family	16	13.6
Cares for other family members	13	11.0
Cares for younger siblings	7	5.9

Table 5

*Level of Support Youth Required to Participate in Household Task*

Household task	<i>N</i>	<i>M (SD)</i>	Level of Support									
			With a lot of assistance		With some assistance		With supervision or monitoring		When asked		On own initiative >50% of time	
			<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	%	<i>n</i>	%
Organizes own belongings for school	73	4.4 (1.1)	3	(4.1)	3	(4.1)	4	(5.5)	14	(19.2)	49	(67.1)
Puts own laundry in hamper	107	4.4 (1.0)	4	(3.7)	4	(3.7)	5	(4.7)	26	(24.3)	68	(63.6)
Makes self a snack	100	4.4 (1.1)	4	(4.0)	6	(6.0)	10	(10.0)	8	(8.0)	72	(72.0)
Organizes after-school belongings	64	4.4 (1.0)	2	(1.7)	2	(1.7)	6	(5.1)	14	(11.9)	40	(33.9)
Makes self a cold meal	80	4.3 (1.2)	5	(6.3)	4	(5.0)	6	(7.5)	12	(15.0)	53	(66.3)
Cares for other family members	12	4.3 (0.6)	0	(0)	0	(0)	1	(8.3)	7	(58.3)	4	(33.3)
Gets the mail or the newspaper	83	4.2 (0.9)	1	(1.2)	3	(3.6)	8	(9.6)	36	(43.4)	35	(42.2)
Puts away own clean laundry	79	4.1 (1.1)	3	(3.8)	4	(5.1)	9	(11.4)	26	(32.9)	37	(46.8)
Takes a phone message	30	4.1 (1.6)	0	(0)	5	(16.7)	3	(10.0)	6	(20.0)	16	(53.3)
Puts clean clothes away	77	4.1 (1.1)	4	(5.2)	4	(5.2)	9	(11.7)	26	(33.8)	34	(44.2)
Makes self a hot meal	52	3.9 (1.4)	4	(7.7)	7	(13.5)	7	(13.5)	4	(7.7)	30	(42.3)
Takes out garbage/ recycling	75	3.9 (1.1)	5	(6.7)	4	(5.3)	5	(6.7)	40	(53.3)	21	(28.0)
Puts laundry away for family	16	3.9 (1.0)	0	(0)	2	(12.5)	2	(12.5)	8	(50.0)	4	(25.0)
Cares for plants	17	3.9 (1.3)	2	(11.8)	0	(0)	2	(11.8)	7	(41.2)	6	(35.3)
Feeds pet	53	3.8 (1.2)	6	(11.3)	1	(1.9)	4	(7.5)	27	(50.9)	15	(28.3)
Makes own bed	74	3.8 (1.4)	9	(12.2)	8	(10.8)	3	(4.1)	22	(29.7)	32	(43.2)
Runs washer/dryer	59	3.8 (1.3)	5	(8.5)	6	(10.2)	8	(13.6)	16	(27.1)	24	(40.7)
Cares for younger siblings	5	3.8 (0.8)	0	(0)	0	(0)	2	(40.0)	2	(40.0)	1	(20.0)
Dries dishes (unloads dishwasher)	76	3.8 (1.2)	5	(6.6)	8	(10.5)	9	(11.8)	30	(39.5)	24	(31.6)
Dusts own room	29	3.7 (1.1)	2	(6.9)	3	(10.3)	2	(6.9)	17	(58.6)	5	(17.2)
Brings in or puts away groceries	88	3.6 (1.1)	7	(8.0)	9	(10.2)	7	(8.0)	52	(59.1)	13	(14.8)
Sorts laundry for family	35	3.6 (1.1)	2	(5.7)	4	(11.4)	7	(20.0)	15	(42.9)	7	(20.0)
Sets or clears the table	83	3.6 (1.0)	5	(6.0)	8	(9.6)	13	(15.7)	48	(57.8)	9	(10.8)
Washes dishes (loads dishwasher)	67	3.6 (1.3)	6	(9.0)	9	(13.4)	11	(16.4)	23	(34.3)	18	(26.9)

Table 5 (continued).

Household task	<i>N</i>	<i>M (SD)</i>	Level of Support									
			With a lot of assistance		With some assistance		With supervision or monitoring		When asked		On own initiative >50% of time	
			<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	%	<i>n</i>	%
Cleans up after own activities	105	3.5 (1.4)	16	(15.2)	11	(10.5)	14	(13.3)	32	(30.5)	32	(30.5)
Sweeps or vacuums own room	54	3.5 (1.2)	8	(14.8)	5	(9.3)	7	(13.0)	26	(48.1)	8	(14.4)
Dusts the house	22	3.5 (1.1)	2	(9.1)	1	(4.5)	7	(31.8)	9	(40.9)	3	(13.6)
Picks up own bedroom	88	3.4 (1.4)	12	(13.6)	17	(19.3)	8	(9.1)	24	(27.3)	27	(30.7)
Sweeps or vacuums home	54	3.4 (1.3)	8	(14.8)	5	(9.3)	7	(13.0)	26	(48.1)	8	(14.8)
Picks up area shared by others	72	3.4 (1.2)	9	(12.5)	8	(11.1)	12	(16.7)	33	(45.8)	10	(13.9)
Prepares a cold meal for family	22	3.2 (1.4)	5	(22.7)	1	(4.5)	4	(18.2)	9	(40.9)	3	(13.6)
Cleans bathroom	32	3.1 (1.4)	7	(21.9)	3	(9.4)	8	(25.0)	9	(28.1)	5	(15.6)
Runs errands	23	3.0 (1.7)	8	(34.8)	2	(8.7)	2	(8.7)	5	(21.7)	6	(26.1)
Prepares a hot meal for family	19	2.8 (1.7)	7	(36.8)	2	(10.5)	2	(10.5)	4	(21.1)	4	(21.1)

*Note.* This table represents only youth whose parents responded that they participated in these household tasks.



Table 6

*Reasons Why Youth did not Participate in Household Tasks*

Household task	N	Do not expect this of my child		Child cannot perform task	
		n	%	n	%
Cares for younger siblings	110	65	55.1	42	35.6
Cares for other family members	104	57	48.3	44	37.3
Puts laundry away for family	102	73	61.9	26	22.0
Cares for plants	101	74	62.7	25	21.2
Prepares a hot meal for family	99	45	38.1	53	44.9
Prepares a cold meal for family	96	63	53.4	31	26.3
Dusts the house	96	60	59.3	22	18.6
Runs errands	95	40	33.9	53	44.9
Dusts own room	88	63	53.4	21	17.8
Takes a phone message	88	21	17.8	28	23.7
Sorts laundry for family	83	59	50.0	21	17.8
Cleans bathroom	85	49	41.5	34	28.8
Makes self a hot meal	65	22	18.6	43	36.4
Sweeps or vacuums home	64	40	33.9	22	18.6
Feeds pet	63	42	35.6	18	15.3
Sweeps or vacuums own room	61	38	32.2	21	17.8
Runs washer/dryer	59	34	28.8	24	20.3
Organizes after-school belongings	53	25	21.2	26	22.0
Washes dishes (loads dishwasher)	51	31	26.3	19	16.1
Organizes own belongings for school	45	21	17.8	23	19.5
Makes own bed	44	24	20.3	18	15.3
Picks up area shared by others	44	25	21.2	16	13.6
Takes out garbage/ recycling	43	24	20.3	19	16.1
Dries dishes (unloads dishwasher)	42	25	21.2	15	12.7
Puts clean clothes away	40	20	16.9	18	15.3
Makes self a cold meal	38	15	12.7	22	18.6
Puts away own clean laundry	38	18	5.3	18	5.3
Sets or clears the table	35	23	19.5	10	8.5
Gets the mail or the newspaper	35	21	17.8	13	11.0
Picks up own bedroom	30	12	10.2	13	11.0
Brings in or puts away groceries	30	17	14.4	11	9.3
Makes self a snack	18	6	5.1	12	10.2
Cleans up after own activities	12	3	2.5	5	4.2
Puts own laundry in hamper	11	3	2.5	7	5.9

Table 7

*Vocational Index – Parent Expectations for Future Employment*

Vocational Outcomes	<i>n</i>	%
Community employment <i>without</i> supports greater than 10 hours a week (no time spent in sheltered settings)	23	19.5
Community employment <i>without</i> supports for 10 hours a week or less (no time spent in sheltered settings)	4	3.4
Community employment <i>with</i> supports greater than 10 hours a week (no time spent in sheltered settings)	40	33.9
Community employment <i>with</i> supports for 10 hours a week or less (no time spent in sheltered settings)	10	8.5
Sheltered vocational setting (e.g., sheltered workshop or adult day center) and employment in the community – total activities greater than 10 hours a week	12	10.2
Sheltered vocational setting and volunteering in the community greater than 10 hours a week	8	6.8
Sheltered vocational setting greater than 10 hours a week (with no community employment/volunteering)	3	2.5
Sheltered vocational setting for 10 hours a week or less	7	5.9
Volunteering with no other vocational activities	3	2.5
No vocational activities	8	6.8

Table 8

*Type of Job Parents Expect for Their Child*

Job Type	<i>n</i>	%
Food Service	23	19.5
Office/Clerical	11	9.3
Janitorial	10	8.5
Assembly and packaging	7	5.9
Landscaping	5	4.2
Inventory	5	4.2
Data Entry	4	3.4
Cashier	2	1.7
Other	48	40.7
Missing	3	2.5

Table 9

*Univariate Analyses of Characteristics of Household Task Participation*

Characteristics	Mean (SD)	F	t	r	ANOVA Follow-up	p	Effect size
Youth level of disability		6.82				< .001	.13
Mild	18.7 (6.7)				Mild < Profound	.020	
Moderate	18.5 (7.1)				Moderate < Profound	< .001	
Severe	14.8 (7.5)						
Profound	9.9 (5.7)						
Youth activity participation							
School-based activity			-1.28			.204	.24
Yes	17.3 (7.5)						
No	15.5 (7.5)						
Community-based activity			-2.08			.040	.45
Yes	17.2 (7.1)						
No	13.9 (8.23)						
Paid employment			-4.61			< .001	.88
Yes	20.3 (5.8)						
No	14.2 (7.5)						
Youth age				.17		.076	.03
Youth gender			-0.88			.382	.02
Male	16.0 (7.2)						
Female	17.3 (8.2)						
Number of hours participant worked per week			0.001			.999	-.02
None	16.4 (7.4)						
Part-time (less than 37 hours)	16.5 (7.9)						
Full time ( $\geq$ 37.5 hours)	16.4 (7.5)						
Number of hours spouse worked per week			.82			.443	.00
None	16.2 (8.6)						
Part-time (less than 37 hours)	19.3 (5.7)						

Table 9 (continued).

Characteristics	Mean (SD)	F	t	r	ANOVA Follow-up	p	Effect size
Full time ( $\geq 37.5$ hours)	16.2 (7.4)						
Number of children in the home				.02		.803	.00
Number of adults who live in the home				.01		.896	.00
Race		.39				.761	-.02
White	16.3 (6.7)						
African American	19.5 (11.4)						
Hispanic or Latino	17.2 (12.1)						
Other	15.9 (8.7)						
Income		.43				.827	-.03
Less than \$15,000	15.6 (2.3)						
\$15-29,999	14.2 (14.3)						
\$30-49,999	17.5 (8.1)						
\$50-69,999	14.1 (6.7)						
\$70-99,999	16.7 (7.3)						
Over \$100,000	16.5 (7.1)						

Table 10

*Multiple Regression Analysis for Youth Participation in Household Tasks*

CHORES Total Score	<i>B</i>	95% CI for <i>B</i>		<i>SE B</i>	$\beta$	<i>p</i>	$R^2$	$\Delta R^2$
		<i>LL</i>	<i>UL</i>					
Model							.27	.22
Constant	11.97	-1.21	25.14	6.65		.075		
Moderate disability	0.82	-3.76	5.40	2.31	.06	.722		
Severe disability	-1.67	-6.60	3.26	2.49	-.10	.504		
Profound disability	-5.94	-11.68	-0.20	2.90	-.25	.043*		
School activity	.78	-2.04	3.59	1.42	.05	.584		
Community activity	3.26	.20	6.32	1.55	.19	.037*		
Paid employment	4.59	1.56	7.62	1.53	.30	.003**		
Child age	0.03	-0.63	.69	.33	.01	.923		

*Note.* *B* = unstandardized regression coefficient; CI = confidence interval; *LL* = lower limit; *UL* = upper limit; *SE B* = standard error of the coefficient;  $\beta$  = standardized coefficient;  $R^2$  = coefficient of determination;  $\Delta R^2$  = adjusted  $R^2$ .

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

Table 11

*Categories, Codes, and Exemplars: Why Youth Participate in Household Tasks*

Category	Codes	<i>n</i>	%	Exemplar
Benefits to youth		66	(67.1)	
	Opportunity for youth to be a contributing member of the family	23	(23.7)	<i>“All other members of the household participate, he is expected to contribute, as he is able, and with the necessary supports”</i>
	Fosters independence	12	(12.3)	<i>“I want him to be as independent as possible, and it is easy to start with household tasks”</i>
	Prepares youth for independent living	11	(11.3)	<i>“He does participate in household chores so that he will know what to do when he lives independently”</i>
	Provides youth with sense of pride	10	(10.3)	<i>“He is proud that he does things without being asked”</i>
	Teaches youth responsibility	9	(9.3)	<i>“I have him participate in household tasks to have a sense of responsibility”</i>
Capitalizing on youth skills	Develops job skills	1	(1.0)	<i>“Taking care of household tasks also provides the basis for rudimentary job skills”</i>
		14	(14.4)	
	Youth displays a willingness to help	5	(5.2)	<i>“She feels useful and likes to help where she can”</i>
	Youth skills aligned with tasks assigned	5	(5.2)	<i>“We share the household chores based on his ability he does some jobs with support in place”</i>
	Youth engages in tasks independently	4	(4.1)	<i>“He actually engages in most household tasks without being asked”</i>

Table 12

*Categories, Codes, and Exemplars: Why Youth Do Not Participate in Tasks*

Category	Codes	<i>n</i>	%	Exemplar
Parent perception of youth barriers		77	50.3	
	Resisting tasks	21	13.7	<i>“There's a fight almost every time she's asked to do something”</i>
	Physical limitations	18	11.7	<i>“He has limited endurance due to heart defect and some tasks are too physical”</i>
	Safety concerns	13	8.5	<i>“She does not understand the dangers associated with many household chores”</i>
	Requires supervision	12	7.8	<i>“Any task would require constant prompting and supervision”</i>
	Performs tasks carelessly	10	6.5	<i>“She can be in a hurry &amp; doesn't always pay attention to the details”</i>
	Displays no interest	3	2.0	<i>“If my child takes the initiative to want to participate, I will allow it but, he has no real interest”</i>
Parent concerns		53	34.6	
	Difficulties involving youth in tasks	25	16.3	<i>“It takes more effort to explain and assist her than doing it myself”</i>
	Holding low expectations' for youth participation	13	8.5	<i>“I sometimes assume my child cannot perform those types of tasks, so I guess I never tried to teach him those tasks/skillsets”</i>
	Lacking time to involve youth in tasks	12	7.8	<i>“The time and effort I would have to put in for him to learn those skills with even some supervision is way beyond what I'm willing to do”</i>
	Lack of supports	3	2.0	<i>“Any task would require constant prompting and supervision.. having outside support would help”</i>
Task barriers		23	15.0	
	Tasks not expected of youth	23	15.0	<i>“They're either not applicable (i.e. don't have plants) or just not something I've ever asked or expected him to do as a member of the family”</i>



Table 13

*Categories, Codes, and Exemplars: Challenges of Youth Participation in Tasks*

Category	Codes	<i>n</i>	(%)	Exemplar
Parent perceptions of youth challenges		185	(78.7)	
	Resisted doing tasks	38	(16.2)	<i>“She is not cooperative &amp; refuses to participate in chores”</i>
	Requires supervision	31	(13.2)	<i>“He needs consistent and continued reminders and assistance”</i>
	Performs tasks carelessly	29	(12.3)	<i>“He does tasks quickly and without putting effort in to do them properly”</i>
	Difficulty following directions	16	(6.8)	<i>“He can become very confused if directions are not broken down when learning a new skill”</i>
	Safety concerns	16	(6.8)	<i>“Some things are just too dangerous due to her level of understanding (like hot food items, using the stove, cleaning certain things)”</i>
	Easily distracted	15	(6.4)	<i>“Getting her to focus long enough to complete the task”</i>
	Physical limitations	13	(5.5)	<i>“She has limited hand/ body strength”</i>
	Hard to teach youth	11	(4.7)	<i>“She does not like to be corrected and during the teaching process she tends to have a lot of behavior so that is a challenge”</i>
	Lacks concept of why chores need to be done	9	(3.8)	<i>“He has a problem participating in any task that he doesn't see the value in”</i>
	Slow worker	7	(3.0)	<i>“He has no hurry mode and if someone asks him to or gets upset with his slow mode, it makes him even slow down further”</i>
Parent perceptions of parent challenges		50	(21.3)	
	Lack of time	35	(14.9)	<i>“The biggest challenge is that I have to take the time to teach the skill”</i>
	Difficulty involving youth in tasks	15	(6.4)	<i>“Many tasks are difficult for him to do, so it is many times more difficult for me to have him help”</i>

## Appendix A: Parent Recruitment E-Mail

Dear \_\_\_\_ (Insert PTI contact name if known),

My name is Kimberly Patton and I am a doctoral candidate in Special Education at the University of Illinois at Urbana-Champaign working under the advisement of Drs. Stacy Dymond and Meghan Burke. We are conducting an exciting research study and are looking for participants. Specifically, we are looking for legal parents of children between the ages of 14-22 with intellectual disability who live in their parents' or step-parents' home. This study seeks to understand the extent that youth with intellectual disability are engaging in household tasks and with what level of support. Additionally, we aim to understand the relation between engagement in household tasks and parental expectations for employment outcomes.

We hope after reading the description of the study below that you will forward the attached parent recruitment flyer to any parents who are members of your Parent Training and Information Center (PTI). It can be distributed through listservs, website posting, social media outlets, face-to-face events, or any other ways in which you contact families.

***Can you please email me at [kagentry@illinois.edu](mailto:kagentry@illinois.edu) and let me know if you are willing to distribute the flyer to members of your PTI and how you will distribute it? Also, can you let me know how many families your PTI serves?***

**Title of the Project:** Household Tasks and Parent Expectations for Employment

**About the Project:** Participants will complete an online questionnaire that should take about 20 minutes. Participants can also choose to take the questionnaire in a paper format that can be mailed to them with a self-addressed stamped return envelope included. We believe the information in this questionnaire will help to identify factors that influence engagement in household tasks and contemplate what schools can do to support parents in involving their adolescent and young adult children in household chores.

**Potential Participants:** Parents should consider participating in this study if:

- (a) They are the legal parent of a transition-aged youth (i.e. between the ages of 14-22) with intellectual disability, and
- (b) their child currently lives with them.

***If parents meet the criteria for the study and choose to complete the questionnaire, they will have the option to participate in a drawing to receive one of 25 \$20 Amazon gift cards.***

If you have any questions about this study, please contact Kimberly Patton by email at [kagentry@illinois.edu](mailto:kagentry@illinois.edu). Parents are asked to contact Kimberly to indicate their interest to receive a link to participate in the study or indicate their preference for a paper format of the questionnaire.

Thank you for your assistance in distributing the parent recruitment flyer!

Best regards,

Kimberly Patton, M.Ed  
Doctoral Candidate  
University of Illinois  
Department of Special Education  
[kagentry@illinois.edu](mailto:kagentry@illinois.edu)

## Appendix B: Parent Recruitment Flyer

# Parents of Transition-Aged Children with Intellectual Disability Needed for Research Study

**Greetings!** My name is Kimberly Patton and I am a doctoral student in Special Education at the University of Illinois at Urbana-Champaign working under the advisement of Drs. Stacy Dymond and Meghan Burke. We are looking for participants for an exciting research project that focuses on the extent that individuals between the ages of 14-22 with intellectual disability are engaging in household tasks. Additionally, this study seeks to understand the relation between engagement in household tasks and parental expectations for employment outcomes. We hope after reading the description of the study below that you will contact us if you would like to participate or if you have any questions.

**Title of the Project:** Household Tasks and Parent Expectations for Employment

**About the Project:** As a participant, you will complete an online questionnaire that should take about 20 minutes. If you would prefer to complete the questionnaire in a paper format, please let us know and we will send the questionnaire by mail with a self-addressed stamped return envelope. We believe the information in this questionnaire will help to identify factors that influence engagement in household tasks and contemplate what schools can do to support parents in involving their adolescent and young adult children in household chores.

**Potential Participants:** Please consider participating in this study if:

- (a) You are the legal parent of a transition-aged youth (i.e. between the ages of 14-22) with intellectual disability, and
- (b) your child currently lives with you.

***If you choose to complete the questionnaire, you have the option to participate in a drawing to receive one of 25 \$20 Amazon gift cards.*** This is optional and your enrollment into the drawing will not be linked to your questionnaire responses.

If you are interested in participating in this study, please contact Kimberly Patton by email at [kagentry@illinois.edu](mailto:kagentry@illinois.edu) and you will be sent a link to participate. If you prefer a paper format of the questionnaire, please indicate your preference along with a mailing address, and you will be mailed a paper version that includes a self-addressed stamped return envelope.

*Also, please consider forwarding this information on to any parents who might be interested in participating in the study.*

Thank you,  
Kimberly Patton, M.Ed  
[kagentry@illinois.edu](mailto:kagentry@illinois.edu)

Thank you for considering participating in our project!

## Appendix C: Follow-up Email to Organizations

Dear \_\_\_\_ (Insert PTI contact name if known),

I am reaching out again to remind you of an exciting research study we are conducting. My name is Kimberly Patton and I am a doctoral student in Special Education at the University of Illinois at Urbana-Champaign working under the advisement of Drs. Stacy Dymond and Meghan Burke. We are conducting an exciting research study and are looking for participants. Specifically, we are looking for legal parents of children between the ages of 14-22 with intellectual disability who live in their parents' or step-parents home. This study seeks to understand the extent that youth with intellectual disability are engaging in household tasks and with what level of support. Additionally, we aim to understand the relation between engagement in household tasks and parental expectations for employment outcomes.

We hope after reading the description of the study below that you will forward the attached parent recruitment flyer to any parents who are members of your Parent Training and Information Center (PTI). It can be distributed through listservs, website posting, social media outlets, face-to-face events, or any other way in which you contact families.

*Can you please email me at [kagentry@illinois.edu](mailto:kagentry@illinois.edu) and let me know if you are willing to distribute the flyer to members of your PTI and how you will distribute it? Also, can you let me know how many families your PTI serves?*

**Title of the Project:** Household Tasks and Parent Expectations for Employment

**About the Project:** Participants will complete an online questionnaire that should take about 20 minutes. Participants can also choose to take the questionnaire in a paper format that can be mailed to them with a self-addressed stamped return envelope included. We believe the information in this questionnaire will help to identify factors that influence engagement in household tasks and contemplate what schools can do to support parents in involving their adolescent and young adult children in household chores.

**Potential Participants:** Parents should consider participating in this study if:

- (a) They are the legal parent of a transition-aged youth (i.e. between the ages of 14-22) with intellectual disability, and
- (b) their child currently lives with them.

*If parents meet the criteria for the study and choose to complete the questionnaire, they will have the option to participate in a drawing to receive one of twenty-five \$20 Amazon gift cards.*

If you have any questions about this study, please contact Kimberly Patton by email at [kagentry@illinois.edu](mailto:kagentry@illinois.edu). Parents are asked to contact Kimberly to indicate their interest and preferred format for participating.

Thank you for your assistance in distributing the parent recruitment flyer!

Best regards,

Kimberly Patton, M.Ed  
Doctoral Candidate  
University of Illinois  
Department of Special Education  
[kagentry@illinois.edu](mailto:kagentry@illinois.edu)

## Appendix D: Response Email to Online Participants

Dear,

Thank you for your interest in participating in this study. The purpose of this study is to investigate the extent that individuals between the ages of 14-22 with intellectual disability are engaging in household tasks. Additionally, this study seeks to understand the relation between engagement in household tasks and parental expectations for employment outcomes.

As a reminder, to be eligible to participate in this study you need to be:

- (a) A legal parent of a transition-aged youth (i.e. between the ages of 14-22) with intellectual disability, and
- (b) your child currently lives with you.

Below is a link to take the questionnaire online. The questionnaire should take less than 20 minutes to complete.

To thank you for your participation, you will have the option to participate in a drawing to receive one of twenty-five \$20 Amazon gift cards. This is optional and your enrollment into the drawing will not be linked to your questionnaire responses.

Please let me know if you have any questions about this study.

Warm regards,

Kimberly

Kimberly Patton  
Doctoral Candidate  
University of Illinois  
Department of Special Education  
[kagentry@illinois.edu](mailto:kagentry@illinois.edu)

## Appendix E: Response Email to Paper Questionnaire Requests

Dear \_\_\_\_ (Insert parent/guardian name if known),

Thank you for your interest in participating in this study. The purpose of this study is to investigate the extent that individuals between the ages of 14-22 with intellectual disability are engaging in household tasks. Additionally, this study seeks to understand the relation between engagement in household tasks and parental expectations for employment outcomes.

As a reminder, to be eligible to participate in this study you need to be:

- (a) A legal parent of a transition-aged youth (i.e. between the ages of 14-22) with intellectual disability, and
- (b) your child currently lives with you.

A copy of the questionnaire has been mailed to the address you provided. Included is a self-addressed stamp return envelope.

***To thank you for your participation, you will have the option to participate in a drawing to receive one of twenty-five \$20 Amazon gift cards.*** This is optional and your enrollment into the drawing will not be linked to your questionnaire responses.

Please let me know if you have any questions about this study.

Warm regards,

Kimberly

Kimberly Patton  
Doctoral Candidate  
University of Illinois  
Department of Special Education  
[kagentry@illinois.edu](mailto:kagentry@illinois.edu)



## Appendix F: Reminder Email to Online Participants

Dear \_\_\_\_ (Insert parent/guardian name if known),

Thank you again for your interest in participating in this study. As a reminder, the purpose of this study is to investigate the extent that individuals between the ages of 14-22 with intellectual disability are engaging in household tasks. Additionally, this study seeks to understand the relation between engagement in household tasks and parental expectations for employment outcomes.

As a reminder, to be eligible to participate in this study you need to be:

- (a) A legal parent of a transition-aged youth (i.e. between the ages of 14-22) with intellectual disability, and
- (b) your child currently lives with you.

Below is a link to take the questionnaire online. The questionnaire should take less than 20 minutes to complete.

***To thank you for your participation, you will have the option to participate in a drawing to receive one of twenty-five \$20 Amazon gift cards.*** This is optional and your enrollment into the drawing will not be linked to your questionnaire responses.

Please let me know if you have any questions about this study.

Questionnaire link: \_\_\_\_\_

Warm regards,

Kimberly

Kimberly Patton  
Doctoral Candidate  
University of Illinois  
Department of Special Education  
[kagentry@illinois.edu](mailto:kagentry@illinois.edu)

## Appendix G: Reminder Email Paper Questionnaire

Dear \_\_\_\_ (Insert parent/guardian name if known),

Thank you again for your interest in participating in this study. As a reminder, the purpose of this study is to investigate the extent that individuals between the ages of 14-22 with intellectual disability are engaging in household tasks. Additionally, this study seeks to understand the relation between engagement in household tasks and parental expectations for employment outcomes.

As a reminder, to be eligible to participate in this study you need to be:

- (a) A legal parent of a transition-aged youth (i.e. between the ages of 14-22) with intellectual disability, and
- (b) your child currently lives with you.

A copy of the questionnaire was mailed to you on (provide date) at the address you provided. A self-addressed stamp return envelope was included. Please let me know if you did not receive the questionnaire or have any other questions about this study.

***To thank you for your participation, you will have the option to participate in a drawing to receive one of twenty-five \$20 Amazon gift cards.*** This is optional and your enrollment into the drawing will not be linked to your questionnaire responses.

Warm regards,

Kimberly

Kimberly Patton  
Doctoral Candidate  
University of Illinois  
Department of Special Education  
[kagentry@illinois.edu](mailto:kagentry@illinois.edu)

## Appendix H: Survey Instrument

**Throughout this questionnaire, you will be asked to answer questions about yourself and your child. You may skip any question that you are uncomfortable answering.**

**Parent Demographic Questions: Please answer the following demographic questions about yourself and your spouse or partner.**

1. Who are you as the respondent?
  - Mother
  - Father
  - Other (please specify) \_\_\_\_\_
  
2. In what year were you born? \_\_\_\_\_
  
3. What is your current marital status?
  - Married
  - Not married, but living together with partner
  - Never Married
  - Separated/Divorced
  - Widowed
  
4. Please choose your highest level of education.
  - Some high school
  - High school graduate
  - Some college
  - College graduate
  - Graduate school
  
5. What is your 6-digit zip code? \_\_\_\_\_
  
6. What is your annual household income?
  - Less than \$15,000
  - \$15-29,999
  - \$30-49,999
  - \$50-69,999
  - \$70-99,999
  - Over \$100,000
  
7. Which ethnicity are you?  
(Select all the apply)
  - White
  - Black or African-American
  - Hispanic, or Latino
  - Asian or Asian Indian

- American Indian or Alaska Native
- Middle Eastern or North African
- Native Hawaiian or Other Pacific Islander
- Other (please specify) \_\_\_\_\_

8. Which gender do you identify as?

- Female
- Male
- Other (please specify) \_\_\_\_\_

9. How many hours do you work each week in a job for which you are paid?

- Less than 5 hours
- 5-10 hours
- 11-20 hours
- 21-37 hours
- 37.5+ hours
- N/A

10. How many hours a week does your spouse or partner who lives with you work?

- Less than 5 hours
- 5-10 hours
- 11-20 hours
- 21-37 hours
- 37.5+ hours
- N/A

11. How many children currently live in your household? \_\_\_\_\_

- How many children are older than your child aged 14-22 with a disability? \_\_\_\_
- How many children are younger than your child aged 14-22 with a disability? \_\_\_\_

12. How many adults including yourself currently live in your household? \_\_\_\_\_

13. With whom does the child currently live (check all that apply):

- a) both his or her parents (mother/father, mother/mother/, or father/father)
- b) mother and stepfather/stepmother
- c) father and stepmother/stepfather
- c) father only,
- d) mother only, or
- e) other arrangement

**Child Demographic Questions: Please refer to your child aged 14-22 with intellectual disability when answering these questions. If you have more than one child who fits this description, please choose your child with the most significant intellectual disability.**

14. How old is your child with a disability? \_\_\_\_\_(years)
15. What gender does your child identify as?
- Female
  - Male
  - Other (please specify) \_\_\_\_\_
16. What, if any, additional disabilities does your child have? Check one or more of the following:
- Down syndrome
  - Autism
  - Multiple disabilities
  - Blind/vision impairment
  - Cerebral palsy
  - Hearing impairment
  - Health condition (please specify) \_\_\_\_\_
  - Other (please specify) \_\_\_\_\_
17. In general, how would you describe your child's overall level of intellectual disability?
- a) Mild (intermittent supports [support is rarely needed])
  - b) Moderate (limited supports [support is sometimes needed])
  - c) Severe (extensive supports [support is often needed])
  - d) Profound (pervasive supports [support is always needed])
18. Which of the following best describes your child's primary method of communication?
- a) Verbal
  - b) Sign language
  - c) Communication device
  - d) Gestures
  - e) Other
19. In the past year, has your child participated in any school-based extracurricular activities?  
Yes  No
20. In the past year, has your child participated in any community-based extracurricular activities?  
Yes  No
21. Has your child ever had paid employment outside of the home?  
Yes  No

**Household Tasks.**

**This set of questions ask about your child’s participation in household tasks and the level of support they need to participate in household tasks. For each task, record yes or no if the child participates in the task. Then, for each task that you indicated your child participates in, you will be asked to choose which level of support the child needs to participate on the following page. For each task that you indicate your child does not participate in, you will be asked the reason the child does not participate for each task on an additional page.**

	Does your child participate in this task?	Child <i>does</i> task					Child <i>does not</i> do task	
		On own initiative >50% of time	When asked	With supervision or monitoring	With some assistance	With a lot of assistance	Child cannot perform task	Do not expect this of my child
Household task	Y/N	6	5	4	3	2	1	0
22. Cleans up after own activities								
23. Picks up own bedroom								
24. Makes own bed								
25. Picks up area shared by others								
26. Puts clean clothes away								
27. Makes self a snack								
28. Makes self a cold meal								
29. Prepares a cold meal for family								
30. Makes self a hot meal								
31. Prepares a hot meal for family								
32. Sets or clears the table								
33. Brings in or puts away groceries								
34. Washes dishes (loads dishwasher)								
35. Dries dishes (unloads dishwasher)								
36. Takes out garbage/recycling								
37. Cleans bathroom								
38. Puts own laundry in hamper								
39. Puts away own clean laundry								
40. Sorts laundry for family								
41. Puts laundry away for family								

42. Runs washer/dryer								
43. Sweeps or vacuums own room								
44. Dusts own room								
45. Sweeps or vacuums home								
46. Dusts the house								
47. Cares for plants								
48. Feeds pet								
49. Cares for younger siblings								
50. Cares for other family members								
51. Organizes own belongings for school								
52. Organizes after-school belongings								
53. Takes a phone message								
54. Runs errands								
55. Gets the mail or the newspaper								

(Here is an example of how the branching logic will look when the question is asked in Survey Monkey. Each task would be set up this way with the same response options for all tasks.)

Household Task:	Does your child participate in this task?
Cleans up after own activities	<input type="checkbox"/> Yes <input type="checkbox"/> No

If yes, the following choices will be provided:

Please pick the response option that best describes the level of assistance your child needs to complete the task:

- 6- Perform task on own initiative more than 50% of the time
- 5- Child performs task when asked
- 4- Child performs task with supervision or monitoring
- 3- Child performs task with some assistance
- 2-Child performs task with a lot of assistance

If no, the following choices will be provided:

Please pick the response option that best describes why your child does not participate in this task:

- 1- Child cannot perform task
- 0- Child is not expected to perform task

56. What are the reasons you do (or do not) have your child participate in household tasks?

---

57. What are the challenges of having your child participate in household tasks?

---

**Vocational Expectations: The follow questions ask you to think about the expectations you have for your child’s employment after exiting school.**

58. Which of the following describes your expectations that your child will ever have a paying job?

Definitely will not	Probably will not	Probably will	Definitely will
---------------------	-------------------	---------------	-----------------

59. Which of the following describes your expectations that your child will ever be self-supporting?

Definitely will not	Probably will not	Probably will	Definitely will
---------------------	-------------------	---------------	-----------------

60. Which of the following vocational expectations do you believe is the most realistic outcome for your child after they exit school? \*(Note: sheltered vocational setting includes settings such as sheltered workshops or adult day centers.)

60. Which of the following vocational outcomes do you believe is the most realistic outcome for your child after they exit school?

9	Community employment <i>without</i> supports greater than 10 hours a week (no time spent in sheltered settings)
8	Community employment <i>without</i> supports for 10 hours a week or less (no time spent in sheltered settings)
7	Community employment <i>with</i> supports greater than 10 hours a week (no time spent in sheltered settings)
6	Community employment <i>with</i> supports for 10 hours a week or less (no time spent in sheltered settings)
5	Sheltered vocational setting* and employment in the community – total activities greater than 10 hours a week
4	Sheltered vocational setting* and volunteering in the community greater than 10 hours a week
4	Sheltered vocational setting* greater than 10 hours a week (with no community employment/volunteering)
3	Sheltered vocational setting* for 10 hours a week or less
2	Volunteering with no other vocational activities
1	No vocational activities

61. Which type of job do you expect your will child obtain after exiting school?

- a. Food Service
- b. Cashier
- c. Inventory



- d. Janitorial
  - e. Office/Clerical
  - f. Assembly and packaging
  - g. Landscaping
  - h. Data Entry
  - i. Construction
- Other (please specify): \_\_\_\_\_

Thank you for taking the time to complete this questionnaire! We greatly appreciate your input. If you would like to be entered into a drawing for one of 25 \$20 Amazon gift cards, please provide your email address below. You will be notified at the conclusion of the study by email if you were selected. Your email address will only be used for the purposes of this drawing and no identifying information will be used when analyzing the data from this questionnaire.

Your email address: \_\_\_\_\_

If you would like to be contacted about participating in a follow-up research study, please provide your email address.

\_\_\_\_\_.

How did you hear about the study?

- a) My local Parent Training and Information Center
- b) Friend/Family member
- c) I was contacted by the researcher
- d) Other (please specify) \_\_\_\_\_

## **Appendix I: Consent Letter**

### **Household Tasks and Parent Expectations for Employment**

You are being asked to participate in a voluntary research study. The purpose of this study is to examine the extent that transition-aged individuals with intellectual disability are engaging in household tasks. Additionally, this study seeks to understand the relation between engagement in household tasks and parental expectations for employment outcomes. Participating in this study will involve participating in an online questionnaire and your participation should take about 20-25 minutes. There are no known or expected risks to you as a participant in this study and you can withdraw at any point by exiting your browser. You are free to decline to answer any particular question you do not wish to answer for any reason. Your participation in this study will help to identify factors that influence engagement in household tasks and contemplate what schools can do to support parents in involving their adolescent and young adult children in various household chores.

Principal Investigator Name and Title: Dr. Meghan Burke  
Department and Institution: Department of Special Education, University of Illinois at Urbana-Champaign

#### **Why am I being asked?**

You have been asked to participate in this research because you have indicated are a parent of a transition-aged youth with intellectual disability who lives at home with you. Approximately 500 participants will be involved in this research at the University of Illinois at Urbana-Champaign.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Urbana-Champaign. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

#### **What procedures are involved?**

This an online survey study. This questionnaire should take approximately 20 minutes to complete and can be saved after starting and completed at another time.

#### **What are the potential risks and discomforts?**

There are no known or expected risks to you as a participant in this study and you can withdraw at any point by exiting your browser. You are free to decline to answer any particular question you do not wish to answer for any reason.

#### **Are there benefits to participating in the research?**

Your participation in this study will help to identify factors that influence engagement in household tasks and contemplate what schools can do to support parents in involving their adolescent and young adult children in various household chores.

#### **Will my study-related information be kept confidential?**

Faculty, students, and staff who may see your information will maintain confidentiality to the extent of laws and university policies. Personal identifiers will not be published or presented.

**Will I be reimbursed for any expenses or paid for my participation in this research?**

Upon completion of the questionnaire, you will have the option to participate in a drawing to receive one of 25 \$20 Amazon gift cards. This is optional and your enrollment into the drawing will not be linked to your questionnaire responses. The questionnaire responses will initially be identifiable via email addresses but then de-identified once you've added your email address to receive payment.

**Can I withdraw or be removed from the study?**

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

**Will data collected from me be used for any other research?**

**Who should I contact if I have questions?**

Contact the researchers Kimberly Patton, M.Ed. at [kagentry@illinois.edu](mailto:kagentry@illinois.edu), or Dr. Meghan Burke at [meghanbm@illinois.edu](mailto:meghanbm@illinois.edu) if you have any questions about this study or your part in it, or if you have concerns or complaints about the research.

**What are my rights as a research subject?**

If you have any questions about your rights as a participant in this study, please contact the University of Illinois at Urbana-Champaign Office for the Protection of Research Subjects at 217-333-2670 or [irb@illinois.edu](mailto:irb@illinois.edu).

\*Electronic Consent: I have read the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. Please select your choice below. You may print a copy of this consent form for your records. Clicking on the "Agree" button indicates that:

- 1) You have read the above information
- 2) You voluntarily agree to participate
- 3) You are 18 years of age or older
- 4) You are the parent of an individual between the ages of 14-22 with intellectual disability
- 5) Your child currently lives with you.

\_\_\_ Agree

\_\_\_ Disagree

Paper Consent: I have read the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. By completing and returning the questionnaire, I agree that:

- (a) I voluntarily agree to participate in this research
- (b) I am 18 years of age or older
- (c) I am the parent of an individual between the ages of 14-22 with intellectual disability
- (d) My child currently lives with me

\*The electronic consent will be used for online questionnaires. The paper consent form will be used for paper questionnaires.

## Appendix J: IRB Approval Form



### OFFICE OF THE VICE CHANCELLOR FOR RESEARCH

Office for the Protection of Research Subjects  
805 W. Pennsylvania Ave., MC-095  
Urbana, IL 61801-4822

#### Notice of Exempt Determination

August 20, 2019

<b>Principal Investigator</b>	Meghan Burke
<b>CC</b>	Kimberley Patton, Stacy Dymond
<b>Protocol Title</b>	<i>Household Responsibilities and Parent Expectations for Employment</i>
<b>Protocol Number</b>	20096
<b>Funding Source</b>	Unfunded
<b>Review Category</b>	Exempt 2 (iii)
<b>Determination Date</b>	August 20, 2019
<b>Closure Date</b>	August 19, 2024

This letter authorizes the use of human subjects in the above protocol. The University of Illinois at Urbana-Champaign Office for the Protection of Research Subjects (OPRS) has reviewed your application and determined the criteria for exemption have been met.

The Principal Investigator of this study is responsible for:

- Conducting research in a manner consistent with the requirements of the University and federal regulations found at 45 CFR 46.
- Requesting approval from the IRB prior to implementing major modifications.
- Notifying OPRS of any problems involving human subjects, including unanticipated events, participant complaints, or protocol deviations.
- Notifying OPRS of the completion of the study.

Changes to an **exempt** protocol are only required if substantive modifications are requested and/or the changes requested may affect the exempt status.

UNIVERSITY OF ILLINOIS AT URBANA-CHAMPAIGN

IORG0000014 • FWA #00008584  
217.333.2670 • irb@illinois.edu • oprs.research.illinois.edu