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Navigating the Road From Adolescence to Adulthood for Youth With and Without Developmental Disabilities: Parent Perspectives

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Navigating the Road From Adolescence to Adulthood for Youth With and Without Developmental Disabilities: Parent Perspectives

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Elina Veytsman

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ABSTRACT OF THE DISSERTATION

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by

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Doctor of Philosophy, Graduate Program in Education
University of California, Riverside, June 2022
Dr. Jan Blacher, Chairperson

Transition to adulthood can be a stressful time for all parents, but particularly so if the young adult has a disability. Young adults with autism spectrum disorder (ASD) and intellectual disability (ID) have less successful outcomes in the education, employment, social, and independence domains compared to their typically developing (TD) peers (e.g., Grigal et al., 2011; Newman et al., 2010; Shattuck et al., 2012). As parents play a crucial role in transition for young adults with ASD and ID, understanding their perspectives and expectations for their young adults is crucial to understanding the factors that affect transition outcomes (Sosnowy et al., 2018). Relatively little research has been devoted to understanding how young adult outcomes are aligned with the priorities of parents, or how parental wellbeing impacts young adult outcomes. This study used qualitative analysis of semi-structured interviews to describe mothers' (*N*=109) desired outcomes, challenges, and worries for their young adults ages 20 to 25 with ASD, ID, and TD, participating in a 20-year longitudinal study. Quantitative analyses examined the relationship between mothers' desired outcomes, maternal wellbeing, and youth transition outcomes. Mothers of young adults with and without disabilities broadly reported common concerns and goals for their young adults, but some themes were unique to mothers of youth with disabilities, reflecting additional challenges for these families. Consistent with previous research, transition outcomes were less positive for young adults with ID or ASD. More successful young adult outcomes were associated with greater maternal wellbeing, more positive outlook, and higher expectations. Discussion provides implications for transition planning and emphasizes how to support parents as facilitators of successful transition.

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For all parents, the adolescent's transition from high school to the world of adulthood can be a challenging and tricky time. Having a disability makes this transition period even more difficult, as demonstrated by poor transition outcomes among adults with developmental disabilities (e.g., Howlin, Goode, Hutton, & Rutter, 2004; Kraemer, McIntyre, & Blacher, 2003; Shattuck et al., 2012). Parents play a crucial role in the transition for young adults with disabilities, offering not only financial and emotional support, but help accessing services and employment opportunities. While many studies have examined young adult outcomes during this period of "emerging adulthood" (Arnett, 2004), there is a paucity of research on the experiences of parents during this time of family transformation (Kloep & Hendry, 2010). This dissertation examined the perspectives of parents of young adults with intellectual disability (ID), autism spectrum disorder (ASD), and typical development (TD) around the transition to adulthood. The parent experience is described in terms of parents' reported challenges, concerns, and goals for their young adults. In addition, quantitative analyses examined the relationship among parent expectations, parent wellbeing, and youth transition outcomes.

Transition to Adulthood

The transition period has been described as a period of "emerging adulthood," from about 18 to 25 years of age, when a person begins to take on adult roles and responsibilities and explore various possible lifestyles (Arnett, 1998; 2004; 2007). Young adults have to make important life decisions during this period, including whether or not to go to college, and whether to stay at home or move out on their own. There is evidence that it takes longer today to reach adulthood than it did in the past, likely due to macro-level changes in society and the economic realities of our time (Arnett, 2004). Though it was previously expected that young adults in their twenties would have a stable job, be married with children, and have a mortgage, the shifting values in society (e.g., from manufacturing to information) have shifted the expected trajectory of adulthood (Arnett, 2007). Rather than entering straight into the workforce after high school, many young adults enroll in postsecondary education to increase their chances of finding a stable job (Hamilton & Hamilton, 2006). At the same time, young adults are now leaving home later and often returning home when they cannot afford to live independently. Given the changing nature of transitioning into adulthood, researchers have described a new and distinct period (i.e., "emerging adulthood") in between the end of adolescence and the beginning of adulthood (Arnett, 2007).

Research on transition patterns demonstrates that today's young adults differ from those of previous generations in their amount of education, work experiences, timelines for starting a family, and living arrangements (Vespa, 2017). Reflecting the societal changes over the last few decades, data from the General Social Survey (Smith et al., 2012) show that American adults (ages 18 and older) ranked educational and economic accomplishments, as opposed to marriage and children, as extremely important markers of adulthood. Specifically, completing college, having a full-time job, and achieving financial independence and stability were ranked as the most important milestones to becoming an adult (Vespa, 2017). Living independently from parents was ranked as less important, but still higher than marriage and children, which half of Americans ranked as not important for becoming an adult (Vespa, 2017). In contrast to the values reported by young Americans, today's young adults are less likely to complete their education, live independently, and become financially independent than those of the previous generation (Vespa, 2017; Fingerman, 2017).

Research has demonstrated widely heterogeneous pathways to adulthood, which are affected by various macro, meso, and micro factors (Wood et al., 2018; Shanahan, 2000). At a macro level, societal expectations and influences impact the trajectory of the transition. Meso-level factors such as parent-child relationships and socioeconomic status, and micro-level influences such as cognitive development, identity information, and resilience all contribute to the success of the transition.

Transition Outcomes for Emerging Adults

The study of adult outcomes has generally focused on the domains that are valued and associated with success in Western culture, namely work and romantic relationships (Roisman et al., 2004). To identify what predicts successful adult outcomes in these areas, research has shed light on the specific developmental tasks during emerging adulthood that are most likely to lead to success in later adulthood. In a longitudinal study of typically developing young adults, Roisman and colleagues (2004) evaluated the predictive value of well-established developmental tasks of adolescence (i.e., friendship, academic performance, and conduct) during emerging adulthood (i.e., age 20) on future adult outcomes (i.e., age 30) in employment, education, and social and romantic relationships. They found that success in these three domains (i.e., academics, friendships/social competence, and conduct/law abidingness) during emerging adulthood predicted success ten years later, above and beyond work and romantic relationships.

However, other studies have shown that work experience can also play an important role in the transition to adulthood, especially for adolescents who do not pursue higher education (Mortimer et al., 2003). In addition, there is consensus among young adults that independence is an important indicator of attaining adulthood, including accepting responsibility for oneself, making decisions independently, and becoming financially self-sufficient (Wood et al., 2018; Arnett, 1998). Thus, when evaluating successful transition outcomes during the period of emerging adulthood, the primary areas of interest in the literature have been educational attainment and/or employment, independence (including financial independence and independent living), and social relationships (e.g., Arnett, 1998; Taylor, 2009). These outcomes are often combined to form an overall measure of adult functioning (e.g., Henninger & Taylor, 2013).

Educational/Employment Outcomes. More youth today are pursuing higher education than ever before, with 40% of emerging adults ages 18-24 attending college in 2016 (National Center for Education Statistics, 2017). More than a third of young adults between the ages of 25 and 34 now have a bachelor's degree or higher, with women outpacing men in educational attainment (Ryan & Bauman, 2015; Vespa, 2017). This increase in educational attainment provides more opportunities for social mobility among young adults, as higher educational attainment is associated with higher socioeconomic status (SES), as well as enhanced psychosocial development (Evans & Cassells, 2014). However, the pursuit of higher education rather than employment relates to an increased reliance on parental support, as college students receive more financial and emotional support from their parents compared to nonstudents (Fingerman, 2017). Unsurprisingly, young adults from lower SES backgrounds are less likely to enroll in postsecondary education, with only 22% of young adults from low-income families earning an associate's degree or higher, compared to 48% of young adults from higher-income families (Evans & Cassells, 2014).

Though most American adults believe that the ideal age to complete formal schooling and become employed full-time is 22, only 52% complete school and only 37% are employed full-time by this age (Vespa, 2017). However, more young adults today are working full-time compared to the previous generation. Among young adults between the ages of 25 and 34, 77% were employed in 2016, with 57% working full-time (Vespa, 2017). Interestingly, the percentage of men employed full-time has not changed since 1975, while the percentage of women employed full-time has risen from approximately one-fourth to half (Vespa, 2017). Though young adults today are more likely to have a college degree and work full-time, they are less likely to live independently in their own home; this is especially true for men, who are living with their parents at disproportionate rates (Vespa, 2017).

Independence. Contrary to the belief held by most American adults that youth should ideally be financially independent from their parents by age 21, data from the U.S. Census Bureau show that only 29% of youth met this milestone by that age (Vespa, 2017). Few young adults between the ages of 18 and 34 are financially independent, with about a third relying on their parents for financial support (Schoeni & Ross, 2005). In addition, half of young adults ages 25 to 34 fall at the bottom of the economic ladder (i.e., making less than $30,000 a year; Vespa, 2017; Fingerman, 2017). Correspondingly, the most common living situation among young adults ages 18 to 34 is their parents' home, with a third of all young adults (or 24.2 million) living at home (American Community Survey, 2015; Vespa, 2017). The proportion of emerging adults ages 18 to 24 living at home is even higher (more than half; Vespa, 2017). Whereas in 2005, the predominant living arrangements of young adults were their own independent households in 35 states, this was only the case in 6 states in 2015 (Vespa, 2017).

The rapid decline in the prevalence of independent living among young adults may coincide with an increased reliance on parents during the transition period. Previous research has suggested that young adults who remain at home for too long may take longer to gain independence from their parents, all of which affects their overall wellbeing and adjustment (White, 2002). Of those young adults ages 18 to 34 living with their parents, 81% are engaged in work or education. However, among the older group of young adults ages 25 to 34 living with their parents, approximately one fourth are not working or in school (Vespa, 2017). Notably, 28% of all older young adults living with their parents have a disability (Vespa, 2017), reflecting the additional challenges experienced by youth with disabilities in attaining independence (described in more detail in the following section). Though some research has suggested positive effects of this increased parental involvement in their young adults' lives, other research has demonstrated greater ambivalence or negative feelings among parents towards their young adults (Fingerman, 2017).

Social Relationships. With society shifting away from viewing marriage and children as markers of adulthood, marriage rates among young adults (ages 18-34) have unsurprisingly decreased from 59% in 1978, to 30% in 2018. The percentage of young adults living with a spouse also decreased from 57% in 1975, to 27% in 2016 (Vespa, 2017); among emerging adults (ages 18-24), only 7% were living with a spouse in 2018 (U.S. Census Bureau, 2018). However, in the same period, the percentage of young adults living with a partner increased from 0.1% to 12%, while those living with roommates increased from 11% to 21%. These statistics reflect a societal shift in living arrangements, with cohabitation and living with roommates now more common among young adults than living with a spouse (Vespa, 2017).

Beyond their living arrangements, developing meaningful interpersonal friendships is one of the most salient tasks of young adulthood. Friendships provide young adults with social support and companionship and support their identity development (Barry & Madsen, 2010), surpassing even sibling relationships in closeness and associated positive feelings (Pulakos, 2001). Most emerging adults spend significant amounts of time with close friends and relationship partners; these social relationships undoubtedly have significant influence on their lives. Though the U.S. Census Bureau does not provide data on the social relationships of emerging adults, extensive research has demonstrated that high-quality friendships and relationships are associated with happiness (Demir, 2008; Demir & Weitekamp, 2006) and overall wellbeing across the lifespan (Hartup & Stevens, 1997). For example, Pittman & Richmond (2008) found that college students who perceive greater social satisfaction are more likely to have higher self-esteem and less likely to have internalizing and externalizing behavior problems.

Reis and colleagues (1993) found that emerging adults often belonged to peer groups, which supported their transition to college.

Transition Outcomes for Youth With DD/ID

Youth with intellectual disability (ID), a developmental disability characterized by below average intellectual and adaptive functioning, may still be struggling with the developmental tasks of adolescence throughout the transition period (Marshak et al., 1999). As youth with DD and ASD exit the public-school system, they are faced with what has been referred to as the "service cliff," in which they no longer have access to the services and accommodations provided through the Individuals with Disabilities Education Act (IDEA). These youth are less likely than their TD peers to pursue postsecondary education (Grigal et al., 2011; Newman et al., 2010) and to be gainfully employed (Grigal et al., 2011; Bouck, 2012). Data from the National Longitudinal Transition Study-2 (NLTS-2), a 10-year prospective study (2000-2009) which included a nationally representative sample of over 11,000 youth receiving special education services, show that 69.2% of individuals with ID did not have a paid job in the first three years after high school (Bouck, 2012). Further, research shows that young adults with ID who do obtain employment are more likely to be earning less than minimum wage compared to individuals with other disabilities (Grigal et al., 2011). Notably, Kraemer and colleagues (2003) conducted a study examining quality of life for young adults with intellectual disability, finding that young adults who were employed perceived higher quality of life in terms of their competence/productivity, empowerment/independence, and social belonging/community integration. This did not include those working in sheltered workshops or day activity centers.

In terms of educational outcomes, NLTS-2 data show that within eight years following high school, only 30% of students with ID participated in postsecondary education, compared to 56% of students from all disability groups (Grigal et al., 2011). Notably, higher parental expectations for academic and career success have been shown to be associated with higher postsecondary school attendance rates (Wagner et al., 2007). Unfortunately, postsecondary expectations for youth with DD in general tend to be low, with 62% to 70% of parents *not* expecting their youth with ID, ASD, or multiple disabilities to pursue education after high school (compared to 38% for youth from all disability groups) (Newman, 2005).

As for TD youth, the transition to adulthood for youth with DD is highly variable, and may be impacted by many individual, environmental/cultural, and family factors. Blacher presents a conceptual model for understanding the correlates of successful transition for youth with ID (Blacher, 2001). Individual characteristics may include age, gender, cognitive functioning, adaptive functioning, social and behavioral functioning, and mental health (Blacher, 2001). For example, social competence has been found to be associated with employment outcomes for young adults with DD (e.g., Hanley-Maxwell et al., 1986). Environmental/cultural variables impacting the transition include SES (e.g., Eilenberg et al., 2019), social support (e.g., Suarez & Baker, 1997), service utilization (e.g., Shattuck et al., 2011), and religious/cultural beliefs and practices (e.g., Magaña, 1999). For example, Latinx young adults may be more likely to live at home compared to

White or African American young adults, likely due to cultural values of familism (i.e., interdependence among family members) and family cohesion (Blacher, 2001; Magaña, 1999). Additionally, family involvement is critical to transition success. In contrast to the individuation from parents that occurs for TD young adults, young adults with DD are likely to rely on their parents for support throughout the transition period. Parental involvement with accessing services, finding employment opportunities, and making residential placement decisions is associated with more successful transition outcomes for young adults with DD (Steere et al., 1996; Nisbet et al., 1992). Furthermore, young adults whose parents have higher expectations for them may be more likely to have higher expectations for their own success (Newman, 2005). Additionally, adaptive behavior, parenting stress, parents' knowledge of the adult service system, and the number of friends in the young adult's social network have been identified as significant predictors of overall quality of life for young adults with ID (Kraemer et al., 2003).

According to NLTS-2 data, parents' most frequently reported goal for their youth with ID was to prepare for independent living (50%; Grigal et al., 2011). Among youth with mild ID, a third reported living independently within eight years after leaving high school (Bouck, 2014). Despite these seemingly low rates of independent living, they are comparable to those of youth with other disabilities (25%; Newman et al., 2009), as well as youth with typical development (Vespa, 2017). Notably, the prevalence of mental health disorders and behavior problems is much higher in youth with ID compared to TD youth (McIntyre et al., 2002), with an estimated 48% of young adults with ID screening as at-risk for clinically significant mental health problems (Cooper et al., 2007).

Transition Outcomes for Youth With ASD

1 in 59 children in the United States are estimated to have ASD (Baio et al., 2018), a neurodevelopmental disorder characterized by difficulties with social communication and restricted or repetitive behavior patterns. Each year, an estimated 50,000 individuals with ASD age out of the educational system and transition into adulthood (Anderson et al., 2018), a number that is expected to increase by over 120% in the next decade (Kirby, 2016). Research has consistently demonstrated that young adults with ASD experience difficulties in the transition to adulthood in multiple domains, including employment, education, independence, and social engagement (e.g., Howlin & Moss, 2012; Howlin et al., 2013). Data from the NLTS-2 show that young adults with ASD perform at lower levels than their peers with other disabilities (including speech–language impairment, learning disability, emotional disturbance, and ID) on several indicators of postsecondary education, employment, and living independently (Shattuck et al., 2012; Sosnowy et al., 2018). For example, only 69% of youth with ASD, compared to 85% of youth across all disability categories, were productively engaged in employment, postsecondary education, or job training within six years of leaving high school. Similarly, only 11.8% of youth with ASD, compared to 35.7% of all youth with disabilities, were living independently. These outcomes are most comparable to those of youth with ID, of whom 69% were productively engaged and 21% were living independently within six years of high school (Sanford et al., 2011).

Notably, research has shown that youth with ASD without co-occurring ID are less likely to be involved in post-school activities compared to those with ASD with ID

(Taylor & Seltzer, 2011). In addition, young adults with ASD have been found to have poorer social outcomes compared to young adults with DD, reporting lower levels of community involvement and social integration (Bernheimer et al., 2006; Hall et al., 2006; Maughan et al., 1999). These poor outcomes may be due to young adults with ASD not qualifying for services and supports after high school, as well as their challenges with social skills and emotion regulation (Hatfield et al., 2018). A review of the research on adult outcomes shows that few young adults with ASD develop meaningful friendships and relationships, and even fewer get married (Levy & Perry, 2011). These young adults often have limited social engagement and are likely to rely on parents to organize social activities (Levy & Perry, 2011; Howlin et al., 2013). In contrast, young adults with DD are more likely to have long-term relationships, get married, and have children (Hall et al., 2006; Maughan et al., 1999); however, their outcomes are still worse when compared to TD young adults (Levy & Perry, 2011).

Several predictors of young adult transition outcome have been identified in the research literature for adults with ASD, including the youth's cognitive status and language skills (Levy & Perry, 2011; Liptak et al. 2011; Seltzer et al. 2004), family background/socioeconomic status (Wei et al., 2015; Kirby, 2016), poor person-environment fit (Giarelli et al., 2013; Anderson et al., 2018), and a lack of comprehensive or integrated services (e.g., poor interagency collaboration between high schools and adult service providers; Chiang et al., 2013; Anderson et al., 2018). Kirby (2016) found that family background (i.e., White race, income, and mother's education) and youth functional performance (i.e., academic performance, self-care skills, and social skills) were significant predictors of young adult outcomes. Furthermore, a recent review of the literature on transition in ASD found that the poor transition outcomes experienced by youth with ASD are in part a result of the uncertainty about the role of parents during transition (Anderson et al., 2018). For example, parents often report feeling responsible for educating support professionals in postsecondary settings about their young adults with ASD, but in many cases, have been advised to play a more limited role in their young adults' lives (Peña & Kocur, 2013; Anderson et al., 2018). The research on parent perspectives of the transition period across diagnostic groups is described in more detail in the next section.

Parent Experience During Transition to Adulthood

The changing life trajectories in modern Western society are likely to impact the experiences of parents during the transition period. Adults are assuming parenting responsibilities later than in earlier generations and continue to have these responsibilities for a longer period of the life course (Arnett, 2007). In effect, parents are reaching "emerging middle age" when their young adults are becoming "emerging adults," which represents a significant turning point in their lives (Kloep & Hendry, 2010; Fingerman, 2017). Various theoretical perspectives posit that the parent experience will be affected by their young adult's experience, and that parent expectations will, in turn, impact their young adult's outcomes. For example, family systems theory suggests that changes in the young adult's life circumstances will reverberate throughout the family (Fingerman & Bermann, 2000). Similarly, developmental stake theory suggests that parental investment and involvement in their young adults' lives will impact parents' current and future wellbeing (Birditt et al., 2015). The expectancy-value theory of motivation posits that the expectations for the future that an individual has for oneself, as well as the expectations of others close to this individual, will impact that individual's likelihood of future success. Considering the bleak outcomes among young adults with ID and ASD, it is important to examine the way in which these outcomes impact the parent experience, as well as how parental expectations impact youth outcomes.

With the delayed onset of adulthood, the role of parents in their young adults' lives has transformed, with many parents concerned about the autonomy of their young adult children (Fingerman, 2017), and others feeling reluctant to "let go" (Kloep & Hendry, 2010). Across diagnostic groups, the level of parent involvement during the transition period depends on various youth and family factors, such as the youth's cognitive abilities, behavior, and gender, and the family's race/ethnicity, cultural background, and SES (Newman, 2005). Though parent involvement varies widely, parents of youth with ID and ASD, who experience greater difficulties transitioning into adulthood, are likely to play a larger role in their youth's lives (Whitney-Thomas & Hanley-Maxwell, 1996). Thus, the parent experience of the transition period across diagnostic groups deserves greater attention.

Parent Experience for TD Youth

Early studies suggest that parents cope fairly well during the transition to adulthood for TD children when their children leave the home (e.g., Adelmann, Antonucci, Crohan, & Coleman, 1989). For example, Adelmann and colleagues (1989) found that the wellbeing of mid-life mothers was not affected much by having an "empty nest." However, when young adults did not leave the home, parents believed they had failed to prepare their children to be independent (Clemens & Axelson, 1985). It is important to note that these studies were conducted at a time when it was socially normative for young adults to leave the home in their early twenties. Correspondingly, Clemens and Axelson (1985) found that in their western Virginia sample, 80% of parents of young adults age 22 or older who were living at home had not planned to have the child at home. These parents were also generally not willing to have their young adults continue living with them and hoped they would soon be out on their own. Of course, cultural norms can play a role in whether living at home is seen as socially acceptable (Fingerman, 2017). U.S. Census data show that Latinx and Black young adults are more likely to live at home compared to White and Asian young adults (Vespa, 2017). These racial/ethnic differences are consistent with differences in cultural values and beliefs; young adults are more likely to reside with parents if their cultures value parental involvement with grown children (Fingerman, 2017). Unfortunately, culture was not a variable in the 1985 study, as Clemens and Axelson's first sample of six married couples was all Caucasian, and they did not report the ethnic demographics of their second sample of 39 respondents.

Another study (Kloep & Hendry, 2010) examined the parent experience during the transition for mid-life parents (ages 34-62) of 63 young adults ages 18-25. A thematic analysis of semi-structured interviews with parents revealed that parents had a range of feelings and concerns surrounding the transition, from pride and relief to feeling that they were no longer needed and even rejected. The authors divided the parents into four clusters, based on their reactions and experiences during the transition. While some parents were "happy to let go" and some "reluctantly accepted" the transition, others felt a sense of "role loss" and seemed to use strategies to delay their children's growing up, sometimes resulting in a "power struggle" for the young adult's independence. Interestingly, there were significantly more young adults still living at home in the group of parents who talked about role loss and missing their children, and who in some way interfered with their children developing independence. On the other hand, parents' willingness to "let go" was affected by whether they saw their young adult as mature and whether they approved of their young adult's lifestyle. Overall, most parents expressed having some type of difficulty with letting go, regardless of whether their child left the home, which contradicts earlier research showing that parents were happy for their children to move out and live independently. Although this study did not demonstrate the direction of the relationship between parents' difficulty letting go and young adults' seeking of independence, the parent's reluctance to let go may go hand in hand with the young adult's ambivalence towards taking on adult responsibilities (Kloep & Hendry, 2010).

Whether or not increased parental involvement in emerging adulthood provides benefit to parents is unclear and may depend on the outcomes of the young adult. One study showed that parents who provided instrumental support to their young adults were likely to have fewer depressive symptoms (Byers et al., 2008), while other studies have shown that parental wellbeing was negatively affected by the problems experienced by the young adult (Fingerman et al., 2012; Pillemer et al., 2017). Specifically, parents who perceived their young adult as more needy than other young adults, and who believed that their young adult should have greater autonomy, were likely to have poorer wellbeing (Fingerman et al., 2012). This finding provides context as to why parents of young adults with DD tend to have poorer wellbeing during the transition period.

Parent Experience for Young Adults With DD

While parent involvement generally fades after the age of 21 for TD young adults, parents of young adults with disabilities may face an even greater burden to provide help and support for their young adults during the transition period (Bianco, Garrison-Wade, Tobin, & Lehmann, 2009). Studies have shown that parents of young adults with disabilities take on many different roles during the transition, acting as collaborators, decision makers, role models, trainers, mentors, and systems-change agents (Wandry & Pleet, 2003; Bianco et al., 2009). Thus, it is not surprising that parents' experiences during transition have been described as times of worry, stress, fear, change, and uncertainty (Boehm, Carter, & Taylor, 2015). Parents' concerns during the transition for young adults with disabilities include identifying where their young adults are going to live; helping their young adults secure employment; helping their young adults find and enroll in social activities and groups that can serve as a source of friends; and finding available agency assistance (Kraemer & Blacher, 2001; Chambers, Hughes, & Carter, 2004; Cooney, 2002; Whitney-Thomas & Hanley-Maxwell, 1996; Bianco et al., 2009).

The limited resources in the adult service system add to the stress parents are faced with (Kraemer & Blacher, 2001; Bianco et al., 2009; Jivanjee, Kruzich, & Gordon, 2009). Consequently, parents have reported feeling powerless during high school transition meetings and helpless when dealing with the adult service world (Cooney, 2002). Parents also expressed apprehension and fear about navigating through adult agency support systems and feeling frustrated about not being able to secure supports (Cooney, 2002). Similarly, Whitney-Thomas and Hanley-Maxwell (1996) found that compared to parents of children without disabilities, parents of children with disabilities (most commonly a learning disability or ID) felt greater discomfort and pessimism as their children prepared to leave high school. While these extra demands are being placed on parents to fill in the gaps of the service systems, parents are often confused and concerned about what role they should play in helping their young adult access supports (Cooney, 2002).

To examine the role parents play in their young adults' lives during the transition, Bianco and colleagues (2009) conducted interviews with nine families of young adults with ID whose living arrangements ranged from living at home to supportive living environments with varying levels of support. These parents felt that they had few opportunities to learn about the new roles they would have to play after their children left high school. Parents also reported feeling unprepared to take on an increase in responsibilities and were stressed, anxious, and fearful about performing these new roles. They often desired to collaborate with service agencies and providers in order to secure services, and they were not always successful, due to high turnover, constant change, and not feeling valued as collaborators in transition planning. When they could not secure services, these parents took it upon themselves to become trainers and mentors for their young adults. This continued parental involvement proved to be time consuming and emotionally demanding for many parents. Moreover, parents desired to find the balance between advocating for and supporting their child, and allowing their child to become their own self-advocate (Bianco et al., 2009). These findings are limited in their generalizability due to the small sample size made up of solely Caucasian middle-class families. However, these results reflect a commonality with the concerns described by parents of TD young adults, in terms of balancing involvement and independence. Nevertheless, parents of young adults with DD may be less likely to feel that their young adult is ready to become independent, and thus continue to maintain a high level of involvement in their lives (Jivanjee et al., 2009).

Sosnowy and colleagues (2018) examined the perspectives of 21 parents of young adults (ages 18-29) with ASD regarding desired transition outcomes and challenges to achieving them. Parents' views about the transition were clustered into three main themes, which were balancing security and autonomy, postsecondary education and holistic support needs, and work as a source of engagement and empowerment. Similar to parents of young adults in other diagnostic categories, these parents acknowledged their desire for their young adults to live independently, but believed the transition to greater independence should be a slow and careful one. Parents' main concerns were related to their young adult's safety and quality of life, as well as their young adult receiving adequate support. Unsurprisingly, parents acknowledged the service drop-off after high school and perceived services and supports post high school to be inadequate. In particular, parents did not feel that available services aligned with the support needs of their young adults. Overall, this study found that parents viewed transition outcomes as more complex than the typical measures, such as postsecondary education, work, and living independently, which they believed were simply a means to achieving broader goals (Sosnowy et al., 2018). This study was limited by its primarily Caucasian sample, which made it impossible to consider cultural variations in parent goals and expectations. Additionally, while these findings are critical for increasing our understanding of parent priorities for their young adults, they do not explain how these priorities relate to young adult outcomes.

The Relationship Between Parent Expectations and Young Adult Outcomes

Relatively little research has been devoted to understanding how young adult outcomes are aligned with the priorities of parents. Understanding parent perspectives and expectations for their young adults, as well as what they see as barriers and facilitators to achieving desired outcomes, is crucial to understanding the factors that affect transition outcomes (Sosnowy et al., 2018). NLTS-2 data show that parent expectations for the future predict youth educational and occupational outcomes, above and beyond the youth's disability status (Newman, 2005). Youth whose parents expect them to participate in postsecondary education and employment are more likely to have positive academic and employment outcomes following high school (Newman, 2005; Carter et al., 2012; Doren et al., 2012). Among youth with severe disabilities, those whose parents expected them to have a paid job following high school were five times more likely to be employed after high school (Carter et al., 2012). Furthermore, higher parental expectations for independent living post-high school are associated with youth taking on more household responsibilities in high school (Newman, 2005). In turn, youth who took on more household responsibilities in high school had higher rates of employment after high school (Carter et al., 2012). In contrast, low parent expectations and involvement contributed to poor adult outcomes in youth with ASD (Chiang et al., 2012; 2013).

Of course, parent expectations of their young adults may be influenced by many variables, such as the youth's disability, race/ethnicity, gender, and SES (Newman, 2005; Doren et al., 2012). For example, studies using NLTS-2 data demonstrate that parents from lower SES and minority backgrounds were found to have lower expectations for their youth's educational and occupational attainment (Newman, 2005; Doren et al., 2012), likely due to having fewer resources and perceiving fewer opportunities. Parents also had lower expectations of financial independence, but higher expectations of postsecondary education, for females (Newman, 2005; Doren et al., 2012). Thus, rather than focusing exclusively on the predictive value of parent expectations, it may be more useful to understand the mediating role of parent expectations on transition outcomes. This would allow for a more comprehensive understanding of where these expectations come from and how they interact with other factors to influence outcomes (Kirby, 2016).

In a study evaluating parent expectations as a mediator on transition outcomes for youth with ASD, parent expectations were found to significantly mediate the effects of family background (i.e., race/ethnicity, income, and education level) and the youth's functional performance (i.e., academics, self-care, and social skills) on adult outcomes (Kirby, 2016). Though family background and functional performance were initially found to predict adult outcomes, when parent expectations were added to the model, they were the only significant direct predictor of adult outcomes. Notably, in the same study, family background and the youth's functional capabilities predicted what parents expected for their youth's futures. Other studies have found that the youth's diagnostic status influenced parents' expectations of their youth (Doren et al., 2012; Blacher et al., 2010; Grigal & Neubert, 2004). For instance, parents of youth with ID had lower expectations that their youth would get a paid job after high school, compared to parents of youth with learning disabilities (Doren et al., 2012). In another study, parents of youth with ASD had lower expectations for community involvement compared to parents of youth with Down's syndrome (Blacher et al., 2010).

Beyond the traditional outcomes of employment and educational attainment, research has shed light on other important domains of adult life of value to parents. In a qualitative study conducted by Chen and colleagues (2019), parents' reported visions for their adolescents with ASD included domains such as community mobility, community participation, peer relationships, personal safety, and self-care, in addition to living situation, post-secondary education, and work. Parents' visions were complicated by their fears and uncertainty about whether their children would be able to live up to these expectations. This study was limited by a lack of cultural diversity (most participants were White) and did not include data about young adult outcomes. Interestingly, Grigal and Neubert (2004) found that among parents of high school students with disabilities, parents' lowest rated priority for transition planning was recreation and social activities; notably, parents of youth with high-incidence disabilities (e.g., learning disabilities, mild intellectual disability) rated these areas lower than parents of youth with low-incidence disabilities (e.g., autism, severe intellectual disability). These findings may in part be due to the limited emphasis placed on recreational and social goals in transition planning (Grigal & Neubert, 2004). More research is needed to understand how parents' social and recreational expectations relate to youth social outcomes.

To obtain a more nuanced understanding of the parent and family factors associated with successful transition outcomes, it is necessary to evaluate other parent variables that may contribute to their expectations. In addition to demographic variables, parent wellbeing and family quality of life during the adolescent years may play a role in parents' expectations for the future. Given the need for parental involvement during the transition period for youth with DD, it is quite possible that this increased pressure affects parents' wellbeing and quality of life. Thus, an evaluation of parental wellbeing and family quality of life from the teenage years and into adulthood is needed to further elucidate the parent factors that affect young adult outcomes.

Parent Wellbeing and Family Quality of Life

Research suggests that family wellbeing can be impacted by the many challenges associated with navigating the transition from school to adult systems (Blacher, 2001). Studies examining family quality of life (FQL) can help elucidate how the transition to adulthood affects parents of youth with DD. The construct of FQL has been defined broadly as ''the goodness of family life'' (Brown & Brown, 2004, p. 29). Most studies on FQL in youth with ASD have been conducted with families of younger children, but it is essential to understand how the transition to adulthood impacts FQL (Boehm et al., 2015). Some studies have examined how family wellbeing is impacted by the transition (e.g., Neece, Kraemer, & Blacher, 2009), highlighting the relationship between family wellbeing and transition satisfaction. For example, Neece and colleagues (2009) examined parent satisfaction with transition outcomes for a culturally diverse sample of 128 young adults with severe ID, and found that aspects of family wellbeing (e.g., maternal depression, overall stress in the family) were affected by the perceived success of the young adult's transition. However, this study does not specifically address how the parent experience evolves during the transition period.

In a longitudinal study, Lounds, Seltzer, Greenberg, and Shattuck (2007) investigated the factors that predict maternal wellbeing and quality of the mother-child relationship in a group of 140 adolescents and young adults ages 13-22 with ASD (63% with comorbid ID). They found that mothers tended to adapt to the challenges of transition, as demonstrated by declines in maternal anxiety and improvements in the mother-child relationship. While mothers generally experienced improvements in wellbeing as their children reached adolescence and young adulthood, 16% of mothers continued to demonstrate significant anxiety and depression. This percentage is significantly higher than the national norm, indicating that these mothers may be at an increased risk for psychological distress. Additionally, young adult factors such as reduction in behavior problems and use of psychotropic medication predicted improved maternal wellbeing and perceived mother-child relationship. Exiting high school was also predictive of improved maternal wellbeing, which may reflect the successful transition outcomes of the young adults who exited high school in this sample. Further, having comorbid ID was associated with declining maternal anxiety and depression. This finding reflects the unique challenges that parents of young adults with ASD face during the transition. Whereas young adults with ID may have greater continuity of support from high school to adulthood, young adults with ASD who have average cognitive functioning may be less likely to have continued formal support. Despite the many methodological strengths of this study, it used a primarily Caucasian middle-class sample and did not examine bi-directional effects, limiting its generalizability and causality inferences (Lounds et al., 2007).

Another study by Boehm and colleagues (2015) examined FQL in a large sample of 425 parents of adolescents and young adults ages 13-21 with ID or ASD, seeking to identify the child and family factors that impact FQL during the transition. These researchers found that parents were generally satisfied with their FQL, reporting the highest satisfaction with physical/material wellbeing, and the lowest satisfaction with emotional wellbeing. Interestingly, about 40% of parents reported dissatisfaction with the availability of support for the “special needs of all family members,” and 30% felt dissatisfied with the availability of support to relieve stress. The strongest positive association to FQL was parents’ religious faith, while the strongest negative associations were the young adults’ presence of challenging behaviors and greater support needs. Overall, these findings are positive, as life satisfaction can serve as a protective factor for these parents and their young adults as they navigate this challenging period. Additionally, the finding that parents were generally satisfied with their quality of life is consistent with research on FQL in younger children with disabilities (e.g., Epley, Summers, & Turnbull, 2011; Wang et al., 2006). However, given the challenges surrounding the transition period, changes in FQL would be expected to occur when young adults exit high school. Unfortunately, this study had too few participants who had left high school to meaningfully examine differences in FQL for young adults who had exited high school compared to those still in school (Boehm et al., 2015). Thus, additional research is needed on FQL for young adults with ASD who have already made the transition out of high school and into adulthood.

There is also limited research on the factors that may impact FQL during the transition out of high school for young adults with ASD. Examining parents' challenges during transition can help shed light on the processes and mechanisms that shape FQL. One study examined the challenges faced by 18 parents as their young adults transitioned from high school to community college (Peña & Kocur, 2013). These parents reported that their main roles were coaching their young adults to navigate services on campus and encouraging them to be more independent in college. The key challenges these parents experienced were navigating the Federal Educational Rights and Privacy Act (FERPA) and finding supportive faculty (Peña & Kocur, 2013). Though the sample in this study was primarily middle-class and ethnicity was not reported, prohibiting generalization, these findings correspond well with the concerns reported by parents of youth with ID. Parents consistently report having to take on the roles of mentor, trainer, and collaborator, in order to fill the voids inherent in the adult service system.

Taken together, the literature demonstrates the impact that transition to adulthood has on families of young adults with disabilities. As services drop off after high school, parents are forced to take on many new roles, which they are often unprepared to manage. Parents seek to find a balance between allowing their young adult to develop independence and providing the necessary support and assistance. Parents report challenges with navigating the adult service system and are concerned about their young adults receiving the supports they need. Despite these challenges, parents seem to be very resilient, adapting to the changes that come with the transition period and maintaining or even improving their overall sense of wellbeing. While many parents feel satisfied with their quality of life, this satisfaction may be related to how successful the transition is for their young adult.

The challenges surrounding the transition period may be more nuanced for young adults with ASD, whose trajectories have been shown to decline after leaving high school. While youth with ASD may continue to demonstrate improvements in ASD symptoms, behavior problems, and relationships with parents while they are in high school, these improvements have been shown to slow down and even cease after leaving high school (Taylor & Seltzer, 2010; 2011). Thus, for young adults with ASD, whose transition outcomes are often worse than their peers with other disabilities, FQL and parent wellbeing may be expected to decline after leaving high school. The studies described above did not find that this was the case.

As much of the research on parent experience and FQL has been conducted with parents of young adults with disabilities more broadly, additional research is necessary to better understand the distinct challenges that parents of children with ASD (without and without ID) and ID (without ASD) are faced with during transition. The few studies that examine the parent experience in parents of young adults with ASD are limited by small homogenous samples (e.g., primarily middle-class Caucasian mothers) and primarily cross-sectional analyses. Studies with more diverse samples are needed to parse out the role of cultural and socioeconomic variables in the parent experience during transition. Furthermore, longitudinal studies are needed to make causal inferences about how the transition out of high school impacts the overall parent experience. Longitudinal data would allow investigators to examine the relationship between transition experiences and outcomes and FQL across the young adult's lifespan (Neece et al., 2009). Additionally, following up with families through the teenage years into adulthood would allow for an examination of the various child, family, and environmental factors that predict FQL during the transition, as well as mediating and moderating mechanisms of the parent experience. Qualitative studies highlighting the unique experiences and challenges of parents of young adults with ASD, ID, and TD during the transition period, as well as potential protective factors, are critical in supporting parents as facilitators of successful transition.

The Protective Impact of Optimism

It is well known that parents of youth with ASD and ID experience heightened parenting stress and higher rates of mental health disorders, such as anxiety and depression (Blacher & Baker, 2017; Fairthorne, de Klerk, & Leonard, 2016). Research has identified various protective factors that may lessen the negative impact of the child with a disability on the parents, including dispositional optimism, or generalized positive expectancies about future outcomes (Carver & Scheier, 2014). Dispositional optimism is a relatively stable trait that has been associated with positive outcomes, such as positive parenting behaviors and decreased parenting stress, for parents of youth with and without disabilities (Ellingsen, Baker, Blacher, & Crnic, 2014). Despite the challenges faced by parents of youth with DD, many parents are reported to have high dispositional optimism (Blacher, Baker, & Berkovits, 2013). For these parents in particular, optimism has been shown to buffer the impact of challenging youth behaviors on parent stress and wellbeing (Blacher & Baker, 2007). There is evidence to suggest that optimistic parents can view the difficult behaviors of their children with DD in a more positive light (Koenig et al., 2010). For example, these parents may have an attentional bias for their children's positive behaviors (Segerstrom, 2001), and may therefore view their children as having a positive impact on the family, regardless of the child's disability.

More recent research has evaluated parent perceptions of the positive impacts of their child on the family (e.g., Blacher et al., 2013; Blacher & Baker, 2017). Similar to the research on dispositional optimism, studies have not found significant differences in parent perceptions of positive impact between youth with DD and TD youth. Moreover, a positive perspective has been found to buffer the impact of child behavior problems on parenting stress (Blacher & Baker, 2007). Surprisingly, in the study just described, dispositional optimism and positive family impact were not significantly correlated, and are therefore thought to reflect different types of positive perceptions. Though parents of youth with DD and TD may have similar levels of optimism and perceive their children to have a similar positive impact on the family, studies have also shown that mothers of youth with ASD and ID perceive higher *negative* impact of the child on the family (e.g., Blacher & Baker, 2017). As parental attitudes can have a significant impact on young adult transition outcomes, maintaining an optimistic outlook during the transition period may be especially important for parents of young adults with DD. Further research is needed to understand the influence of dispositional optimism, parent wellbeing, and perceived family impact on parental attitudes during the transition period and on transition outcomes for young adults across diagnostic groups.

The Context for This Study

This research uses data from the Collaborative Family Study (CFS), a 20-year longitudinal study on the developmental trajectories of children with ASD, ID, and TD and their families from age 3 years to young adulthood. The study was based at three universities: University of California, Riverside, University of California Los Angeles, and Penn State University. Participants were recruited through schools, daycare programs, and agencies serving individuals with developmental disabilities in the respective areas; interested participants contacted the research team directly. Children in the ID group had moderate to borderline cognitive delays (per DSM-IV criteria), were ambulatory, and were not diagnosed with autism. TD children were in the average range of cognitive development, had not been born prematurely, and had no evidence of developmental disability. Children in the ASD group were professionally diagnosed with ASD and/or receiving school-based services for ASD.

Overall, approximately 260 families participated in the longitudinal study. Families were assessed at 10 timepoints between the age of 3 and 15 (i.e., age 3, 4, 5, 6, 7, 8, 9, 12, 13, and 15). Notably, 20% of participants were added to the sample at age 13, as recruitment of ASD participants began at that time. At age 13, diagnostic groupings were determined based on the Wechsler Intelligence Scale for Children, 4th Edition (WISC-IV; Wechsler, 2003) Full-Scale IQ and the Vineland Scales of Adaptive Behavior-II (VABS-II, Sparrow et al., 2005). Youth in the ID group had an IQ between 45 and 84, and a Vineland Adaptive Behavior Composite score at least one standard deviation below the mean (i.e., < 85). Notably, some TD and ID youth who were recruited at age 3 were subsequently diagnosed with ASD and were re-classified into the ASD group. The current study began five years following the age-15 assessment point, and includes a subset of the 214 children (now young adults) and parents who participated in one or both of the most recent assessment points (i.e., age-13 and/or age-15).

Objectives

This study sought to: a) describe parents' reported challenges and expectations for their young adults, parental wellbeing, and family quality of life during the transition to adulthood, and b) identify parent variables in adolescence that may lead to more successful transition. Using a mixed-methods approach involving quantitative analysis of questionnaire data and qualitative content analysis of interview data, the following research questions were addressed:

1) What transition goals do mothers have for their young adults, i.e., (a) Do they differ among mothers of youth with ASD, ID, and TD? (b) Do mothers' goals align with young adult transition outcomes?

2) What challenges do mothers face regarding transition, i.e., (a) What do mothers worry about most for their young adults? (b) How do challenges and/or worries differ among mothers of youth with ASD, ID, and TD?
3) What is the role of maternal wellbeing, i.e., (a) Do maternal wellbeing and optimism during adolescence impact mothers' attitudes towards their child's future in young adulthood? (b) Do maternal wellbeing and optimism impact young adult transition outcomes?

Methods

Participants

Participants included a subsample of 214 families who participated in the age-13 and/or age-15 assessment of the Collaborative Family Study (CFS). 113 young adults and 118 parents participated in the follow-up study. The current study included 109 mothers of young adults (TD=53, ASD=23, ID=33), including three adoptive mothers and one grandmother. Four young adults participated without a parent, either because the young adult did not consent to parent participation or the parent was unreachable; these young adults were excluded from analyses. Additionally, one young adult participated with his father and was excluded from analyses. One mother participated without the young adult, due to the young adult's level of impairment, and was included in analyses. Ten young adults had two parents participate, including eight biological fathers, one stepfather, one adoptive father, and one adoptive mother. Second caregivers were not included in analyses to maintain the assumption of independent data points. Thus, the final N included in analyses was 109 mothers.

At the time of data collection, young adults were between 20 to 25 years of age (*M*=21.7, *SD*=1.2) and 58.7% male. As the typical age of transition out of the public school system is age 18 for diploma track and age 22 for non-diploma track, data collection occurred at the time of transition for some participants, and up to seven years following the transition for others. The average age of mothers was 54.2 (*SD*=7.0). Mothers were 71.7% Caucasian, 17.9% Hispanic/Latinx, 3.8% African American, 1.9% Asian, and 4.7% other. 68.5% of mothers were married, and 71.0% had completed a Bachelor's degree or higher. 72.8% had a family income greater than $70,000. There were no significant diagnostic group differences in mother's age, ethnicity, marital status, education level, or family income.

Notably, there were differences in socioeconomic variables, including mother ethnicity, level of education, and family income, between the 109 follow-up participants and the 105 who dropped out of the study after participating in either the age-13 or age-15 assessment point. Follow-up participants represented a less ethnically diverse (i.e., higher proportion of Caucasian participants) and more educated (i.e., higher proportion with a Bachelor's degree) sample with a higher family income (i.e., higher proportion over $70,000). There were no differences in young adult sex or maternal marital status between participants and drop-outs. Of the 109 follow-up participants included in analyses, eight did not participate at the age-13 assessment point. Thus, maternal wellbeing and IQ for 101 participants comes from age-13. For the other eight participants (including seven with ID and one with ASD), maternal wellbeing data comes from age-15, and IQ and adaptive functioning come from age-5. However, research has demonstrated that IQ and adaptive behavior remain generally stable from preschool to adulthood (e.g., Freeman et al., 1991; Schneider et al., 2014). See Table 1 for a comparison between follow-up participants and drop-outs. See Table 2 for detailed demographic information of families who participated in the follow-up study.

Procedure

All procedures for the larger follow-up study were approved by the Institutional Review Boards (IRB) at the University of California, Riverside (UCR) and the University of California, Los Angeles (UCLA). To recruit families for participation in the follow-up study, the research team (i.e., doctoral students in education and psychology) contacted parents who participated in the 13-year and/or 15-year assessment point by email and/or phone to explain the study and request their child's contact information. As young adult participants were between 20-25 years of age at the time of contact, they were contacted directly and were provided with information about the study. If willing to participate, a member of the research team scheduled a time to speak with the young adult over the phone to obtain informed consent for both themselves and their parent to participate. Young adults provided electronic consent via Qualtrics, a web-based data collection service, where they had the option to decline either their own participation, their parent's participation, or participation altogether.

Procedures differed slightly for the typically developing and diagnostic groups. Following consent for TD participants, a research team member conducted a 30-60 minute semi-structured phone interview with the young adult regarding their experience during the transition from schooling to adulthood. Young adults were then sent a link to complete standardized questionnaires via Qualtrics. If young adults provided consent for their parent to participate, a similar procedure was followed. A research team member contacted the parent to explain the study and obtain informed consent on Qualtrics. The parent then completed a 30-60 minute semi-structured phone interview, and was sent a link to complete online questionnaires. In these interviews and questionnaires, parents were asked to provide their perspectives on their young adult's functioning, as well as on their own experience and wellbeing during this transition period. Interview questions were developed by the research team and were based on the literature on transition to adulthood for youth with DD (e.g., Sosnowy et al., 2018; Grigal et al., 2011).

As the functioning levels of young adults in the sample ranged, a different procedure was utilized for participants with DD (i.e., participants with ASD, ID, and ASD+ID). First, parents of young adults with DD were asked whether they had conservatorship over their young adult; if so, the parent/conservator provided informed consent for themselves and their young adult, and young adults provided assent. Second, data collection for participants with DD occurred in-person at one of two university research centers (UCR or UCLA), to aid in comprehension of the interview questions and standardized questionnaires and to increase validity of responses. If travel to one of these research centers was prohibitive and participants were in Los Angeles, Riverside, or San Bernardino Counties, two members of the research team conducted an in-home visit. However, some appointments for participants with DD were conducted via Zoom due to the participants living out of state or due to in-person restrictions from Covid-19. Regardless, a research team member was present while the young adult completed questionnaires, providing additional explanation and visual supports as needed, and in some cases, administering the questionnaires verbally. In most cases, parents completed their questionnaires during the in-person or Zoom appointments, and a phone interview was scheduled for a later date, to maintain a consistent method of data collection for parents.

Throughout participation for all young adult and parent participants, members of the research team closely monitored responses to selected questionnaire items and interview questions, and followed up on any potential safety concerns (e.g., suicidal ideation). For in-person appointments, assessments of suicidal ideation were conducted during or immediately following the interview. For phone or Zoom appointments, or when potential safety concerns were identified following questionnaire completion, young adults or parents were contacted by phone for a follow-up safety assessment. The research team member who conducted the safety assessment sent a follow-up email with a safety plan and additional resources, as discussed with the participant. Young adult and parent participants were each compensated for their time with a $50 Amazon gift card, which was disbursed to the email address chosen by participants at the completion of questionnaires. Participants were also offered a free consultation and/or a list of resources related to the transition to adulthood.

Measures

As part of the follow-up study, young adults and parents completed several standardized questionnaires assessing their overall functioning, mental health, and wellbeing during the young adult's transition to adulthood. In addition, semi-structured interviews were conducted to obtain qualitative and descriptive information about young adults' and parents' experiences during the transition period. The present study focused on examining the parent experience, parent wellbeing, and protective factors in adolescence that predict successful young adult outcomes. Measures of cognitive functioning and adaptive skills were obtained at the age-13 assessment. However, only the measures central to this dissertation (i.e., measures of parent wellbeing, semi-structured parent interviews, and a composite measure of young adult transition outcome) are described below.

Parent Wellbeing Measures

Parental wellbeing was assessed through measures of parenting stress, perceived positive/negative impact of the child on the family, and dispositional optimism. The following measures were administered at both the age-13 and age-15 assessment points, and again at the young adult follow-up assessment (age 20-25). Age-13 parent wellbeing measures were used in analyses; if data were unavailable at age-15, age-13 data are used.

Symptom Checklist (SCL; Derogatis, 1993). The SCL is a 90-item parent report questionnaire that measures psychological symptoms related to anxiety, depression, hostility, and interpersonal relatedness. The current study utilized an abbreviated 35-item version of the measure. Parents are asked to rate their level of perceived distress for various symptoms (e.g., "feeling no interest in things") on a 5-point scale, ranging from (0) "not at all" to (4) "extremely." The current study utilized the total score of perceived distress (range 0-140), with higher scores reflecting a greater number of psychological symptoms and lower scores indicating greater wellbeing. This measure is well-established and has demonstrated adequate reliability, with a previously reported alpha coefficient of 0.84 (Cicirelli, 2000).

Family Impact Questionnaire (FIQ; Donenberg and Baker 1993). The FIQ is a 50-item parent report questionnaire that asks about the child's impact on the family compared to the impact other children have on their families (e.g., "My child is more stressful."). Parents endorse items on a 4-point scale ranging from (0) "not at all" to (3) "very much." The current study utilized the 20-item negative impact score (range 0-60) and the 7-item positive impact score (range 0-21). Previously reported alpha coefficients for the age-13 sample were 0.94 and 0.84, respectively (Blacher & Baker, 2017). The FIQ negative impact score is considered an indicator of parenting stress (e.g., "My child brings out feelings of frustration and anger more"), with higher scores indicating greater stress. On the other hand, the FIQ positive impact score reflects positive feelings towards parenting (e.g., "My child brings out feelings of happiness and pride more"), with higher scores indicating more positive feelings.

Life Orientation Test – Revised (LOT-R; Scheier, Carver, & Bridges, 1994). The LOT-R is a six-item (plus four filler items) self-report measure of dispositional optimism, or generalized positive (or negative) expectancies about the future. Items include: "In uncertain times, I usually expect the best," and "If something can go wrong for me, it will." Each item is rated on a 5-point scale ranging from (0) "I disagree a lot" to (4) "I agree a lot." Answers to three negatively worded items are reversed, and the six items are summed for a total score (possible range 0–24). Alpha coefficient for the age-13 sample was 0.79 (Blacher & Baker, 2017).

Semi-Structured Parent Interview

As part of a longer interview about their child's transition out of the school system and into adulthood, parents were asked open-ended questions examining their experience during the transition period, their perceived challenges during the transition, their worries and goals for their young adults, and their attitudes towards the future. Using interpretative phenomenological analysis (IPA; Smith, 1996; Smith & Osborn, 2004) and a process like that described by Huws and Jones (2008), qualitative analyses were conducted separately for the following questions and follow-up probes:

(1) What has this period of your child's life been like for you?

Probe: What has been hardest for you about this period in your child's life?

Probe: What do you worry about most for your child?

(2) When you think about your young adult's future, maybe 5 years from now, what are your goals for your young adult?

Probe: What emotions come up for you when you think about your child's future?

The semi-structured interview format enabled the interviewer to interpret and clarify the participants' responses and ask open-ended follow-up questions (e.g., "Can you tell me more about that?"). The interviewer made reflection and summary statements to ensure that the intended responses were captured. As suggested by Smith and Osborn (2004), this process allowed the interview to be guided predominantly by the participant's responses, rather than the researcher's preconceptions. Parent interviews were uploaded to Otter, an electronic transcription service, and the resulting transcriptions were read and edited by extensively trained undergraduate research assistants, who listened to the entire transcription.

Three graduate student coders then used a conventional content analysis approach, otherwise known as inductive category development, to qualitatively analyze the parent interview transcriptions. This approach allows the themes to be generated based on the data, rather than on the researchers' preconceptions (Hsieh & Shannon, 2005). Coders first conducted a preliminary independent analysis of a small set of interviews (*n*=10) and looked for overarching themes. After carefully reading through these transcriptions, coders annotated each transcription by highlighting important points and adding comments paraphrasing and interpreting these points in the right-hand margin. As this process continued, coders condensed their notes into short phrases to represent emerging themes from the data (Huws & Jones, 2008). The coders then met to review their separate lists of themes and determine how to best categorize the data into overarching thematic categories and subordinate themes within each category. This was done separately for the two questions, so that one pair of two coders generated a list of themes for parent challenges and worries, and a second pair of two coders generated a different list of themes for parent goals. Though these themes were derived directly from the data, they were also informed by the researchers' interpretation of the data in the context of their knowledge of the existing literature (Hsieh & Shannon, 2005).

Using the new list of themes, the researchers independently re-coded the small set of interviews, and then met again to consensus code the preliminary set of interviews and finalize the list of themes and subthemes. The coders continued to independently code the remaining parent interviews in sets of 10 to 15, meeting after each set to consensus code until agreement was reached. To adequately capture the richness of the data, the coders added and adjusted themes and subthemes as additional interview transcripts were reviewed. When themes were added or revised, the previously coded interviews were re-coded to ensure consistency across all interviews. If a response fit clearly into more than one code, multiple codes were applied to that response in order to fully capture the content of that response. Quotes that were double coded are indicated in footnotes throughout the Results section. Finally, to examine parents' attitudes towards their child's future, their response to the following question was analyzed: *"What emotions come up for you when you think about your child's future?"* Emotions were coded on a scale of 1 (exclusively negative) to 4 (exclusively positive). Negative emotions included fear and sadness, while positive emotions included hope and happiness. Each parent interview transcript was coded by two coders independently, and the coding pair met to resolve discrepancies until consensus was reached for 100% of the sample. See Tables 2 and 3 for a list of identified themes representing parent challenges/worries and goals. Note that some thematic categories do not have corresponding subthemes (noted as N/A on the tables), as these categories were determined to fully represent the content of parents' responses without the needed for subcategories.

Young Adult Outcome Measure

An overall measure of young adult transition outcome (Transition Outcome Composite; TOC) was developed by the research team based on young adult and parent responses to selected items on the questionnaires and interviews. The TOC is based on three key outcomes of interest, each rated on a 4-point scale from 0 (most successful outcomes) to 3 (least successful outcomes). The domains included in the TOC are 1) participation in professional activities (i.e., employment, higher education), 2) participation in social activities (e.g., friendships, community), and 3) independence (e.g., adaptive skills, living supports). Ratings for each of these three domains are summed to create a functional outcome rating on a 0-9 scale (the overall TOC score). TOC score descriptors are as follows: 0-2 = Very Good Outcome, 3-4 = Good Outcome, 5-7 = Fair Outcome, and 8-9 = Poor Outcome.

Professional transition outcomes were coded based on youth and parent responses to questionnaire items about current employment and post-secondary education enrollment. Codes of 0 indicate full-time employment or enrollment in a four-year university, or a combination of any post-secondary program enrollment with a part-time job, which together are equivalent to full-time. A code of 1 indicates community college enrollment or other part-time post-secondary education enrollment, or part-time paid employment. A code of 2 indicates a supported or sheltered employment or education program (e.g., a transition/independent living skills program). A code of 3 indicates a day center, or no employment or educational enrollment (jobs less than 5 hours per week were considered no employment).

Social involvement outcomes were coded based on young adult responses to questionnaire items asking them to provide a frequency count of how many good friends they have, and to rate their overall satisfaction with their social support on a 7-point scale, in which higher ratings indicate greater social satisfaction. TOC social involvement codes are as follows: 0 = many friends (5 or more friends) and high satisfaction (rating of 6 or 7); 1 = some friends (1-5 friends) and high satisfaction (rating of 6 or 7), or any number of friends with moderate satisfaction (rating of 5); 2 = any number of friends with low satisfaction (rating of 4 or lower); and 3 = no friends, or one friend with low satisfaction (rating of 4 or lower).

To determine independence outcomes, young adult and parent responses to questionnaire items about their current living situation were used to provide initial guidance. In addition, young adults rated their own independence in their living situation, their level of responsibility in the home, and their control of their time on a 7-point scale, with higher numbers indicating greater autonomy. TOC independence codes are defined as follows: 0 = living independently with or without roommates; 1 = in semi-sheltered accommodation (e.g., group home, dormitory) or still at home, high degree of autonomy (self-rating of 6-7); 2 = living with parents, some autonomy (self-rating of 3-5); and 3 = living with parents with limited autonomy or in an institution or residential facility (self-rating of 1-2).

When determining codes for each domain, two coders independently compared young adult and parent responses on questionnaire items. If data were only available for one participant (e.g., only the young adult participated in the study), only that participant's responses were used. If youth and parent responses were aligned, their responses determined the best fitting code. If there was disagreement between young adult and parent responses, coders made an informed decision based on the domain of interest, other indicators available in the data, young adult developmental status, and interview transcriptions and notes. In most cases, this additional information was used to select one reporter's score. For example, if a parent response in the independence domain suggested a 1, but the young adult response suggested a 0, coders would reference the interview transcriptions to investigate which code is a better fit and select a 1 or 0 based on the interview data. In rare cases when young adults and parents were 2 or more points apart, coders used other indicators in the data to either select one reporter's rating or go in the middle. When determining whether to trust the young adult or parent participants' responses, coders were mindful of the literature findings on informant reports. For example, previous research has shown that caregivers of adults with ASD report more difficulties in everyday life skills, compared to what is reported by the adults themselves (Sandercock et al., 2020). Therefore, coders carefully considered multiple data indicators (e.g., parent interviews and responses on questionnaires) and adult developmental status when deciding on the best-fitting codes.

Data Analysis

Qualitative Analyses. To answer research questions #1 and #2a (i.e., *What transition goals do parents have for their young adults? What challenges do parents face regarding transition? What do parents worry about most for their young adults?),* dichotomous codes and percentages were determined for each theme and subtheme endorsed in the parent interviews. The dichotomous codes indicate whether each mother endorsed a certain theme at all during the selected interview questions. The percentages reflect the proportion of mothers in each diagnostic group that endorsed the theme or subtheme. Themes are reported separately for challenges/worries and goals. In addition to these descriptive analyses, representative quotes illustrate each thematic category. Similar to Berkovits and colleagues (2020), qualitative data were used to quantitatively examine the relationship between parent variables in adolescence, parent attitudes towards their children's future in young adulthood, and young adult transition outcomes.

Quantitative Analyses. Quantitative analyses were conducted to understand how parents' expectations relate to young adult transition outcomes, and how parents' mental health and wellbeing predicted adult outcomes. To answer research question #1b (i.e., *Do parent goals align with young adult transition outcomes?)*, descriptive analyses (means, standard deviations, and ranges) are provided for the three domains included in the Transition Outcome Composite (TOC), as well as for the Overall composite. A one-way ANOVA was then conducted to examine differences in the TOC between young adults with ASD, ID, and TD, followed by post-hoc comparisons between groups. To maintain a sufficient sample size for comparison, participants with co-occurring ASD and ID were combined with the ID group. Based on the poor transition outcomes reported for youth with ASD with average cognitive abilities (e.g., Shattuck et al., 2012), it was hypothesized that the differences in outcomes between the ASD and ID groups would be insignificant.

Bivariate Pearson correlations were conducted to examine the relationship between young adult outcomes in the TOC domains (professional, independence, and social) and the presence of mothers' goals (based on qualitative coding) in the respective areas. Mothers' goals that were correlated with the respective outcome areas (e.g., professional goals correlated with professional outcomes) were included as predictor variables in three separate multiple linear regressions, one for each TOC domain. In addition, the young adult's diagnostic status (TD or DD) was added into the model as a predictor. These analyses examined whether mothers' goals in specific areas predicted young adult transition outcomes in the respective areas, controlling for the youth's diagnostic status. It was hypothesized that higher maternal expectations would predict more successful outcomes in each domain, above and beyond the youth's diagnosis.

To address research questions #1a and #2b (i.e., *How do parents' challenges, worries, and goals differ for parents of youth with ASD, ID, and TD?),* a one-way ANOVA was used to compare the frequency of each thematic category endorsed by parents between young adults with ASD, ID, and TD. It was hypothesized that certain thematic categories (e.g., caregiver aging, navigating services, social concerns, independence goals) would be more frequently endorsed by parents of young adults with ASD or ID. It was also expected that there would be minimal to insignificant differences in the themes endorsed by parents in the ASD and ID groups.

To answer research question #3a (i.e., *Do parent wellbeing and optimism during adolescence impact parent attitudes towards their child's future in young adulthood?),* a one-way ANOVA was conducted to examine differences in parent attitudes, as coded on a 1-4 scale (1 = exclusively negative; 4 = exclusively positive), between the ASD, ID, and TD groups. In addition, a one-way ANOVA examined differences in parent wellbeing and optimism (i.e., total score on the Symptom Checklist, positive and negative impact scores on the Family Impact Questionnaire, and total scores on the Life Orientation Test) across diagnostic groups at the age-13 (or age-15) and follow-up assessment points. These analyses allowed for a detailed examination of the relationship between the youth's diagnosis and parental wellbeing and attitudes across time.

Bivariate Pearson correlations were conducted to examine the relationship between maternal wellbeing in adolescence and mothers' attitudes towards their child's future in young adulthood. Two multiple linear regression analyses were then conducted to examine the predictive effect of maternal wellbeing during adolescence on future attitudes. Predictors included SCL total score, FIQ positive and negative impact scores, and LOT total score from the age-13 (or age-15) assessment points. The first analysis examined the predictive effect of maternal wellbeing alone, while the second analysis also included the youth's diagnostic status (i.e., TD vs. DD) as a predictor. These analyses helped to illuminate how various aspects of maternal wellbeing impacted mothers' attitudes towards their child's future, above and beyond the youth's diagnosis. The same procedure was used to answer research question #3b *(i.e., Do parent wellbeing and optimism impact young adult transition outcomes?)*, but the outcome variable in this case was the Overall TOC score (0-9 scale). The aim of these analyses was to identify the parent wellbeing variables in adolescence that impact young adult outcomes, when controlling for the youth's diagnostic status.

Results

Diagnostic Groups

To maintain a sufficient sample size for comparison, young adult participants were grouped into the following three diagnostic groups: TD (*n*=53), ASD (*n*=23), and ID (including ID+ASD; *n*=33). Before combining these groups, one-way ANOVAs were conducted to determine whether there were mean differences in IQ and adaptive behavior between six diagnostic groups: TD, ID, ASD, ASD+ID, borderline ID, and ASD+borderline ID. As expected, the TD group had significantly higher average cognitive functioning than the other groups (all *p*'s<.001), with the exception of the ASD group. The TD group also had higher adaptive functioning compared to all other groups (all *p*'s<.001). As there were no significant differences in cognitive or adaptive functioning between the ASD+ID and the ID groups, participants with co-occurring ASD and ID were combined with the ID group. This allowed for a comparison between the outcomes of young adults with ASD with average to above average cognitive abilities, and those with ID with or without ASD (Baker & Blacher, 2019). Additionally, participants with borderline ID (IQ between 70-84) were combined with the ID group for analyses. Though there were differences in IQ between the borderline ID and ID groups, there were no significant differences in adaptive behavior between participants with borderline ID (IQ between 70-84) and those with ID (IQ < 70). Thus, it was expected that the borderline ID group would be more similar to the ID group than the TD group in terms of functional outcomes.

Comparing the three diagnostic groups used in current analyses, there were significant differences in IQ between the three groups, *F*=169.7, *p*<.001, with the ID group scoring lower than the TD and ASD groups (*p's*<.001). There were no significant differences in IQ between the TD and ASD groups. There were also significant between-group differences in adaptive behavior on the Vineland Adaptive Behavior Scales, *F*=114.6, *p*<.001, with the TD group having significantly higher adaptive functioning compared to the ID and ASD groups (*p*'s<.001). The ID group also had significantly lower adaptive functioning compared to the ASD group (*p*<.01). Group sex differences were also present, *F*=7.0, *p*<.001, such that the ASD group had a higher proportion of males compared to the TD group (*p*<.01).

Primary Results

In the sections below, qualitative results are presented by thematic categories of goals and challenges/worries endorsed by mothers during semi-structured interviews. Representative quotations and details are provided to illustrate each theme and subtheme. Descriptive analyses are also provided to understand the proportion of mothers within each diagnostic group that endorsed each theme, and chi-square statistics are presented for themes that differed by diagnostic group. Regression analyses are then presented to understand how mothers' wellbeing in adolescence related to mothers' future attitudes and their young adult's outcomes.

Transition Goals

The first research question examined what transition goals mothers have for their young adults five years from now, and whether there are different goals among mothers of youth with ASD, ID, and TD. Across diagnostic groups (*N*=108), mothers' most reported transition goals for their young adults fell into three broad categories: Professional (72%; *n*=78), Social (54.6%; *n*=59), and Independence (53.7%, *n*=58). These broad themes and subthemes, as well as other themes captured in interviews are reported below. See Table 5 for differences in mothers' transition goals by diagnostic group.

Professional Goals. Within the category of Professional goals, 39.8% of mothers endorsed the goal of finding a Meaningful Career, while 20.4% hoped their young adult would simply Find a Job, and 34.3% reported Educational goals. Though there were no between-group differences in the percentage of mothers who had overall Professional goals or Educational goals, a higher proportion of mothers of young adults with TD (49.1%) and ASD (52.2%) endorsed the goal of their young adult finding a Meaningful Career than mothers of young adults with ID (15.6%) (χ^2=11.8; p<.01). Correspondingly, more mothers of young adults with ID (37.5%) reported the goal of their young adult Finding a Job, compared to mothers of young adults with ASD (21.7%) or TD (9.4%) (χ^2=9.2; p<.05). Note that Meaningful Career and Finding a Job are mutually exclusive codes, in that Meaningful Career reflects mothers who explicitly stated that they hope their young adult finds a career they are satisfied with or fulfilled by. For example, two mothers of TD or ASD young adults reported goals of finding a Meaningful Career:[1]

> *"My goal for him is that he will finish and be a physical therapist… and be in a successful career somewhere where he wants to be."*
>
> *"I'd love to see him get that four-year degree and have an idea of what he wants to do with it… and get an internship in that field… he went from picking one challenging field to another, so my hope is that he'll be able to find something to do that fits with his strengths."*

In contrast, more mothers of young adults with ID reported the goal of their young adult finding a stable job. As two mothers of young adults with ID put it:

> *"In a perfect world…that he's got a job that seems to be relatively stable."*

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[1] These quotes were also coded as Educational Goals.

> *"One of the big goals we have hopefully is some kind of gainful employment because he does have good skills and we want him using those and we want him to have that sense of accomplishment."*

In addition, over a third of mothers in all diagnostic groups had some type of Educational goal for their young adult, including getting a college or graduate degree, as expressed by these mothers of TD young adults:

> *"That she has an education… that she gets a degree somewhere, somehow, and that she does something for herself."*
>
> *"To have a B.A. and to find some kind of career path."*

Mothers of young adults with ID also had educational goals, including attending a vocational or life skills program. For example, these two mothers reported:

> *"I would like her to be in 5 years…. in a good program. I would love it if it was 5 days a week, even 5 hours a day of something. Like a couple hours of learning and to be more independent with all of her skills – dressing and feeding and the home car, doing her teeth – things like that. And then of course having friends; whatever this program looks like they build friendships again."*[2]
>
> *"Hopefully she will be at a program and she will be doing alright… I hope that she finishes school or is on the way to finish school."*

Social Goals. In the category of social goals, almost a third of all mothers (29.6%) reported marriage/relationship goals, with no significant differences between diagnostic groups. Examples of goals in this area from mothers in the TD group include:

> *"Also, of course, that he has a girlfriend. I don't think I want him to marry before he's 30 but he can date and get to know someone, have a relationship that leads to marriage."*
>
> *"I would like him to have a meaningful relationship that is satisfying."*

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[2] *This quote was also coded as Daily Living Skills and Friendship/Social Support.*

Mothers of young adults with ID and/or ASD also hoped for their children to date and eventually find a relationship, but often worried about their lack of dating experience or anticipated that they would have relationship difficulties. For example, mothers reported:

> *"To have a few experiences with girls. I don't think [he] has kissed anybody before."* – Mother of a young adult with ASD
>
> *"I'd certainly like him to get interested in dating."* – Mother of a young adult with ID
>
> *"I hope that he is either in a relationship with someone that he feels he can have a family with or a life with. I hope he doesn't do that much before then. I think he is too young and he is not ready for that type of relationship."* – Mother of a young adult with ASD
>
> *"I hope in my heart that he does find someone that can tolerate him. He's not easy. He really isn't, I mean we joke about it… I just hope that he can find someone that's you know, like him, that understands him, that can appreciate the good points of who he is and what he's capable of."* – Mother of a young adult with ASD

In addition, 18.5% of mothers reported friendship or social support goals, with a higher proportion of mothers of young adults with ID (31.3%) and ASD (17.4%) endorsing this theme compared to mothers of TD young adults (11.3%) (χ^2=6.4; p<.05). For example, several mothers of young adults with ID and/or ASD hoped for their young adults to develop friendships and be socially engaged with their peers:

> *"[I hope] he goes to work and gets to be around adults his own age… I just think it would give him more opportunities of socializing with his own friends and not with my friends."* – Mother of a young adult with ID
>
> *"I think his top three goals should be relationships. Forming them, making them, like how do I do that. Navigating those kinds of waters."* – Mother of a young adult with ASD
>
> *"I guess he'll have to work out the social on his own pretty much. He used to do play dates and social skills class; he did all that. Outside of school, I took him to*

> *[social activities], and I can't do that anymore, so really he's got to just push himself out there*." – Mother of a young adult with ASD

A smaller overall proportion of mothers (13.0%) hoped their young adult would build their own family and/or have children. More mothers of TD young adults (20.8%) reported this goal than mothers of young adults with ASD (0%) or ID (9.4%) (χ^2=6.8; p<.05). These mothers shared similar sentiments:

> *"I want the best for her, and I want her to be happy, and of course I want grandbabies."* – Mother of a TD young adult

> *"I want grandbabies. You know, he's loved kids, loves, loves, loves kids. And I love kids… so we look forward to family. I don't know how he's going to support them. We don't talk about that yet; he'll figure it out."* – Mother of a young adult with ID

> *"If she wants to have kids, I hope she has kids."*– Mother of a TD young adult

Some young adults in the sample already had their own children, including a young adult with ID who lives at home and whose parents adopted the child. Her mother hoped that she would take parenting classes to learn how to better support her family:

> *"I want to get both her and her boyfriend into parenting classes. They're living under our roof and obviously, we're there 24/7 for her son but I want her to be more hands-on, and as much as we encourage her, I think having an outside party with parenting classes would be very helpful for them."*

A smaller proportion of mothers (6.5%) hoped their young adult would hold off on getting married and/or having children. For example, a mother of a TD young adult reported that she would prefer her daughter waits to get married so that she can focus on her dreams:

> *"She never talks about family or having children, which I'm ok with. I'm ok. I don't want her to get distracted; I want her to fulfill her dream. Later on in life, if she thinks she wants to get married, that's ok."*

Similarly, some mothers expressed that while they hope their young adult will get married eventually, they are not in a rush, such as this mother of a young adult with ASD:

> *"I'd love him to be able to live independently and don't know where the relationship side of things are going to go, but I'm not in a rush for that. I think we're keeping the goals manageable."*

Another mother of a young adult with ID hoped that her daughter would get married someday, but expressed concern over her having children:

> *"To get married someday, I'm on board with that… she wants kids… that's a concern. I don't think she could handle being pregnant or having a child… I don't want to take that away, but I don't know how we'll get there."*

Additionally, 4.6% of mothers hoped their young adult would maintain a close relationship with their current family, such as a mother of a TD young adult, who reported, *"I want him to be around his mom."*

Independence Goals. In the category of Independence goals, almost a third of all mothers (29.6%) reported the goal of their young adult being financial independent or stable. A higher proportion of mothers of TD young adults (41.5%) endorsed this goal compared to mothers of young adults with ASD (26.1%) and ID (12.5%) (χ^2=8.6; p<.05). For example, two mothers of TD young adults reported, *"I would hope that he is financially self-sufficient,"* and *"I want her to help me out with the bills."* Similarly, these mothers of young adults with ASD hoped their children would have a job that would allow them to be self-sufficient:

> *"I'd love it if he has a job and he is reasonably self-sufficient, maybe even still has some services for independent living skills, some kind of support for that, but has his own place, maybe a roommate."*[3]

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[3] This quote was also coded as Finding a Job, Living Independently, and Daily Life Skills.

> *"I'd like him to make a livable wage, which is in this day and age, is impossible for many kids to do that, but I'd like him to have a real job."*[4]

In contrast, some mothers of young adults with ID and/or ASD hoped their young adults would learn how to better understand and manage their finances, as reported by this mother of a young adult with ID:

> *"She understands you need money to pay for things, but she doesn't understand managing her money and prioritizing things… I would want her to have a better understanding of finances and to be more independent with how she spends her money… she was recently buying something… and they were getting her to sign up for their credit card and she had no clue…"*

A quarter of mothers (25.0%) hoped their young adult would live independently from their parents. More mothers of young adults with ID (40.6%) or ASD (43.5%) reported this goal compared to mothers of TD (7.5%) young adults (χ^2=16.5; p<.001). Mothers in the ASD group often hoped their young adult would be living with roommates or in a university housing environment, such as one mother, who reported, *"I'll still help him here and there, but he'll be on a campus, sharing an apartment with roommates, studying."* Several mothers of young adults with ID hoped their young adult would live in an organized or assisted living facility that involved some type of educational or vocational component and social activities, as reported by these mothers:

> *"Five years from now I would like to see her in an independent living situation with roommates in an organized living situation. I am not going to call it a group home because that term and that model is wrong… [but] an organized group home with structured social activities… that to me would be the perfect setup. I sometimes think I'm going to have to be the one to create it.*"[5]

> *"We're also looking at the possibility of getting into an assisted living program. I'm not so keen on that just yet; it's going to take a little convincing for me… But*

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[4] This quote was also coded as Finding a Job.

[5] This quote as also coded as Friendships/Social Support.

> *five years from now… I mean he'll never I don't think live completely on his own, but there are some, I guess you would call it assisted living, where they have eight or ten autistic adults all in one household and they take turns with jobs and such… It's almost like a dormitory situation for college kids but small."*
>
> *"I would love to see him try to live away from me for a short time. We were just talking about a college a couple hours from here that has a pretty incredible special needs program… They will assign them aids for morning, evening, and during the school time to take notes and help with tests… to see what life would be like without me being the primary caregiver. Because as I tell him all the time, I will always be here, so I think this is the time for him to at least get a taste of what living on his own or in a group home or in his own apartment could be like... I would like to see him become part of some sort of a crew and form at least one longer-term friendship."*[6]

Though only 4.6% of mothers reported the goal of their young adult as developing daily life skills, a higher proportion of mothers in the ASD and ID groups endorsed this goal (ASD=8.7%, ID=9.4%, TD=0%; χ^2=6.3; *p*<.05). For example, one mother of a young adult with ASD hoped her son would "*learn life skills like how to save money, and how to invest money.*" Similarly, these mothers of young adults with ID reported:

> *"I would like there to be more programs that help him learn how to be more functioning because 20 years from now, I'm probably not going to be around."*
>
> "*You still need to learn to be independent and be on your own; I'm not always going to be here to take care of you. You have to learn how to do this stuff, figure out how to do it.*"

Some mothers also reported other Independence goals (13.0%) that did not fit into a subtheme. For example, several mothers hoped their young adults would gain independence by driving:

> *"I'd like to see her drive in the future. That would be my main goal to see her drive."* – Mother of a TD young adult

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[6] This quote was also coded as Educational Goals and Friendships/Social Support.

> *"I wish he could drive, even just a little bit. That would lighten my load. Even if he could just drive to where he gets on the bus or something, depending on where his job might be."* – Mother of a young adult with ASD

> *"I want to see her be able to drive a car and to be able to do things on her own."* – Mother of a young adult with ID

Overall Happiness/Fulfillment. In addition to Professional, Social, and Independence goals, another common goal reported by mothers was Overall Happiness and Fulfillment (28.7%; n=31). A higher proportion of mothers of TD young adults (41.5%) endorsed this goal than mothers of young adults with ASD (8.7%) or ID (21.9%) (χ^2=9.7; p<.01). For example, mothers of TD young adults reported:

> *"I would love for her [to be] content with life and [be] functioning well in her life… I don't really care where she chooses to live. I want her to make her way in the world, wherever that takes… I guess being open minded to whatever opportunities are there."*

> *"I hope the happiness and peace of mind she has right now just continue to stay with her because she's really balanced."*

Despite a lower proportion of mothers of young adults with ID and/or ASD endorsing this goal, there were several mothers in these diagnostic groups that reported similar goals. For example, mothers of young adults with ID and/or ASD reported:

> *"I hope she's happy and healthy."*

> *"Just finding something that makes him happy that will allow him to live."*[7]

> "*Really there is only one thing we want from him and that is to be happy."*

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[7] This quote was also coded as Independence: Financial Stability/Career.

Thus, though mothers of ASD and ID often had additional goals that mothers of TD young adults did not, mothers across diagnostic groups reported similar sentiments of wanting their young adults to be happy.

Less Common Goals. Less common goals that were nevertheless reported by mothers across diagnostic groups included Self-efficacy and Motivation (17.6%) and Physical Health (8.3%). In terms of Self-efficacy/Motivation goals, mothers hoped that their young adults would set goals and plan for their future. As one mother of a TD young adult reported:

> *"I want him to continue growing and progressing and doing what he wants to do, setting goals, obtaining goals, figuring out how to be happy, and what that means."*[8]

Some mothers mentioned computers and gaming as potential barriers to motivation, as represented by these quotes:

> *"[I hope] he has more of his own life going on. I don't mean sitting on the computer in his room."* – Mother of a young adult with ID
>
> *"I'd love for him to be healthy and go to the gym because he was doing it for a little while and then he stopped… But also, I think this is also a challenge - a lot of our kids are gamers and gamers don't tend to be real healthy so…"* – Mother of a young adult with ASD[9]

Examples of mothers' Physical Health goals included general statements such as, *"I want her to be healthy,"* as well as specific health concerns and needs. One mother of a young adult with ID reported:

> *"Since he got his power chair, he doesn't do a lot of walking (he used to walk with a walker), and his cardiovascular capacity has really tanked… We are currently working on evaluating him for a new walker. So, getting that daily exercise to*

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[8] This quote was also coded as Overall Happiness/Fulfillment.
[9] This quote was also coded as Physical Health.

> *maintain his major organs and to get him on a program that he can do on his own."*

Furthermore, though between-group differences were not statistically significant due to the low overall percentage of mothers who endorsed these goals, mothers in the TD and ID groups reported some goals that no mothers in the ASD group reported. These included the young adult having Time for Leisure and Hobbies (TD=13.2%, ID=12.5%), and the young adult's Mental Health (TD=7.5%, ID=6.3%) and Safety (TD=1.9%, ID=9.4%). As far as Time for Leisure and Hobbies, mothers in the TD and ID groups hoped their young adults would travel or have time to pursue their interests or volunteer activities, as expressed by these mothers:

> *"I would love her to do singing, whether it be helping with a homeschooled kid's choir, or something like that that would fit into her schedule, something simple on the side. I would love to see her volunteer somewhere… I would love to see her pursue adventures like that."* – Mother of a TD young adult

> *"I would like for her to travel, honestly, before she starts settling down into what she wants to do in medical school. My goodness, you know that's a long haul without a break. So I would love for her to take a year and see the world with a friend, see… what life is like in different places. I would just love her to have this experience before she gets locked into something… Go discover, that's my main goal."*– Mother of a TD young adult

> *"We want to do some camping; we want to travel and have her see more... and learn more about the states."* – Mother of a young adult with ID

A small percentage of mothers in the ID and TD groups reported Mental Health goals, including the following:

> *"I hope that in five years, he is stable, taking his medications."* – Mother of a TD young adult

> *"For him to stay healthy, physically was well as emotionally."* – Mother of a TD young adult[10]

> *"It takes a lot of people, a lot of help. We go to a psychiatrist. He has anxiety and OCD. The doctor gives us advice which is helpful too. Three of us go – my daughter has anxiety and depression; I have anxiety and depression. We understand how he feels. We try to help him and be patient."* – Mother of a young adult with ID

A few mothers of young adults with ID and one mother of a TD young adult reported that they wanted their young adults to be safe, either out in the community, or from victimization or harassment. Safety goals are illustrated by these quotes:

> *"It goes back to her safety. Someone luring her out of work… I've taught her it's okay to talk to people, it's okay to be friendly… But that's it, you don't go with them. I'm afraid that someone will talk her into drugs or give her something."* – Mother of a young adult with ID

> *"Again, safety issues. If somebody get hurts that they know to either go to the hospital or call a doctor."* – Mother of a young adult with ID

> *"I want everything to be safe. It is not a very safe world right now."* – Mother of a TD young adult

Additionally, only mothers of TD young adults reported goals related to Faith/Religion and Meaningful Involvement in Society (5.7% of TD mothers for each goal category). For example, these mothers of TD young adults reported:

> *"I would hope that he has a good relationship with God."*

> *"I would hope that he… continues to grow and learn and be a benefit to this world. I want him to be a contributing human being. He is now and I know that will continue."*

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[10] This quote was also coded as Physical Health.

Mothers' Goals and Young Adult Outcomes

Young Adult Transition Outcomes. To investigate whether mothers' goals are aligned with young adult transition outcomes, descriptive analyses were first conducted to understand young adult transition outcomes on the Transition Outcome Composite (TOC), a measure developed by the research team based on young adult and parent responses to selected items on questionnaires and interviews (see Methods section for more detailed information). Note that TOC domain scores are on a Likert scale from 0 (Very Good) to 3 (Very Poor), with lower scores indicating *more* successful transition outcomes. Ratings for each of the three domains are summed to create an Overall TOC score, rated on a 0-9 scale. Across diagnostic groups, young adults had an average Overall score of 3.25 (*SD*=2.3; Range=0-8). A one-way ANOVA revealed significant between-group differences in young adult transition outcomes on the Overall TOC score by diagnostic group (*F*=49.14; *p*<.001). Results from a Bonferroni post-hoc analysis indicated that the TD (*M*=1.68; *SD*=1.62) group had significantly better overall transition outcomes than the ID (*M*=5.12; *SD*=1.72) and ASD (*M*=4.35; *SD*=1.90) groups (*p*'s<.05). There were no significant differences in overall transition outcomes between the ID and ASD groups.

On the TOC Independence domain, young adults had an average score of 1.1 (*SD*=.89; Range=0-3). A score of 1 in the Independence domain indicates that the young adult is either living at home with a high degree of autonomy, or living in a semi-sheltered accommodation (e.g., group home, dormitory). On the TOC Professional domain, young adults had an average score of .95 (*SD*=1.1; Range=0-3). A score of 1 in this area indicates that the young adult is enrolled either in community college, part-time post-secondary education, or part-time paid employment. On the TOC Social domain, young adults had an average score of 1.18 (*SD*=.99; Range=0-3). A score of 1 indicates that the young adult either has one to five friends with a high level of satisfaction, or any number of friends with moderate satisfaction.

A one-way ANOVA revealed significant differences by diagnostic status in the Independence (*F*=33.61; *p*<.001), Professional (*F*=22.04; *p*<.001), and Social (*F*=22.70; *p*<.001) domains. Compared to young adults with ID and ASD, TD young adults were significantly more successful in the TOC Independence and Social domains (*p*'s<.001). There were no significant differences in the independence or social domains between the ID and ASD groups. In addition, TD young adults had significantly better Professional outcomes compared to young adults with ID (*p*<.001). Notably, the ASD group also had better Professional outcomes compared to the ID group (*p*<.01) and did not differ from the TD group in this area. See Table 6 for young adult transition outcomes by diagnostic group.

Relationship between Goals and Outcomes. Three multiple linear regressions were conducted to examine predictors of young adult transition outcomes in each TOC domain (i.e., professional, social, independence). Mothers' related goals that were correlated with the respective outcome areas were included as predictor variables. In addition, young adult's diagnostic status was dummy coded into a binary variable, with the ASD and ID group combined into one DD (developmental disability) group (i.e., TD=0, DD=1). See Table 7 for results of regression analyses on mothers' goals and diagnostic status predicting young adult transition outcomes.

In the professional domain, mothers' goals of finding a job (r=.37; p<.01) and meaningful career (r=-.30; p<.01) were significantly correlated with young adult outcomes. Results of the multiple regression demonstrated that DD status and the goal of finding a job were significant predictors of professional TOC scores, $F(3, 105) = 15.19$, p<.001, adjusted $R^2 = .28$. Thus, controlling for DD status, young adults whose mothers endorsed the goal of finding a job (as opposed to finding a meaningful career) had significantly less successful outcomes (p<.05). In the social domain, mothers' goal of having a family and/or children was significantly correlated with young adult social TOC scores (r=-.19, p<.05). However, controlling for DD status, this goal was not a significant predictor of young adult social outcomes, $F(2, 106) = 19.33$, p<.001, adjusted $R^2 = .25$. In the independence domain, mothers' goals of living independently from parents (r=.32, p<.01), financial/career independence (r=-.21, p<.05), and daily living skills (r=.23, p<.05) were correlated with young adult TOC independence scores. Mothers' goals did not significantly predict young adult independence outcomes when controlling for youth DD status, F(4, 104) = 16.34, p<.001, adjusted $R^2 = .36$.

Transition Challenges and Worries

The second research question examined the challenges that mothers face during the transition period and what they worry about most for their young adults. Interviews with mothers revealed common themes across diagnostic groups in transition challenges and worries. These include concerns around their young adult's Independence (90.8%), Social Life (48.6%), and Impact on the Family (45.0%). However, the specific concerns noted within these broad themes differed by diagnostic group.

Independence. Within the Independence domain, mothers across diagnostic groups reported worrying about their young adult making life decisions and handling responsibilities (67.0%). For example, a mother of a young adult with TD worried about the impact of making decisions in adulthood:

> *"The terrible twos, no such thing. Tantruming threes, easy. Teenagers, EASY. It's the 20-year-olds that are hard. For me, little kids, little problems, big kids, big problems… once they are launched the whole world's open to them and hopefully you've taught them well and they make good choices… twenty-year olds the decisions they are making are big decisions, whether it be their major, who they date, if they are going to experiment with drinking or drugs. It's bigger, more life changing or life impacting decisions. So, give me my six little kids any day and you can have my twenty-year-olds."*[11]

Another mother of a young adult with ID worried that her daughter would give into peer pressure when making life decisions:

> *"I worry that she will succumb to the pressures of others around her and not have the strength or the courage to stick to what she believes in her heart is right. That she'll be, you know, really easily influenced and swayed, that she'll be the people-pleaser or she'll be afraid of rejection."*[12]

Mothers of all young adults also worried about their young adult's career prospects and/or financial stability (37.6%). For example, one mother of a young adult with ID explained that she worries about her young adult being able to get a job because of his lack of interviewing skills:

> *"I worry that the transition into a career might be difficult because, well first it's going to be difficult for him just to get that job. He is not going to interview well. He is not going to interview well at all. And I think that he applied for and got an*

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[11] This quote was also coded as Impact on Family: Parent-Child Conflict.

[12] This quote was also coded as Social Concerns: Victimization.

> *interview for Target and he wasn't hired. Two interviews and he wasn't hired. More than likely because he doesn't interview very well."*

Another mother of a young adult with ASD expressed concern about her young adult becoming financially independent:

> *"I'm worried that he won't be self-sufficient once I'm gone. I should worry about not being self-sufficient when I'm retired. Hopefully I don't hit that point first. I don't see how I could financially support him when I'm retired."*

Similarly, a mother of a TD young adult expressed worrying about her young adult finding a career that would allow them to live comfortably:

> *"… that they will enjoy the type of life that we have enjoyed. That they will have a career that supports them living comfortably. That's what you hope for your children."*

In addition, 60.6% of mothers expressed concern with finding the right balance between providing guidance/support and allowing their young adults to have greater independence. This theme (Continuum of Dependence) was coded on a 3-point scale with lower scores reflecting greater dependence on caregivers (1=continued dependence on caregiver, 2=struggle with the balance, 3=watching the young adult struggle). Of the mothers who endorsed this theme, almost half (43.9%) were coded as a 2 (struggle with the balance), reflecting a desire for their young adults to become more independent but having difficulty knowing when to provide support and when to let them make their own decisions. Interestingly, 92.3% of mothers in the ASD group had a rating of 2, compared to 29.0% and 36.4% of mothers in the TD and ID groups, respectively. For example, mothers of young adults with ASD shared the following concerns:

> *"I feel like my job is being as supportive as I can while still trying to set appropriate boundaries for somebody living at home… and continue to figure out*

> *the balance of when to parent and when to let him fall and make mistakes. It's very very tricky."*
>
> *"It's been this balance of letting go, because that's the appropriate thing to be doing right here, and making him let go."*
>
> *"It kind of just goes back to making sure we are guiding him down the right path for his future. We worry that if we give him the wrong advice for a career or anything like that. Worried about, wanting him to make decisions, but feeling like he may need help making those decisions. But not wanting to be the reason that path turns out wrong."*

In contrast, 50% of mothers in the ID group had a rating of 1 (continued dependence). For example, a mother of a young adult with ID talked about the need to make financial arrangements and coordinate her son's schedule:

> "*He has done so well yet I still need to make his dentist appointments and make sure he gets there. I need to drive him to wherever he needs to go and some of that stuff is not going to change…financially speaking, we have, in the last couple of years, done a conservatorship."*

Another mother of a young adult with ID explained that the most challenging aspect of transition is the impact of her young adult's continued dependence:

> *"I guess the hardest part for me… so a child needs its mother, right? But at some point, they start not [to]… I never had that… that's hard for the parent because you're done… you're ready to not have to be there every moment… I think it's biological because it is so hard to be there for his every need."*

Notably, no TD mothers had a rating of 1, and most (71.0%) had a rating of 3 (watching the young adult struggle). Correspondingly, a one-way ANOVA demonstrated differences in the Continuum of Dependence rating by diagnostic group. The TD group had a significantly higher average rating on the Continuum than the ID and ASD groups (*F*=27.46; *p*<.001), reflecting greater independence for TD young adults. For example, these mothers of TD young adults shared similar sentiments about watching their children figure out their path from afar:

> *"You just have to be supportive and you can open a door, that's great, but once you open it, it's up to them to step in. That would be the hardest - just watching your child try to get settled into where they are going to be."*
>
> *"I just get to watch her make mistakes and see her fail, and see her make bad choices, and I can encourage her but I can't ground her in, I can't make her do anything, you know. I just have to just watch and see what happens and so that's really hard."*
>
> *"I see him struggling to see what he wants to do. He's 22 and not quite sure where he wants to go. And as a mother, it's hard to watch a kid who is so unbelievingly smart not know where he wants to go and not have too much of a direction yet."*

In sum, results indicate that mothers of young adults with ASD struggled to find balance between allowing independence and providing guidance, mothers of young adults with ID were concerned about the young adult's continued dependence on caregivers, and mothers of TD young adults worried about watching their young adult struggle from afar.

Social Concerns. Approximately half of all mothers (48.6%) indicated some type of social concern. Group differences emerged in the specific concerns noted within the broad theme of Social Concerns. More mothers of young adults with ASD and ID reported concerns with victimization, including exploitation, discrimination, and teasing/bullying, compared to mothers of TD young adults (ID=39.4%, ASD=26.1%, TD=3.8%; χ^2=17.46; p<.001). For example, a mother of a young adult with ID reported being worried *"that someone will take advantage of her."* Another mother of a young adult with ID expressed concerns around her young adult being teased when he is out in the community:

> *"He has his share of moments in the park when's he's separated and someone says something and he responds and they say, "Oh weirdo," you know, that kind of thing. We've tried hard to explain, or have him explain, "Hey, I look at life differently," and there's no stock answer."*

Some mothers also reported concerns around their young adults being discriminated against in the workplace. As reported by one mother of a young adult with ID:

> *"They put him on the schedule but he might be their last choice. Because other people that have been there a shorter amount of time seem to get more hours. So yeah, I worry about potential discrimination."*

Additionally, a higher proportion of mothers in the ASD group worried about their young adult's Social Support, including developing and maintaining friendships, having someone to rely on, and using appropriate social skills (ASD=43.5%, ID=27.3%, TD=11.3%; χ^2=9.89; p<.01). Mothers of young adults with ASD were also more likely to make Comparisons to Peers (ASD=21.7%, ID=12.1%, TD=1.9%; χ^2=8.08; p<.05), reflecting the unique social needs of this group. For example, one mother of a young adult with ASD worried about her son struggling to make friends and being lonely:

> *"Watching him cry because he's lonely and watch what he's going through. I mean, this is, you know, he should be taking care of us at this point and just going out and I see stupid Facebook. I see all of his typical friends and my friends who have kids his age that are typical and oh my god, I mean, they're in Peru, they're in Paris, they're in school for a year in Scotland. They're doing all kinds of grown people activities. My son, again, home alone, so lonely, doesn't know what to do. He's looking at MeetUp for different groups."*[13]

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[13] This quote was also coded as Young Adult Mental Health and Comparison to Peers.

Mothers of young adults with ID also reported more concerns with social support compared to TD youth. One mother of a young adult with ID expressed concerns with her young adult demonstrating appropriate social skills when spending time with family:

> *"He doesn't know how to get along with people without saying sometime that is rude. He tries. When family visits they are patient with him. It's not much, but he knows his family, so he feels more comfortable."*

In addition, over a quarter of all mothers (26.6%) reported worrying about their young adults' romantic relationships and/or their sexual health and education. Though not statistically significant, this theme was mentioned less often by mothers in the ID group (ID=15.2%, ASD=30.4%, TD=32.1%; χ^2=3.2; *p*=.20). The content of mothers' concerns across diagnostic groups also differed, in that mothers of young adults with ID and/or ASD worried about their young adult finding someone accepting and/or lacking dating skills and sexual knowledge, while many mothers of TD young adults worried about their young adult finding the right match and/or being disappointed. A mother of a young adult with ID reported:

> *"I worry about his feelings getting hurt in love relationships. I feel like he has the feelings of wanting to have the girlfriend without the tools, so I worry about romance and sexuality and stuff like that. I think he has a grown-up body and some of the urges, but he doesn't have the skills."*

Mothers of young adults with ASD often worried about their children struggling with initiating a relationship and finding someone who would accept them:

> *"I would like him to have a relationship - a girlfriend. That he initiates, that I have nothing to do with, or his dad."*

> *"I would say love. Will he find a companion that will accept him and support him and love him? I think that's probably my biggest fear or biggest worry."*

In contrast, two mothers of TD young adults expressed concern around their daughters being disappointed in relationships and finding the right match:

> *"She came home one summer and she was crying a lot; I would hear her talk on the phone with him, this was her first relationship and boyfriend, and I would tell her, 'In a relationship you should be happier'... so that was something I worried about the first year."*

> *"She's in a relationship right now, and I just hope that the person that she's with, you know, is a good, match for her."*

Impact on the Family. About half of all mothers discussed Impact on the Family as a challenge or worry. About a quarter of mothers in all diagnostic groups talked about parent-child conflict as a challenge, with a higher proportion of TD mothers endorsing this theme, though this was not statistically significant (TD=34.0%; ID=18.2%; ASD=13.0%). For example, a mother of a TD young adult reported conflict around her son not fulfilling his responsibilities while being financially dependent on parents:

> *"Because he basically is an adult at that point it was his responsibility for him to maintain those grades and maintain those credit levels and keep that scholarship alive. Unfortunately, it was his responsibility but it was our money. So, it was kind of difficult."*

In contrast, a mother of a young adult with ID expressed challenges with managing her young adult's behavior problems:

> *"One day she was at the top of the staircase having a fit. So, I was like you have to go to your room and think it over but no she wouldn't go. So, I went to scoot down to move her and she scooted down and she about knocked me over. So she's learning, so more obstacles physically."*

Additionally, about a quarter of mothers expressed concerns around their own Mental Health. A higher proportion of mothers in the ASD and ID groups reported Mental Health challenges compared to mothers of TD young adults (ID=42.4%, ASD=39.1%, TD=9.4%; χ^2=14.35; p<.01). Many mothers expressed and not having time for themselves due to having to prioritize the young adult's needs. For example, a mother of a young adult with ID reported:

> *"That I've lost who I am because I am only focused on him and then of course my parents, so those are like it's all outward and I don't have time to do anything that I would want to do, and that's really hard."*

Another mother of a young adult with ASD reported feeling overwhelmed and exhausted during the transition period:

> *"The hardest part is being tired. Like, I want to be able to support him to be successful. I want to see his brother be successful. And I'm exhausted. It's like sometimes I have to drag myself out of bed cause I'm so tired and I'm like, 'How much longer can I hang on?'"*

Similarly, a mother of a young adult with ID expressed having too much to handle with navigating services for her young adult and having to put her own needs aside:

> *"They didn't give her social security last year, I had to fight for that. For regional, she just started regional, she doesn't have any services other than this one class. So now I have to look into life skills…it's just never-ending. Like, what about me? What about me? And I don't. I just put all of that to the side."*[14]

Some mothers also discussed feeling a lack of support from others, with more mothers in the ASD group endorsing this theme than mothers in the ID and TD groups (ASD=26.1%; ID=12.1%; TD=3.8%; χ^2=8.21, p<.05). For example, a mother of a young adult with ASD talked about the extended family not understanding her son's needs and excluding him:

> *"He's got 20 cousins on my husband's side but… they don't get it. His family just does not get it and they never made any sort of special considerations for [him], and the cousins all just kind of do their own thing and [he] only sees them at family events and he tries to fit in, but as he tells me… they don't include him or*

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[14] This quote was also coded as Navigating Services.

> *they have conversations and don't talk to him unless he says something first, and they're not interested in anything he's interested in."*

Another mother of a young adult with ASD reported that she did not have anyone to talk to when she was going through a difficult time:

> *"I don't discuss any of these things with anyone anymore. I was having a really hard time, I didn't have anyone to talk to, so I went to a counselor for a while and honestly all it did was make me feel worse, so I finally said, 'You know, I don't think this is working out for me, I'm just gonna live life,' and we just live day to day honestly."*

Additionally, mothers of young adults with ID were more likely to mention Negative Impact on Siblings or other family members as a concern (ID=15.2%, ASD=4.3%, TD=1.9%; χ^2=6.16; *p*<.05). For example, a mother of a young adult with ID worried that her other son would have to take on the caregiving role after she is gone:

> *"I worry about when I'm not here anymore that she's not going to be completely independent and how that's all going to work out? I don't really want to put that on my son but on some level that's where it's going to be."*[15]

Themes unique to ASD/ID groups. A few themes were endorsed by mothers of young adults with ASD and ID that rarely came up for mothers of TD young adults. These include Caregiver Aging, or concerns about what will happen after caregivers pass away (ID=48.5%, ASD=30.4%, TD=1.9%; χ^2=26.92; *p*<.001). As these mothers of young adults with ID stated:

> *"The reality of what's going to happen to her when I'm not here? Who's gonna take over? And help her? And feed her and have her best interest? I know there are people out there that are willing to take her because I know there are programs out there that I could pay for, for her… but I want them to do it for the best interest in heart, not because of the money."*

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[15] This quote was also coded as Caregiver Aging.

> *"I'm just worried, I didn't have him until I was 40, and you know, what is going to happen? I don't know who is going to take care of him. I don't know how he's going to manage when I'm not around or when I am not capable anymore. I am very worried about that."*

Another mother of a young adult with ASD shared similar concerns, and worried about who would take care of them (the caregivers) as they get older:

> "*It scares the crap out of us. What's going to happen to him? He has no siblings… He's going to have nobody. Who's going to take care of us when we're old?"*

In addition, a significantly higher proportion of mothers of young adults with ID reported challenges with Navigating Services compared to mothers in the TD and ASD groups (ID=45.5%, ASD=8.7%, TD=3.8%; χ^2=26.09; p<.001). About a third of mothers in the ID group expressed concerns with adjusting to the adult service system and figuring out what comes next. One mother of a young adult with ID reported feeling that she was on her own navigating the transition out of the school system:

> "*The past couple of years have been all about that because we knew that he was going to be leaving the school district. And from what I could see, we were going to be on our own trying to figure out what was next."*

Another mother of a young adult with ID reported that despite her preparations, the transition out of the school system was challenging:

> "*Personally, it's been very scary. On one hand, having the regular schooling and knowing all the teachers and the routines… we got comfortable, so did he. So now it's a little bit new… we've talked about this for a long time, and it's finally here."*

In addition, mothers expressed concerns about inadequate services, including a mother of a young adult with ID, who stated:

> *"[She] is using three agencies and her brother is using another three, so for me that is six agencies to manage. Sometimes I feel like… what is the alternative? I*

> *wish they could all just go away or, better yet, maybe I can hire someone to coordinate both of their cases and to coordinate all of these services."*

Themes unique to TD group. Compared to mothers of young adults with ASD or ID, mothers of TD young adults more often reported challenges with Transition Loss, including a loss of the caregiving role and being separated from their young adult (TD=50.9%, ASD=17.4%, ID=3.0%). This may reflect the greater dependence on caregivers among young adults in the ASD and ID groups. Rather than losing or separating from their young adult, parents of young adults with disabilities often take on a greater role in helping their young adult access the needed supports. As reported by these two mothers of TD young adults:

> *"The hardest thing for me is just transitioning to the fact that I am going to be an empty nester."*
>
> *"What I wanted to be, as a career, I wanted to be a mom. So, missing that day to day is a little tough, but when she shares a picture at Disneyworld or whatever, that's what makes me happy."*

Almost 40% of mothers of TD young adults reported challenges with being separated or distant from their young adult after they moved out. One mother put it this way:

> *"Just missing him. I miss him… it's just different because he's not here; he's not in my house. So that is a different way of communicating and different way of loving than you're used to as a mom because you are used to him being physically right here. So that's the hardest part, they're not here."*

Additionally, the theme of Overall Happiness/Fulfillment was mentioned as a worry by almost a fifth of mothers in the TD group, but not by any mothers in the ASD group, though this result was only marginally significant (TD=18.9%; ID=12.1%; ASD=0%; χ^2=5.12; *p*<.08). For example, a mother of a TD young adult reported:

> *"Being a young adult and just everything that's going on, for her to find her niche, her happiness, and be financially independent, I mean that, and finding her happiness, you know what I mean, that's what I worry about."*[16]

Similarly, a mother of a young adult with ID worried about her young adult's future, and hoped that he would find happiness in his career. When asked what she worries about most, she reported:

> *"His future. I want him to find something. He looks at majors and thinks what one makes a lot of money. Well, if you're not happy then there is no point. So, I want him to find something that he enjoys doing, loves doing. So he can have a happy future."*

Though four mothers in the ID group mentioned Overall Happiness/Fulfillment as a challenge or worry, the higher proportion of TD mothers who endorsed this theme may reflect the multitude of challenges that mothers of young adults with disabilities are faced with. Put simply, these mothers already have enough to worry about.

Common themes across diagnostic groups. Mothers of all young adults also reported challenges and concerns around Safety (28.4%) and Young Adult Mental Health (26.6%). Safety concerns included staying safe in the community and online, and making safe decisions. For example, a mother of a young adult with ID worried about her daughter's safety on social media:

> *"For her I worry a lot about the things she cannot understand like what's good and what's bad. I worry for her about the older people that are on social media and her not understanding what's right or wrong on social media."*[17]

Another mother of a TD young adult expressed concerns about her son making decisions that negatively impact his health:

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[16] This quote was also coded as Independence: Financial Stability/Career.

[17] The quote was also coded as Victimization and Making Life Choices.

> *"Just sometimes when we watch him make poor decisions [vaping] that will affect his health. That's hard as a parent to watch. That's the hardest part."*

Additionally, mothers expressed concerns about their young adult's safety in the community, including staying safe while driving. For example, these two mothers of TD young adults reported:

> *"I always have an unreasonable fear about my children driving on the freeway which is unreasonable. But that's funny even my 24-year-old I'm like, oh no, he drives to work on the freeway. I know that's silly, and it's unreasonable. I worry about accidents. They're military, but I worry about them driving on the freeway."*
>
> *"I do her 'Find my Friends' so I know when she leaves the room and I know when she comes back to the room. So at least I know that she is safe and that she is not in a ditch somewhere. That's helpful."*

Similarly, some mothers expressed worries about their young adult being out alone in the world, including this mother of a young adult with ASD:

> *"I worry about… he's doing something very different this weekend that he's never done before and it involves being away, and I worry about him being out there in the world on his own (ha-ha). Taking a train, you know? It's a very huge step. He's doing a vacation with his girlfriend and she's also on the spectrum, and it's just like, 'Okay, let's see how it goes!' and I'm kind of like, 'Ahh, ok. Hands off.'"*

In addition, over a quarter of mothers across diagnostic groups expressed concerns around their young adult's mental health, including depression, anxiety, and addiction, as reflected by these quotes:

> *"The anxiety, depression, nursing school, all that, and I'm like, 'Oh dear goodness make it stop.'"* – Mother of a TD young adult
>
> *"She's still you know battling her depression.. I would say it's for her to each time be able to bounce back from these setbacks. It sometimes it takes her weeks, sometimes it takes her months. Like right now I know she feels very sad about losing this person who's working with her, so now she has no one."* – Mother of a young adult with ID

> *"The things that she went through… either drugs or alcohol. Those were the toughest things. At one point we just sat down with her and told her, 'Hey, if you don't clean your act up, you're gonna have to go to rehab.' …And we wouldn't take her because she didn't want to go through with the program. So, we had to go through that. And then she got a sponsor and she started going to AA and that helped a lot."* – Mother of a TD young adult

See Table 8 for differences in mothers' challenges and worries by diagnostic group.

Mothers' Attitudes Towards the Future

The third research question examined the role of maternal wellbeing and optimism in adolescence on mothers' attitudes towards their child's future in young adulthood. Attitudes towards the future were coded based on mothers' response to the question, "What emotions come up for you when you think about your child's future?" Note that this was a follow-up question to, "Think about the future, maybe five years from now; what goals do you have for your young adult?" Their attitude towards the future was coded on a 1-4 Likert scale with the following score descriptors: 1 = exclusively negative (e.g., depressed, concerned, anxious); 2 = leaning negative (e.g., doubtful, insecure, but hopeful); 3 = leaning positive (e.g., excitement with some worry); 4 = exclusively positive (e.g., hope, happiness, pride). See Table 9 for examples of mothers' responses in each attitude category.

A chi-square analysis demonstrated significant differences in the proportion of mothers who fell into each attitude category (χ^2=14.80; p<.05). 60.4% of TD mothers had exclusively positive emotions, compared to about a third of mothers in the ID (33.3%) and ASD (30.4%) groups. On the other hand, there was a larger proportion of mothers in the ID (39.4%) and ASD (30.4%) groups with exclusively negative emotions, compared to mothers of TD young adults (9.4%). Correspondingly, a one-way ANOVA also demonstrated significant between-group differences in mother's attitude (*F*=6.33; *p*<.01), with post-hoc tests showing that mothers in the TD group had significantly more positive attitudes towards the future (*M*=3.3, *SD*=1.0) compared to mothers in the ID (*M*=2.5, *SD*=1.3) and ASD (*M*=2.6, *SD*=1.2) groups. See Table 10 for differences in mothers' attitudes towards the future by diagnostic group.

Maternal Wellbeing in Adolescence and Adulthood

A one-way ANOVA examined differences in maternal wellbeing and optimism across diagnostic groups at the follow-up (current) and age-13 or age-15 assessment points. At the follow-up assessment, there were significant differences by diagnostic group in all maternal wellbeing variables. Bonferroni post-hoc tests demonstrated significant differences between mothers in the TD and ID groups on all variables (all *p*'s<.05). In other words, mothers of TD young adults reported lower parenting stress and mental health symptoms, higher optimism, and rated their young adults as having a greater positive impact on the family, compared to mothers of young adults with ID. Mothers in the ASD group had average scores that were right in between mothers in the other diagnostic groups, such that there were no significant differences between the ASD group and the ID or TD groups. See Table 11 for differences in maternal wellbeing and optimism at the current assessment point.

Similar patterns were observed at the age-13 or age-15 assessment points, except at that time, mothers in the ASD group differed significantly from the TD group and had more similar scores to the ID group in parenting stress on the FIQ and mental health symptoms on the SCL. Additionally, during adolescence, mothers of young adults with

ASD had significantly lower optimism on the LOT compared to mothers of young adults with TD and ID (*p*'s<.05). Note that all maternal wellbeing scores at follow-up were correlated with their scores from the age-13 or age-15 assessment points.

The Impact of Maternal Wellbeing on Future Attitudes

Bivariate Pearson correlations were conducted to examine whether maternal wellbeing and optimism during adolescence were related to mothers' attitudes towards their child's future in young adulthood. FIQ Negative Impact (parenting stress) scores in adolescence were negatively correlated with maternal attitudes (r= -.39, p<.01), indicating that less parenting stress was associated with more positive attitudes. Similarly, there was a correlation between SCL mental health symptoms and future attitudes (r= -.25, p<.05), indicating that lower mental health symptoms were associated with more positive attitudes. Additionally, higher optimism scores on the LOT in adolescence were correlated with more positive attitudes in adulthood (r=.28, p<.01). FIQ Positive Impact scores were not significantly correlated with future attitudes.

A multiple regression was then conducted to examine the predictive effect of maternal wellbeing during adolescence on future attitudes. When diagnostic status was not included in the model, higher optimism and lower parenting stress in adolescence were significant predictors of more positive attitudes towards their young adult's future (*p*'s<.05), while self-reported mental health symptoms were not a significant predictor, F(3, 87) = 6.40, p<.01, adjusted R^2 = .15. A second regression analysis included the youth's diagnostic status (i.e., TD vs. DD) as a predictor, in addition to the two maternal wellbeing variables that were found to predict future attitudes in the first analysis (i.e., LOT and FIQ Negative Impact scores). Controlling for diagnostic status and optimism, greater negative impact of youth on the family (i.e., greater parenting stress) in adolescence predicted more negative maternal attitudes towards their youth's future, F(3, 94) = 7.90, $p<.001$, adjusted $R^2 = .18$. When controlling for maternal wellbeing variables, DD status was not a significant predictor of mothers' future attitudes. See Table 12 for results of regression analyses on maternal wellbeing and diagnostic status predicting mothers' attitudes towards their youth's future.

The Impact of Maternal Wellbeing on Young Adult Outcomes

Bivariate Pearson correlations were conducted to examine whether maternal wellbeing during adolescence were related to young adult transition outcomes. All maternal wellbeing variables were correlated with young adult outcomes on the Overall TOC and TOC domains. Higher maternal optimism in adolescence was associated with more successful Overall ($r= -.39$, $p<.01$), Social ($r= -.33$, $p<.01$), Professional ($r= -.33$, $p<.01$), and Independence ($r= -.24$, $p<.05$) outcomes on the TOC. Similarly, greater perceived positive impact of the youth on the family in adolescence was related to more successful Overall ($r= -.31$, $p<.01$), Social ($r= -.25$, $p<.05$), and Professional ($r= -.36$, $p<.01$) outcomes on the TOC, but not to Independence outcomes. On the other hand, greater perceived negative impact of the youth on the family (i.e., parenting stress) in adolescence were related to less successful Overall ($r=.50$, $p<.01$), Social ($r=.41$, $p<.01$), Professional ($r=.41$, $p<.01$), and Independence ($r=.35$, $p<.01$) TOC outcomes. Similarly, greater mental health symptoms were related to less positive TOC Overall ($r=.38$, $p<.01$), Social (r=.30, p<.01), Professional (r=.26, p<.05), and Independence (r=.37, p<.01) outcomes.

A multiple regression was conducted to examine the predictive effect of maternal wellbeing variables during adolescence and youth DD status on young adult TOC outcomes. Maternal wellbeing variables and diagnostic status accounted for 51% of the variance in Overall TOC scores, F(5, 88) = 20.60, p<.001, adjusted R^2 = .51. In addition to the predictive value of DD status (p<.001), maternal optimism in adolescence (p<.05) significantly predicted young adult transition outcomes above and beyond the youth's DD status. When controlling for DD status, no other maternal wellbeing variables were significant predictors of young adult outcomes. See Table 13 for results of regression analyses on maternal wellbeing and diagnostic status predicting young adult outcomes.

Discussion

This mixed-methods study sought to a) describe mothers' challenges and goals for their young adults during the transition to adulthood and b) examine maternal wellbeing variables that may lead to more successful transition. Interviews with mothers of young adults with ASD, ID, and TD illustrated commonalities in mothers' challenges and goals for their young adults across diagnostic groups. Several themes were unique to mothers of young adults with disabilities, while others only emerged for mothers of TD youth. In addition, findings revealed a relationship between mothers' goals and their young adult's professional outcomes, in that higher expectations were associated with more successful outcomes. Results also highlight a relationship between maternal wellbeing in adolescence (age-13 or age-15) and mothers' attitudes towards their young adult's future at age 20-25, based on mothers' expressed emotions towards the future during interviews. Lower parenting stress and higher optimism in adolescence were predictive of more positive maternal attitudes in adulthood. Greater maternal wellbeing was also related to more successful young adult professional, social, and independence outcomes, as measured by a transition outcome composite (TOC) measure.

Transition Outcomes

Consistent with previous findings on transition outcomes among adults with developmental disabilities (e.g., Shattuck et al., 2012; Grigal et al., 2011), TD young adults in this sample had more positive social and independence outcomes on the TOC than young adults with ID and/or ASD. In the TOC professional domain, young adults with ASD and TD had comparable outcomes, while young adults with ID had less positive outcomes. It is important to note that young adults in the ASD group had average to above average cognitive abilities, and research has shown that IQ is highly predictive of adult outcomes, including more successful employment and educational outcomes (e.g., Levy & Perry, 2011). At the same time, studies have shown that among adults with ASD, even those with high intellectual abilities struggle to maintain gainful employment and are often underemployed, due to difficulties with social competence (e.g., Howlin, 2005; Shattuck et al., 2012). The professional outcome measure used in this study was based on full-time versus part-time employment/education status and did not take job status into account, so it is possible that some young adults were working in jobs below their abilities.

Transition Goals

Over half of mothers reported some type of professional (e.g., employment, education), social (e.g., friendship, relationship/marriage, family/kids), or independence (e.g., living independently from parents, financial independence) goal for their young adult. These themes are consistent with findings from previous qualitative research examining parent perspectives of desired transition outcomes (e.g., Sosnowy et al., 2018). Within the broad thematic categories of professional, social, and independence goals, interesting differences emerged between diagnostic groups in the specific types of goals reported. For example, a higher proportion of mothers of young adults with TD and ASD reported the goals of their young adults finding a meaningful career, living independently, and being financially self-sufficient, compared to mothers of young adults with ID. This finding may reflect the higher professional outcomes among young adults with ASD compared to those with ID in this study, as well as the impact of cognitive status on employment and independent living prospects (e.g., Levy & Perry, 2011). Relatedly, previous research has reported high unemployment rates and less positive educational outcomes even among young adults with mild ID, which may be due to limited suitable employment options and or difficulties finding and keeping a job (Grigal et al., 2011; Howlin, 2005). On the other hand, some studies have found that only 3-25% of individuals with ASD have “optimal outcomes” in terms of their ability to work, live, and function independently (Helt et al., 2008). Thus, it may be that mothers in the ASD group perceived their young adults as having the potential to find a fulfilling career that allows them to be financially stable and live independently, while mothers in the ID group were realistic about their young adult’s employment, housing, and financial prospects.

Notably, some group differences were observed in the content of mothers’ goals even within the same subtheme. For example, over a third of mothers reported some type of educational goal for their young adult, but mothers of young adults with TD and/or ASD often described the goal of getting a college or graduate degree, while mothers of young adults with ID were more likely to describe vocational or life skills educational programs. Furthermore, when discussing the goal of independent living, mothers of young adults with ASD often referenced their young adults living with roommates or in university housing, while mothers of young adults with ID referenced assisted living or other organized living experiences. Similarly, many mothers expressed hope that their young adult would develop financial independence, but the meaning of financial independence differed across groups. For mothers in the TD and ASD groups, it often meant being completely self-sufficient (e.g., living independently and paying their own bills), while for mothers of youth with ID, it often meant leaning how to better understand and manage finances.

Further reflecting the unique perspectives among mothers of youth with disabilities, some mothers of young adults with ASD and ID expressed the hope that their young adult would develop the life skills to function independently in their parents’ absence; this goal did not emerge for TD mothers. In contrast, a few mothers in the TD group expressed the goal of their young adult having a connection to their faith or contributing meaningfully to society; these goals were not reported by any mothers of young adults with ASD or ID in this sample. Another interesting finding was that no mothers of young adults with ASD reported engaging in hobbies and/or leisure activities as a goal, while about 12-13% of mothers in the TD and ID groups did. This is consistent with previous research demonstrating lower expectations for community involvement and social/recreational activities among parents of youth with ASD compared to parents of youth with ID (Blacher et al., 2010; Grigal and Neubert, 2004). It may also relate to a higher emphasis placed on professional outcomes as opposed to recreational activities in the ASD group, which may better channel the unique strengths and talents of individuals with ASD.

In addition, while almost a third of mothers across diagnostic groups expressed the goal of their young adult dating or getting married, for mothers of young adults with ID and/or ASD, this goal was often accompanied by concerns about their young adult dating or having difficulties navigating relationship. Relatedly, mothers of TD young adults were more likely to express the goal of their young adult building a family and/or having children compared to mothers of young adults with ID, reflecting the lower rates of marriage and children in adults with ID (Levy & Perry, 2011). Notably, no mothers of young adults with ASD in this sample reported this goal. This finding corresponds with the differential outcomes documented between young adults with ID and ASD in terms of forming romantic relationships, getting married, and having children, with young adults with ID having more positive outcomes in these areas compared to young adults with ASD (Hall et al., 2005; Maughan et al., 1999). As the social challenges among young adults with ASD make developing long-term relationships challenging, it may be that in the social arena, their parents are less focused on them having a family and children, and more concerned with them having friends and dating. Correspondingly, some mothers (in all diagnostic groups) preferred that their young adults hold off on having a family or children and instead focus on pursuing their goals.

Furthermore, mothers in the ID and ASD groups reported friendship or social support goals more often than mothers of TD young adults. This finding suggests that while social success of some kind is common for all mothers, mothers of youth with disabilities have different social priorities. This may reflect limited opportunities for social engagement or a lack of meaningful social connections for young adults with ID and ASD (Levy & Perry, 2011). Interestingly, despite research suggesting poorer social outcomes among youth with ASD (Bernheimer et al., 2006; Hall et al., 2005; Maughan et al., 1999), a higher proportion of mothers of young adults with ID in this study reported friendship and/or social support goals. As quality and quantity of social support is likely to impact transition outcomes (Suarez & Baker, 1997), developing meaningful friendships and relationships may be an important intervention target for both young adults with ID and ASD.

Transition Challenges

Consistent with their goals, mothers expressed broad challenges and worries around their young adults' independence, social life, and impact on the family. Themes were consistent with the changing life trajectories and norms in Western society in terms of the delayed onset of living independently and becoming financially independent, a shift that has led to the establishment of a new and distinct period known as "emerging adulthood" (Arnett, 2007). Themes were also aligned with previous research on parents' concerns during the transition period (e.g., Fingerman, 2017). Mothers in all diagnostic groups expressed concerns about their young adults making life-impacting decisions, such as choosing the right educational or career path or the right partner, and making healthy and safe decisions. Other common concerns across groups included the young adult's financial independence, safety, and mental health, and parent-child conflict. Several concerns were specific to mothers of young adults with disabilities, and others were unique to mothers of TD young adults. Surprising, overall, were the similarities rather than the differences among groups.

In line with previous research on parent perspectives (e.g., Bianco et al., 2009), a key theme that emerged for over 60% of mothers was finding the balance between allowing their young adult to make their own decisions and providing guidance and support. Similar to Kloep and Hendry's (2010) study on the parent experience during transition for TD youth, in which parents described a "power struggle" for the young adult's independence, mothers in this study appeared to be at different points on a continuum of balancing independence and guidance. Mothers' reports illustrated ranging levels of young adult dependence, with some young adults continuing to be dependent on their parents, and others struggling to find their own way. As expected, a higher proportion of mothers of young adults with ID reflected on their young adult's continued dependence, while a higher proportion of mothers of TD young adults reflected on watching their young adults figure out their path from afar. Interestingly, over 92% of mothers in the ASD group were right in the middle; these mothers illustrated the challenges of knowing when to provide support and structure and when to let their young adult make their own mistakes. Their young adults were also the ones who had the cognitive capabilities to become independent, but consistent with the autism spectrum, they lacked many of the social and adaptive skills to make the transition smoothly.

The greater willingness among mothers in the ASD group to "let go" compared to mothers in the ID group may relate to their young adults' higher professional outcomes in this sample, as measured by a researcher-developed composite measure of their employment and educational outcomes. Additionally, the higher cognitive abilities of young adults with ASD in the current study may contribute to their mothers' perceptions of greater independence (even in the absence of commensurate adaptive skills). In contrast, young adults with ID were perceived as less further along in seeking independence and taking on adult responsibilities, as reflected by their mothers' descriptions of coordinating their schedules, driving them to where they need to be, and taking care of their financial and health needs. This is consistent with previous research suggesting that parents of young adults with ID remain highly involved in their young adults' lives, due to their young adults' continued dependence (Jivanjee et al., 2009). As Kloep and Hendry (2010) highlighted, the current findings suggest that mothers' willingness to "let go" was related to their perceptions of their young adult's readiness to become independent.

Though safety concerns were a common theme across diagnostic groups, a higher proportion of mothers of young adults with ID and ASD reported concerns around their youth being victimized, taken advantage of, or discriminated against because of their differences, further highlighting the unique social needs of young adults with disabilities. This reflects research indicating higher rates of social victimization among individuals with DD (Fisher et al., 2012). Additionally, mothers in the ASD group were particularly worried about their young adults having the social skills to form high quality friendships and social support networks. This concern was related to that of parents in another study who worried that their autistic youth would be socially isolated without parental facilitation of social activities (Sosnowy et al., 2018). A few mothers in the ASD group here also compared their young adults' social life with that of typical peers, reflecting concerns around their young adults' limited social connections and greater loneliness.

Another key theme that was much more prevalent among mothers of young adults with disabilities was navigating the adult service system, including figuring out what comes next after exiting the public school system, adjusting to the "service cliff," and dealing with inadequate services (e.g., poorly coordinated care, lack of appropriate support). Similar to the reports of others (e.g., Bianco et al., 2009; Boehm, Carter, & Taylor, 2015), mothers here described the transition out of the school system as stressful, scary, frustrating, and confusing, despite their preparations. Interestingly, almost half of mothers in the ID group expressed concerns with navigating services, compared to less than 10% of mothers in the ASD group. In other words, because many of the young adults with ASD in this sample were pursuing higher education and/or demonstrating high employment prospects, mothers in the ASD group may have been less concerned about finding services, and more focused on providing support for their young adult to achieve their full potential. It is also likely that services to assist these mothers were largely few and far between (e.g., Anderson and Butt, 2018).

A related challenge unique to mothers of young adults with ASD and ID was the concern about who would take care of their young adult after parents pass away. Despite awareness of supportive living programs, mothers worried about the quality of care their young adults would receive in these programs, i.e., one would care for their young adult in the way they have. Additionally, some mothers (mostly in the ID group) discussed plans for family members to take on a caregiving role and worried about the impact of this responsibility on their other adult children. Given the added responsibilities mothers take on during the transition to help their young adult access services, combined with the pressure of knowing they will not be here to support their young adult forever, it is not surprising that about 40% of mothers in the ASD and ID groups reported their own mental health challenges. These mothers expressed feeling overwhelmed, exhausted, having too much to handle, and putting their own needs aside to prioritize the needs of their young adult. Mothers of young adults with ASD, in particular, expressed feeling a lack of support from others, including a lack of understanding from family members or having no one to rely on during difficult times. This finding aligns with previous research demonstrating higher levels of stress and the impact on their own mental health in parents of children with ASD compared to children with other developmental disabilities (e.g., Blacher & Baker, 2017; Schieve et al., 2007), often related to fears around their children's independence, disapproval of their children's behavior from family members, and limited social support (Sharpley et al., 1997).

It is noteworthy that over a quarter of mothers in all diagnostic groups expressed concerns with their young adult's mental health, including depression, anxiety, and substance use. Thus, despite research indicating a higher prevalence of mental health disorders and behavior problems in youth with ID compared to TD youth (McIntyre et al., 2002; Cooper et al., 2007), mothers of TD youth also noted significant mental health concerns. This finding highlights the unstable nature of the period of emerging adulthood (Arnett, 2014) and the worsening mental health trajectories of TD youth over the last decade (e.g., Mojtabai et al., 2016). It should also be noted that while most data were collected prior to the COVID-19 pandemic, data for approximately 20 mothers was collected after the start of the pandemic, possibly contributing to worsened mental health symptomatology in some young adults (e.g., Horigian et al., 2021).

As with goals, qualitatively different concerns were observed within several themes. For example, while it was common for all mothers to have concerns around their young adult's career prospects, mothers of young adults with ID and/or ASD often described additional challenges, such as their young adult having difficulty obtaining employment due to a lack of interviewing skills or a lack of suitable job opportunities. Similarly, many mothers expressed concerns around their young adults' romantic relationships, but mothers of young adults with ID and/or ASD often reported additional challenges with their young adults' lack of dating skills/experience and/or sexual knowledge. Mothers of young adults with disabilities also worried about their young adult finding someone who would accept and love them for who they are. In contrast, mothers of TD young adults often expressed worries about their young adult finding the right partner or experiencing the typical ups and downs of dating and relationships. Further, though parent-child conflict was reported as a challenge across diagnostic groups, this conflict was more reflective of behavioral and emotion regulation problems in the ASD and ID groups, as opposed to a power struggle for independence in the TD group.

One key theme that came up for over half of mothers in the TD group was experiencing a loss of the caregiving role or having a hard time being separated from their young adult when they moved away from home. This theme is consistent with Kloep and Hendry's (2010) finding that some parents of TD young adults felt a sense of "role loss" and missed their children. Not surprisingly, given the increased dependence of young adults with disabilities on their parents during the transition period, this theme came up much less often for mothers of young adults with ASD, and even less for mothers of young adults with ID. Another concern that was more common among mothers of TD young adults was their young adult living a happy and fulfilling life. Though it is safe to assume (e.g., from mothers' overall interview responses) that mothers across diagnostic groups wanted their young adults to be happy and fulfilled, the data suggest that with the added challenges and worries among mothers of young adults with disabilities, this may not be at the top of their list of concerns.

Mothers' Goals and Young Adult Outcomes

Findings from regression analyses demonstrated that young adult developmental disability (DD) status was a significant predictor of less successful young adult outcomes in all areas. However, in line with research suggesting that young adults whose parents have higher expectations have higher expectations for themselves (Newman, 2005), young adults whose mothers reported more ambitious professional goals had more successful professional outcomes. For example, controlling for the youth's diagnostic status, the expectation of finding a job predicted less successful professional transition outcomes compared to the goal of finding a meaningful career. Additionally, mothers' higher expectations in the social and independence domains were correlated with more positive young adult outcomes in these areas. For example, the goals of having a family and/or children and becoming financially independent were associated with more positive social and independence outcomes, while the goals of developing daily living skills and living independently from parents was associated with less successful independence outcomes. However, mothers' social and independence goals did not predict young adult outcomes when controlling for the youth's diagnostic status.

Maternal Wellbeing and Young Adult Outcomes

Corresponding to the more positive transition outcomes among TD young adults, mothers in the TD group reported lower parenting stress and mental health symptoms and higher optimism, and rated their young adults as having a greater positive impact on the family, compared to mothers of young adults with ID. This highlights the very different experiences of the two groups of mothers, as well as the potential downstream impact on their physical and psychological health (e.g., Johnson et al., 2011). On the other hand, results of a regression analysis revealed that higher maternal optimism in adolescence predicted more successful young adult transition outcomes, regardless of the youth's diagnosis. This finding reflects the importance of harnessing positivity early on to foster more positive young adult outcomes.

Interestingly, for mothers of youth with ASD, wellbeing appeared to improve from adolescence to adulthood. When their children were age 13 or 15, these mothers' self-rated stress and mental health symptoms were similar to mothers in the ID group, but in young adulthood, they rated their wellbeing right in the middle of the other two groups (i.e., their wellbeing did not differ significantly from mothers in the TD and ID groups). This apparent improvement in wellbeing may relate to the ASD group's positive educational and/or employment outcomes. This finding can also be viewed in the context of previous research suggesting that parental wellbeing is lower among parents who perceive their young adult as more needy and less autonomous (Fingerman et al., 2012). As reflected by the higher professional outcomes in the ASD group, young adults with ASD in this sample may have had a higher level of autonomy than young adults with ID. In turn, the continued dependence on caregivers among young adults with ID may go hand in hand with lower maternal wellbeing in this group. These relationships were supported by the regression analyses.

Maternal Wellbeing and Future Attitudes

When asked to identify the emotions that came up when thinking about their young adult's future, mothers expressed a range of attitudes and often had mixed emotions. Many mothers expressed cautious optimism about their youth's future, and reported emotions such as hope and excitement, in addition to fear and uncertainty. On average, mothers of TD young adults expressed more positive emotions towards their young adult's future, compared to mothers of young adults with ID and ASD. These group differences in mothers' attitudes towards the future may be best viewed in the context of family systems theory, in that mothers' experiences during the transition period are inextricably tied to their young adults' experiences (Fingerman & Bermann, 2000; Pillemer et al., 2017). For example, the complex challenges of young adults with disabilities inevitably impacts mothers' perceptions of their young adult's likelihood of success, and this in turn impacts their outlook on their young adult's future prospects.

In addition, more positive maternal attitudes in adulthood were associated with greater maternal wellbeing in adolescence. Thus, mothers who were more optimistic and had less stress and fewer mental health symptoms when their children were 13 or 15 had more positive outlooks towards their youth's future in adulthood. Interestingly, regression analyses suggested that parenting stress in adolescence predicted mothers' attitudes towards their youth's future in adulthood, above and beyond the youth's diagnostic status. This finding has important implications for intervention, as it suggests that regardless of the youth's diagnosis, addressing parenting stress early on is likely to have downstream effects on mothers' outlooks later in life.

Strengths and Limitations

This research provided some new perspectives on the experiences of mothers of youth with ASD, ID, and TD during the transition to adulthood. The mixed-methods approach allowed for a detailed understanding of the multifaceted experiences of mothers in their own words, as well as an examination of the relationship between maternal wellbeing, expectations, and young adult transition outcomes. The longitudinal design allowed for an investigation into maternal wellbeing variables in adolescence that predicted successful adult outcomes. Furthermore, the inclusion of three distinct diagnostic groups provides clarity about the unique needs of each group.

A notable limitation is the absence of fathers' perspectives. Though 11 fathers were recruited for participation, father data were not included in analyses to maintain the assumption of independent data. In general, the literature on fathers of youth with disabilities is limited (Macdonald & Hastings, 2010), and narrative descriptions of fathers' experiences during transition to adulthood are particularly scarce (Potter, 2016). The few qualitative studies that have investigated fathers' perspectives suggest that they perceived similar challenges as mothers, such as difficulties navigating the limited services (Burrell et al., 2017); fathers also described similar experiences, roles, and goals (Meadan et al., 2015). Future research should strive to recruit more fathers to better understand their experiences during the transition period specifically. Additionally, though the current study only included the perspectives of mothers, young adults' perspectives were obtained through semi-structured interviews as part of the larger study. Thus, this study was consistent with the value of person-centered and self-directed transition planning (e.g., Shogren & Plotner, 2012), by including both the narrative perspectives of parents and young adults.

Another limitation is the underrepresentation of culturally and socioeconomically diverse families, as is common in autism research in general (Ratto et al., 2017). Follow-up participants represented a less ethnically diverse (i.e., majority Caucasian), more educated, and higher income group than the original sample recruited for the larger study.

Thus, attrition rates were higher for families who were culturally diverse and of lower socioeconomic status, which is consistent with research on disparities in service access and use (Smith et al., 2020). Though families were compensated for their participation, the two-hour time commitment and logistics of in-person visits (for families of youth with disabilities) may have posed a barrier. Given racial and ethnic disparities in educational and occupational attainment for young adults in general (Newman, 2005; Doren et al., 2012), as well as variations in cultural norms for independence and parental involvement (Fingerman, 2017), future studies should prioritize the recruitment and retention of culturally and socioeconomically diverse samples.

Implications

Overall, findings highlight the need to support parents of young adults with disabilities during their youth's transition out of the school system. It goes without saying that school support professionals can benefit from the knowledge gained from this study. Because parents are key to facilitating successful transition outcomes for young adults with disabilities, understanding their perspectives is critical to inform transition planning, which is mandated for all students beginning at 16 years of age who have an Individualized Education Program (IEP) in K-12 education (IDEIA, 2004). The current findings can aid educators in developing individualized transition goals and activities that are more aligned with the needs of their students and families. For instance, mothers' reported goals and concerns illuminated the distinct transition challenges of young adults with ASD. Despite positive professional outcomes, these youth struggled in the social and independence domains, highlighting social and life skills as important intervention targets for this group.

The information gleaned from this study may be particularly relevant to school psychologists, who often take on leadership roles in transition planning and preparation (Wilczenski et al., 2017). The goals and concerns identified by parents can potentially guide school psychologists seeking to develop system-wide transition supports and services in their school districts for both students and parents. At the student level, such supports may include advocating for the postsecondary, employment, and social needs of students with ASD and/or ID and providing direct services to aid students in career development and self-determination skills. Supports for parents may include facilitating more effective collaboration with community organizations and agencies serving adults (e.g., Noonan et al., 2008), and providing resource guides and individualized support strategies based on parents' professional, social, and independence goals. An example of such a guide created by the author for distribution to parents of transition-aged youth in Southern California can be provided upon request. In addition, school psychologists may be well-positioned to conduct psychoeducational workshops for parents focused on navigating the transition (e.g., providing information about independent living, postsecondary education, employment, social activities, and financial/legal resources) and/or parent support groups for parents of transition-aged youth.

This study also illuminates the parent wellbeing variables that may contribute to more successful adult outcomes, thereby informing researchers and mental health professionals about potential intervention targets for parents of children and adolescents.

As higher maternal wellbeing in adolescence was associated with more positive attitudes towards their youth’s future as well as with more successful young adult outcomes, parent interventions may have a longer-lasting impact on both the parent and youth if they address parenting stress. It has been well-documented, for example, that mindfulness-based interventions demonstrate positive long-term effects for improving both parental wellbeing and child behavior (Cachia et al., 2016). These interventions need not be restricted to parents of youth with disabilities; as illustrated by mothers’ concerns about their youth’s mental health across diagnostic groups, transition can be a challenging time regardless of whether the young adult has a disability. In addition, results suggest that higher maternal expectations were related to more successful youth outcomes. Though the direction of this relationship was not established, the importance of high parental expectations has been highlighted in other studies (e.g., Kramer & Blacher, 2001; Grigal et al., 2011), and should be emphasized in parent training programs.

Conclusion

This study adds to the literature on parent perspectives of the transition to adulthood for young adults with and without disabilities. Interviews with mothers of young adults with ASD, ID, and TD illustrated how challenging the transition can be regardless of disability status and revealed additional challenges for mothers of young adults with disabilities. Findings reflect the “in-between” nature of emerging adulthood, in that individuals in this age group may see themselves neither as adolescents nor as adults (Arnett, 2014). Concerns reported by mothers suggest that they similarly perceive their young adults as “in-between,” which makes it challenging to know when and how much support to provide.

The close examination of parent perspectives provided by this research can guide important conversations among educators, researchers, and mental health professionals about the design and delivery of effective transition services for young adults and their parents. In particular, the understanding of the distinct challenges and goals of parents of youth with ASD and ID gleaned from this study helps inform the unique transition planning needs across diagnostic groups. Ideally, this research can help foster a shared understanding among educators, mental health professionals, researchers, and parents, so that they can more effectively work together towards achieving the desired outcomes.

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Table 1. Comparison of follow-up study participants to drop-outs

	Follow-up participants (*n*=109)	Drop-outs (*n*=105)	χ^2
Youth sex (% Male)	57.5	62.8	.56
Mother ethnicity (% Caucasian)	71.4	50	12.04*
Mother marital status (% married)	72.3	61.2	3.7
Mother education (% Bachelor's degree or above)	60.4	43.5	5.48*
Family income (% > $70 K)	64.5	42.2	10.68**

Note. Pearson chi-square test; ***p*<.01, **p*<.05.

Table 2. Youth, mother, and family characteristics from follow-up assessment point

	Typically Developing (*n*=53)	Autism Spectrum Disorder (*n*=23)	Intellectual Disability (*n*=33)	F
Full Scale IQ	110.7 (12.1)	106.8 (14.5)	61.5 (12.4)	169.7***
Adaptive behavior	97.6 (8.6)	77.7 (8.3)	70.1 (9.5)	114.6***
Youth sex (% male)	43.9	87.0	61.8	7.0**
Mother age	54.6 (6.0)	52.1 (9.3)	55.1 (6.5)	1.4
Mother ethnicity (% Caucasian)	75.5	68.2	67.7	2.9
Mother marital status (% married)	79.8	60.9	71.9	.15
Mother education (% Bachelor's degree or above)	76.0	78.3	56.3	2.3
Family income (% > $70 K)	72.9	72.3	73.0	.17

Note. One-way ANOVA; ****p*<.001; ***p*<.01. ID group includes participants with co-occurring ASD+ID and participants with borderline ID (IQ between 70-84). Full Scale IQ was estimated by the WISC-IV, and adaptive behavior was measured by the Vineland Adaptive Behavior Composite at age 13 (with the exception of 8 participants, for whom IQ and adaptive functioning were measured at age 5, and IQ was estimated using the Stanford-Binet).

Table 3. Thematic coding system: Parent challenges and worries

Themes	Subthemes
1) Transition Loss	a) Loss of caregiving role b) Separation (e.g., not having as much contact)
2) Independence	a) Financial stability/career b) Making life choices/handling responsibilities c) Continuum of dependence on the caregiver 1 = continued dependence 2 = in-between 3 = watching the YA struggle
3) Navigating Services	a) Figuring out what comes next/adjusting to change b) Inadequate services
4) Impact on the Family	a) Parent mental health: i. Loss of self, feeling exhausted/ overwhelmed ii. Lack of support, judgment from others b) Negative impact on siblings/other family members c) Parent-child conflict
5) Social Concerns	a) Victimization (e.g., exploitation, discrimination, teasing/bullying) b) Social support/fitting in with peers c) Romantic relationship/sexual concerns
6) Comparison to Others	a) Siblings b) Peers
7) Overall Happiness/ Fulfillment	N/A
8) Safety	N/A
9) Caregiver Aging	N/A
10) Young Adult Mental Health	N/A

Table 4. Thematic coding system: Parent goals

Theme	Subtheme
Professional Goals	Meaningful career
	Finding employment
Social Goals	Marriage/relationship
	Hold off on marriage/kids
	Family/kids
	Closeness with parents/other relatives
	Friendships
Independence	Financial independence
	Living independently from parents
	Daily living skills
	Other, general
Health	Physical
	Mental
Overall Happiness/Fulfillment	N/A
Safety	N/A
Financial Stability	N/A
Time for Leisure/Hobbies	N/A
Self-Efficacy/Motivation	N/A
Faith/Religion	N/A
Meaningful involvement in society	N/A

Table 5. Mother's transition goals by diagnostic group (%)

	Typically Developing (*n*=53)	Autism Spectrum Disorder (*n*=23)	Intellectual Disability (*n*=32)	All dx groups (*N*=108)	χ^2
Professional	69.8	87.0	65.6	72.2	3.2
Meaningful career	**49.1**	**52.2**	**15.6**	**39.8**	**11.8****
Finding employment	**9.4**	**21.7**	**37.5**	**20.4**	**9.2***
Educational goals	34.0	43.5	28.1	34.3	1.1
Social	54.7	52.2	56.3	54.6	0.2
Relationships/marriage	34.0	26.1	25.0	29.6	1.1
Hold off on marriage/kids	5.7	13.0	3.1	6.5	2.4
Family/kids	**20.8**	**0.0**	**9.4**	**13.0**	**6.8***
Closeness with family	7.5	0.0	3.1	4.6	2.4
Friendships	**11.3**	**17.4**	**31.3**	**18.5**	**6.4***
Independence	49.1	56.5	59.4	53.7	1.2
Financial	**41.5**	**26.1**	**12.5**	**29.6**	**8.6***
Living independently	**7.5**	**43.5**	**40.6**	**25.0**	**16.5*****
Daily life skills	**0.0**	**8.7**	**9.4**	**4.6**	**6.3***
General/other	9.4	13.0	18.8	13.0	1.4
Happiness/fulfillment	**41.5**	**8.7**	**21.9**	**28.7**	**9.7****
Self-efficacy/motivation	17.0	17.4	18.8	17.6	.02
Time for leisure/hobbies	13.2	0.0	12.5	10.2	3.3
Health: physical	11.3	4.3	6.3	8.3	1.3
Health: mental	7.5	0.0	6.3	5.6	1.8
Safety	1.9	0.0	9.4	3.7	4.1
Faith/religion	5.7	0.0	0.0	2.8	3.3
Meaningfully involved in society	5.7	0.0	0.0	2.8	3.3

Note. Pearson chi-square test; ***p<.001, **p<.01, *p<.05.

Table 6. Transition Outcome Composite (TOC) by diagnostic group; *[M (SD)]*

	Typically Developing (*n*=57)	Autism Spectrum Disorder (*n*=23)	Intellectual Disability (*n*=34)	Total (*N*=114)	F
Independence	.58 (.75)	1.48 (.51)	1.75 (.76)	1.11 (.89)	33.61***
Professional	.42 (.84)	.96 (1.07)	1.72 (.92)	.95 (1.10)	22.04***
Social	.68 (.70)	1.91 (1.04)	1.56 (.95)	1.18 (.99)	22.70***
Overall	1.68 (1.62)	4.35 (1.90)	5.12 (1.72)	3.25 (2.32)	49.14***

Note. One-way ANOVA; ****p*<.001. TOC = Transition Outcome Composite. TOC domains (Independence, Professional, and Social) are rated on a 4-point scale from 0 (most successful outcomes) to 3 (least successful outcomes). Domains are combined to form an Overall TOC score, rated on a 0 to 9 scale, with lower scores indicating more successful outcomes.

Table 7. Mothers' goals and youth diagnostic status predicting young adult TOC domain scores

Variable	R^2 adjusted	B	SE	ß	t	p
Professional Goals	.28					
Constant		.51	.17		3.10	.003**
Meaningful Career		-.31	.20	-.14	-1.57	.120
Finding a Job		.57	.25	.21	2.32	.022*
DD Status		.84	.18	.39	4.58	.000***
Social Goals	.25					
Constant		.73	.13		5.60	.000***
Family/Kids		-.22	.25	-.08	-.87	.384
DD Status		.98	.17	.50	5.79	.000***
Independence Goals	.36					
Constant		.64	.12		5.42	.000***
Daily Living Skills		.42	.32	.11	1.34	.182
Independent Living		.21	.17	.10	1.21	.228
Financial/Career		-.18	.16	-.09	-1.12	.266
DD Status		.92	.16	.51	5.74	.000***

Note. Multiple linear regression; ****p*<.001, **p*<.01, **p*<.05. Three separate regression analyses were conducted to examine mothers' goals and young adult developmental disability (DD) status as predictors of young adult transition outcome composite (TOC) scores in the professional, social, and independence domains (e.g., professional goals predicting professional outcomes). TOC domain outcomes were coded on a 0-3 scale with *lower* scores indicating *more* successful outcomes.

Table 8. Mothers' transition challenges and worries by diagnostic group (%)

	Typically Developing (*n*=53)	Autism Spectrum Disorder (*n*=23)	Intellectual Disability (*n*=33)	All dx groups (*N*=109)	χ^2 or *F*
Transition loss	**50.9**	**17.4**	**3.0**	**29.4**	**24.53*****
Loss of caregiving role	**22.6**	**13.0**	**3.0**	**14.7**	**6.31***
Separation	**39.6**	**13.0**	**3.0**	**22.9**	**17.02*****
Independence	92.5	91.3	87.9	90.8	.52
Financial stability/career	45.3	39.1	24.2	37.6	3.87
Making life choices/handling responsibilities	77.4	60.9	54.5	67.0	5.28
Continuum of dependence	58.5	56.5	66.7	60.6	.77
Dependence rating[a] (*M*)	**2.7**	**1.9**	**1.6**	**2.2**	**27.46*****
Navigating services	**3.8**	**8.7**	**45.5**	**17.4**	**26.09*****
Figuring out what's next/adjusting to change	**3.8**	**8.7**	**30.3**	**12.8**	**13.24****
Inadequate services	**0.0**	**0.0**	**33.3**	**10.1**	**28.18*****
Impact on family	37.7	52.2	51.5	45.0	2.18
Parent mental health	**9.4**	**39.1**	**42.4**	**25.7**	**14.35****
Overwhelmed/loss of self	**5.7**	**30.4**	**33.3**	**19.3**	**12.35****
Lack of support	**3.8**	**26.1**	**12.1**	**11.0**	**8.21***
Negative impact on siblings	**1.9**	**4.3**	**15.2**	**6.4**	**6.16***
Parent-child conflict	34.0	13.0	18.2	24.8	4.87
Social concerns	39.6	60.9	54.5	48.6	3.56
Victimization	**3.8**	**26.1**	**39.4**	**19.3**	**17.46*****
Social support	**11.3**	**43.5**	**27.3**	**22.9**	**9.89****
Romantic relationship	32.1	30.4	15.2	26.6	3.20
Comparison to others	7.5	26.1	21.2	15.6	5.32
Siblings	5.7	4.3	9.1	6.4	.61
Peers	**1.9**	**21.7**	**12.1**	**9.2**	**8.08***
Caregiver aging	**1.9**	**30.4**	**48.5**	**22.0**	**26.92*****
Young adult mental health	26.4	21.7	30.3	26.6	.51
Safety	26.4	26.1	33.3	28.4	.56
Overall happiness/fulfillment	18.9	0.0	12.1	12.8	5.12

Note. Pearson chi-square test; ****p*<.001, ***p*<.01, **p*<.05.

[a]Dependence rating refers to the young adult's level of dependence on caregivers, coded on a scale from 1 to 3 with the following score descriptors: 1=continued dependence on caregiver, 2=in-between, 3=watching the young adult struggle. A one-way ANOVA was conducted to examine group differences for this variable.

Table 9. Mothers' attitudes towards the future: Representative quotations

Code	TD	ASD	ID
Exclusively positive (4)	"I think it would be really cool to have a grandchild. I would love that. That would make me ecstatic. I'll be happy just to see him continue to do whatever he's doing that floats his boat."	"I'm proud of how well he's done despite his disability. He's really worked hard to achieve what he's achieved. It takes him twice as long to do assignments as others, but he doesn't shy away from doing them. I'm proud of him and the work he's put into being a successful student."	"I think his future is pretty bright. I think we live in a time where people are more open, more inclusive, more likely to accept people with disabilities… people with Down Syndrome have come a long way and I think they're making great progress."
Leaning positive (3)	"I'm proud of where he is now and where he's going. It makes me happy that he's doing well, it makes me sad when he's growing up, but I guess they gotta do that. But I'm happy for him, I'm proud of him."	"I have sadness and fear but overall hope. Because if I give up hope, I fall into a pit of despair that does no one any good and I know that. I feel like I'm a cautious optimistic. It's hope grounded with honest fear for him."	"Anxiety. Some fear… curiosity. I feel uncertain in certain areas, but I feel that she is gaining the tools to have something a little more tangible to work for. So I'm hopeful, and somewhat encouraged."
Leaning negative (2)	"Wishful thinking is one of them. Yeah, pretty much wishful thinking. She's very content to live off of unemployment. These couple of classes are not doing anything."	"Fear… If you go down the rabbit hole too far you start to feel bad, and you start second guessing if it is ever going to happen to him. But he has friends that are lower functioning than him that are at four-year universities so that gives us hope."	"Right now I'm feeling very doubtful and insecure about it. But I'm wanting to be hopeful about it."
Exclusively negative (1)	"I get nervous that I might live an airplane away. I have 3 children and I would like to live driving distance from them. I doubt these days that will happen. So that worries me. I get sad."	"Every year goes by and I'm kind of concerned about it. There are days when I feel depressed and I get really upset because I think about his future, and it's pretty sad that all this time, no matter what I've done, it hasn't been enough to help him succeed as an independent person."	"I'm just anxious… I don't even know what he would be without me. That's very scary to me… there is going to come a point where I am not going to be able to be there for him. He might have to take care of him. He's not going to handle anything like that… I think he will always need me."

Table 10. Mothers' attitudes towards the future by diagnostic group *[% (n)]*

	Typically Developing (*n*=53)	Autism Spectrum Disorder (*n*=23)	Intellectual Disability (*n*=33)	*F* or χ^2
Attitude Rating [M (SD)][a]	3.3 (1.0)	2.6 (1.2)	2.5 (1.3)	6.33**
Crosstabs Analysis[b]				14.80*
Exclusively negative	9.4 (5)	30.4 (7)	39.4 (13)	
Leaning negative	11.3 (6)	8.7 (2)	9.1 (3)	
Leaning positive	18.9 (10)	30.4 (7)	18.2 (6)	
Exclusively positive	60.4 (32)	30.4 (7)	33.3 (11)	

Note. [a]One-way ANOVA; ***p*<.01. [b]Chi-square test; **p*<.05.

Table 11. Maternal wellbeing in young adulthood by diagnostic group *[M (SD)]*

	TD	ASD	ID	*F*
FIQ Positive Impact	17.4 (6.1)	15.1 (6.6)	13.1 (6.6)	4.45*
FIQ Negative Impact	9.2 (10.4)	13.9 (10.3)	18.3 (11.2)	7.39**
SCL Total	12.9 (13.6)	16.5 (10.7)	21.2 (16.2)	3.45*
LOT Total	19.2 (3.7)	17.0 (5.8)	16.7 (4.8)	3.44*

Note. One-way ANOVA, *p<.05, **p<.01. FIQ = Family Impact Questionnaire; SCL = Symptom Checklist; LOT = Life Orientation Test.

Table 12. Maternal wellbeing and youth diagnostic status predicting mothers' future attitudes

Variable	R^2 adjusted	B	SE	ß	t	p
Maternal wellbeing only	.15					
Constant		2.26	.59		3.86	.000*
FIQ Negative Impact		-.03	.01	-.33	-2.58	.012*
LOT Total		.06	.03	.23	2.20	.031*
SCL Total		.004	.01	.06	.45	.658
Wellbeing and DD status	.18					
Constant		2.78	.57		4.85	.000*
FIQ Negative Impact		-.03	.01	-.25	-2.29	.024*
LOT Total		.04	.03	.16	1.48	.143
DD Status		-.43	.26	-.18	-1.65	.103

Note. Multiple linear regression; *$p<.05$. Two separate regression analyses were conducted to examine mothers' wellbeing variables in adolescence (age-13 or age-15) as predictors of mothers' attitudes towards their young adult's future in adulthood (age 20-25). The second analysis included young adult developmental disability (DD) status as a predictor. Mothers' attitudes were coded on a 1-4 scale with lower scores indicating more negative attitudes. FIQ = Family Impact Questionnaire; SCL = Symptom Checklist; LOT = Life Orientation Test.

Table 13. Maternal wellbeing and youth diagnostic status predicting young adult TOC overall score

Variable	B	SE	ß	t	p
Constant	3.95	1.16		3.41	.001
SCL Total	-.004	.02	-.03	-.28	.783
FIQ Negative Impact	.03	.03	.13	1.01	.314
FIQ Positive Impact	-.03	.04	-.08	-.87	.385
LOT Total	-.10	.04	-.19	-2.34	.022*
DD Status	2.65	.43	.55	6.23	.000***

Note. Multiple linear regression; $***p<.001$, $*p<.05$. R^2 adjusted = .51. Maternal wellbeing variables in adolescence (age-13 or age-15) were examined as predictors of overall young adult outcomes on the transition outcome composite (TOC; coded on a 0-9 scale with lower scores indicating *more* successful outcomes). FIQ = Family Impact Questionnaire; LOT = Life Orientation Test; SCL = Symptom Checklist.