Families of Adolescents and Adults With Intellectual and Developmental Disabilities

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Abstract

This chapter focuses on past and present themes in research on families of adolescents and adults with intellectual and developmental disabilities (IDD), as well as suggested future directions. We focused on three types of family relationships: relationships between the parent and the adolescent/adult with IDD (including parental well-being), parents’ marital relationships, and sibling relationships (including sibling well-being). A common past theme for each of these types of relationships was a focus on between-group differences, which encompassed comparisons between disability and typically developing samples, as well as comparisons between disability groups. Present research themes included investigation of risk and protective factors, a widening of the outcomes that are investigated, and recognition of the interactive influences of multiple relationships. A number of suggestions for future research are described, including the need for more diverse samples, importance of longitudinal research, incorporating the perspectives of all members of the family, and developing effective family supports and interventions.

The family has long been acknowledged as a critical context for development for children without disabilities. Various family factors such as specific parenting behaviors (Borkowski, Ramey, & Bristol-Powers, 2002), the quality of the physical and emotional home environment (Totsika & Sylva, 2004), and parental psychological well-being (Natsuaki et al., 2014) exert influence across childhood and into adulthood. Over the past several decades there has been increasing focus in the field of developmental disabilities on the family, with studies showing the impact of having a loved one with a disability on family functioning (e.g., Tint & Weiss, 2016) as well as studies indicating how family factors predict life course outcomes (for reviews see Hatton & Emerson, 2003; Warren & Brady, 2007).

Although individuals with intellectual and developmental disabilities (IDD) spend the majority of their lives in adulthood, until recently much of the family research has focused on families of children. Yet parent—child and sibling relationships begin to deviate even further from the norm as individuals with IDD age through adolescence and adulthood. According to Family Life Cycle theory (Carter & McGoldrick, 1989), parents of typically developing youth launch their children out of the family home during this stage, resulting in reorganization of parent and sibling relationships to become adult-to-adult, and leaving parents with more time to focus on their own relationships and goals. Yet, for many parents of individuals with IDD, intensive caregiving continues until parents are no longer able to provide care—often over five to six decades—at which point siblings may take over the primary caregiving role (Lounds & Seltzer, 2007).
from the typical family life cycle affects all members of the family, resulting in altered relationships and implications for quality of life and well-being.

In this 50th Anniversary chapter we take stock of the state of knowledge on families of adolescents and adults with IDD, focusing on past and present research themes. We focus on three family bonds: the parent—child relationship (including parental well-being); parents’ marital relationship; and the sibling relationship (including sibling well-being). At the end of the chapter, we discuss a number of future research directions.

1. PARENT WELL-BEING AND THE PARENT—CHILD RELATIONSHIP IN FAMILIES OF ADOLESCENTS AND ADULTS WITH IDD

1.1 Past Research

As noted by Hodapp (2002), from a historical perspective, early studies of parenting in families of individuals with IDD were often limited in scope, with minimal consideration of genetic factors. These studies also often lagged behind research on families of typically-developing children in regards to the complexity of the theoretical models being tested. Subsequently, although some early studies focused on the quality of parent—child interactions (eg, Floyd, Costigan, & Phillippe, 1997; Tannock, 1988), much of the past literature on families of individuals with IDD centered on documenting the negative consequences for parental and family well-being, particularly later in the life course.

As a result of this long-standing research emphasis, the heightened level of stress experienced by parents of individuals with IDD is very well established (eg, Hayes & Watson, 2013; Lee, 2013). High levels of stress and caregiving burden have been observed across the lifespan, with parents reporting elevated levels of stress compared to controls during the early childhood years as well as in adolescence and adulthood (Baker et al., 2003; Eisenhower, Baker, & Blacher, 2005; Emerson, 2003). High levels of parental stress subsequently can take a toll on parent’s physical and psychological well-being; relative to parents of typically developing individuals, parents of individuals with disabilities have been found to have higher levels of anxiety and depression and more physical health problems (Smith, Seltzer, & Greenberg, 2012).

In addition to the historical emphasis on the burden of caregiving, much past research on parent—child relations during adolescence and adulthood focused on family life course transitions, specifically considerations for
out-of-home placement, including long-term decision making and planning (eg, Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1989). For example, Seltzer, Krauss, Hong, and Orsmond (2001) found that aging mothers were highly involved in the planning and relocation process and continued to have high levels of contact and emotional involvement with their adult child following an out-of-home placement. Mothers’ satisfaction with their contact with their adult child increased over time and their sense of burden decreased after placement (Seltzer et al., 2001). In another older study, higher levels of informal support were associated with lower levels of caregiving burden among parents of adult children with IDD who continue to coreside, whereas desire for out-of-home placement was linked with having fewer support resources (Heller & Factor, 1993).

Since these earlier studies, new research has continued to document the toll of lifelong caregiving on older parents of adult children with IDD, with studies showing that caregiving burden is often exacerbated by poor future planning and lack of adult services (Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014). One example of recent work with robust methods and public health implications can be found in Seltzer, Floyd, Song, Greenberg, and Hong (2011). In a large, population-based, and longitudinal study, these authors found that, compared to matched controls, parents of individuals with IDD have poorer physical and mental health than their peers, especially as they entered old age. More recent work on residential transitions also has expanded to include the impact of social networks and family dynamics in predicting residential outcomes (eg, Woodman, Mailick, Anderson, & Esbensen, 2014). It will be critical for future work to continue to probe with rigorous methodologies these questions regarding for whom and when families experience burden, as the answers to these questions have important implications for timing and delivery of formal and information supports and services.

As a final comment regarding the history of parent—child research in IDD, it is worth noting that the field’s emphasis on investigating child-to-parent effects (eg, focus on caregiving stress) rather than parent-to-child effects may be, at least in part, a reaction against very early blaming of families for children’s developmental difficulties. Specifically, in the 1950s and 1960s, mothers of children with autism spectrum disorders (ASD) were blamed for causing their child’s condition, as poor parenting was the prevailing theory regarding etiology of ASD at the time (for a review, see Folstein & Rosen-Sheidley, 2001). This idea has since been discredited, and it is now
widely accepted that ASD is a complex genetic disorder and not caused by parenting style. Both of these perspectives, however, have shifted attention away from the role of families and parenting in influencing developmental trajectories for individuals with ASD and other genetic conditions. However, contemporary research has an increased focus on understanding contextual as well as endogenous factors associated with development and outcomes for individuals with IDD, which we review in the next section.

1.2 Present State of Research

We are currently in an exciting time in family research in IDD, as the field is evolving to consider new theoretical perspectives for understanding parent—child relations across development. Investigators are moving away from purely descriptive studies focusing on elevated levels of stress and burden to examine more sophisticated models of family dynamics including (1) diathesis-stress models, which answer questions of why some but not all parents experience difficulties, (2) transactional models, which explore bidirectional influences between parents and children and how they change over time, and (3) ecological models, which emphasize how contexts (including cultural issues) are critical for understanding developmental processes (Carroll, 2013). There has also been an expansion in the field regarding outcomes of interest, with an increased focus on the biological impact of caregiving (taking a biopsychosocial perspective) and the positive impacts of caregiving including adaptation and personal growth (taking a positive psychology perspective). We review in the following discussion a selection of studies which highlight some of these recent trends.

Moving beyond group differences to consider risk and protective factors. One key advance of family IDD research has been in moving beyond identifying the implications of having a child with a disability on the family, to instead also consider why these families are affected. What, exactly, is it about having a child with a disability that influences the family, and might there be moderators of a family’s experiences? Increasing numbers of studies now examine mechanisms influencing family stress and adaptation. Repeatedly across studies of children, adolescents, and adults with IDD, for example, the challenging behaviors of individuals with IDD are among the most significant predictors of parental burden and distress (Hastings et al., 2005; Herring et al., 2006; Lounds, Seltzer, Greenberg, & Shattuck, 2007; Seltzer et al., 2010). Studies also have found child behavior problems to act as a significant predictor of parenting quality and the parent—child relationship. For example, in a study of individuals with ASD during adolescence and
adulthood, predictors of mother—child relationship quality included the child having less severe behavior problems, better health and less social impairment (Orsmond, Seltzer, Greenberg, & Krauss, 2006). These studies highlight that it is not the presence of offspring with a developmental difference, per say, which infers risk to parental well-being and behavior, but rather specific aspects of a child’s phenotype that challenge families.

Also being explored are several potential protective factors. For example, coping strategies such as planful problem solving and cognitive reframing have been found to buffer stress for aging parents of children with disabilities and these benefits of coping are especially strong when offspring are coresiding with their parents (Piazza, Floyd, Mailick, & Greenberg, 2014). Coping may be particularly impactful when child behavioral challenges are greater, and parents may gain skill in applying coping strategies as their children move into adolescence and adulthood (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008).

Other studies have demonstrated that social support can be beneficial for parental well-being as parents age (Smith, Greenberg, & Seltzer, 2012). A study by Woodman (2014) found that in addition to child behavior problems, maternal social support and a positive family climate predicted stress trajectories from childhood through adolescence for mothers and fathers of children with IDD. Interestingly, mothers and fathers within the same family had similar trajectories of stress over time, although there were some differences between mothers and fathers in the factors that predicted stress. For example, although child behavior problems predicted stress during early childhood for both mothers and fathers, the child’s adaptive behavior predicted initial levels of stress for fathers only. Furthermore, father’s report of family climate predicted mother’s report of stress, but not vice versa (Woodman, 2014). These types of nuanced analyses are very valuable when moving beyond descriptions of group differences to instead create models of targeted services and supports for families.

Considering parent-to-child effects and bi-directionality in family relations. As noted earlier, in the general child and adolescent development literature, parenting and the family environment have long been recognized as critical predictors of life course outcomes. This perspective has been extended to individuals with IDD, with several studies now documenting the impact of the parent—child relationship on children’s outcomes across a range of disabilities. Notably, significant and long-term effects of the family context have been demonstrated in samples of individuals with known genetic conditions at multiple points in the lifespan, highlighting how environmental factors
shape the developmental course regardless of etiology. For example, in a longitudinal study of mother–child dyads of children with fragile X syndrome (FXS), maternal responsivity during early childhood predicted language development at age 9 years, even after controlling for level of autism symptoms, nonverbal intelligence quotient (IQ), and maternal education (Brady, Warren, Fleming, Keller, & Sterling, 2014). As an example of family environmental impacts later in the life course, in a 22-year longitudinal study of 75 adults with Down syndrome, Esbensen, Mailick, and Silverman (2013) found that earlier levels of maternal depressive symptoms predicted later life outcomes among their offspring with IDD including functional abilities, behavior problems, and even dementia status.

In addition to studies that document parent-to-child effects, several studies now examine bidirectional effects between parents and children (e.g., Neece, Green, & Baker, 2012). For example, in a study testing a transactional model of stress and behavior problems for families of children with developmental disabilities, Woodman, Mawdsley, and Hauser-Cram (2015) found support for both child-driven and parent-driven effects over a 15-year period from age 3 to age 18. Findings also suggested important differences in the strength of effects depending on the child’s developmental stage. For instance, there were bidirectional effects between internalizing behavior problems and parent stress during early childhood; during middle childhood the direction of effects was mainly from child to parent, whereas in adolescence it was from parent to child (Woodman, Mawdsley et al., 2015). Relatively, for adolescents and adults with ASD, studies have shown that experiencing a family environment characterized by high levels of praise and warmth is associated with reductions in autism symptoms, behavior problems, and psychological symptoms over time, with effects going mainly from parent to child (Smith, Greenberg, Seltzer, & Hong, 2008; Woodman, Smith, Greenberg, & Mailick, 2015). Studies such as these which test richer conceptualizations of family dynamics are needed to guide timely and effective models of intervention.

Considering a wider range of outcomes. As another contemporary trend, current research is expanding in its scope of family impacts as well as the specificity of measurement. For example, the field is now beginning to follow past recommendations to examine both positive and negative outcomes for families of individuals with disabilities (Blacher, Neece, & Paczkowski, 2005; Hastings, Allen, McDermott, & Still, 2002). A review by Tint and Weiss (2016) found that, although the majority of studies of family well-being have focused on negative outcomes, positive outcomes
are observed and predictors of outcomes are now a focus of current research. Similarly, in a comprehensive review of family support for adults with disabilities, Heller, Caldwell, and Factor (2007) suggested that many aging families show signs of adaptation. We hope that this more comprehensive focus on diverse family impacts from a positive psychology perspective will continue in the future.

As another example of expanded measurement, current research has been moving toward a better understanding of the biological implications of caregiving stress. Multiple studies have now explored diurnal cortisol, a biomarker of stress, among parents of children with IDD; in general, such studies have found patterns of dysregulation relative to parents of children without disabilities. In a population-based sample of midlife parents of children with disabilities and matched controls, cortisol expression differed significantly between groups, with more pronounced differences for parents who spent more time with their children (Seltzer et al., 2009). Similarly, Seltzer and colleagues examined differences in cortisol expression between mothers of adolescents and adults with ASD and mothers of aged-matched offspring without disabilities. They found that mothers of individuals with ASD had significantly hypoactivated cortisol levels, particularly those mothers whose children had the most significant behavioral challenges (Seltzer et al., 2010). Other cortisol studies have suggested that, compared to other parents, parents of adolescent and adult offspring with ASD may have more stress reactivity (Wong, Mailick, Greenberg, Hong, & Coe, 2014). Furthermore, research among mothers of adolescents and adults with FXS (who typically are carriers of the premutation of FXS) has indicated that there are gene-by-environment interactions in the prediction of cortisol, such that mother’s own level of genetic risk moderates the impact of stress on health and well-being (Hartley, Seltzer, Hong, et al., 2012; Seltzer, Barker, Greenberg, Hong, Coe, & Almeida, 2012). Further exploration of the role of genetics in parent outcomes will be an important area for future research.

Another biomarker receiving research attention is telomere length. Shortened telomeres are thought to be associated with accelerated cellular aging due to stress exposure and have been found in a range of health conditions (Verhoeven et al., 2014; Willeit et al., 2010). Related to IDD, Epel et al. (2004) found a relationship between caring for children with special health care needs or disabilities and telomere shortening, with women who had been providing care for the longest duration having the shortest telomere lengths. An interesting study of families of young children with
ASD found that mothers, children with ASD, and their infant siblings all had shortened telomeres compared to typically developing controls (Nelson, Varcin, Coman, DeVivo, & Tager-Flusberg, 2015). In addition to suggesting that all family members may be at-risk, these findings raise question as to which genetic/biological mechanisms may be at play in regulating telomeres and response to stress (Drury, 2015). More work is needed to continue to understand the gene-by-environment effects in families of children with IDD and how these associations may vary by child age and life stage. Taken together, these findings regarding the biological impact of stress clearly highlight the significant risks to health associated with raising a son or daughter with IDD, which appear to compound over time. These findings also underscore the need for appropriate intervention services to help reduce stress for the entire family system across the life span.

In the next section we continue to focus on parents, by summarizing the past and present research on marital quality among parents of adolescents and adults with IDD.

2. MARITAL QUALITY IN FAMILIES OF ADOLESCENTS AND ADULTS WITH IDD

2.1 Past Research

Although a growing body of research examines marital quality in parents of individuals with IDD, most studies have focused on the early parenting years. While these findings can help us understand marital quality in parents of adults with IDD to some degree, the later parenting years are deserving of their own studies. Given the lifelong nature of IDD, parenting challenges and the need for caregiving often extends into the adulthood of the son or daughter with IDD (Seltzer et al., 2009; Smith et al., 2010). However, the nature of parenting challenges, as well as parents’ ability to cope and manage these challenges, changes across the life course of an individual (Benson, 2014; Grein & Glidden, 2015). Moreover, couple relationships also have their own developmental life course; marital satisfaction, risk of divorce, couple coping, and couple conflict all shift across the life of a relationship (eg, Dush, Taylor, & Kroeger, 2008). Thus, relative levels of marital quality, as well as the factors and mechanisms that shape marital quality, are likely to differ in parents of adults with IDD than in parents of children with IDD. There is also the need to consider selection effects, as couples who remain married to the same partner into the adulthood of their son or
daughter with IDD differ from those whose partnership ended earlier on (eg, Freedman, Kalb, Zablotsky, & Stuart, 2012; Hartley et al., 2010).

When considering the past of marital relationship research for parents of adolescents and adults with ASD, the most common trend has been to examine whether these marital relationships are at-risk. Across studies, there is evidence that on average, parents of individuals with IDD as a group have a slightly increased risk of divorce (eg, Hartley et al., 2010; Risdal & Singer, 2004; Witt, Riley, & Coiro, 2003) and lower average level of marital satisfaction (eg, Brobst, Clopton, & Hendrick, 2009; Florian & Findler, 2001; Gau et al., 2012) than comparison groups of parents of individuals without disabilities. However, findings are mixed, with other studies reporting no difference in the risk of divorce (eg, Freedman et al., 2012; Urbano & Hodapp, 2007) or in average level of self-reported marital satisfaction (eg, Floyd & Zmich, 1991; Rodrigue, Morgan, & Gerffken, 1992) between parents of individuals with IDD and comparison groups. Moreover, within studies, researchers report substantial variability in marital quality among parents of individuals with IDD, with outcomes widely ranging from highly dissatisfying relationships to highly satisfying and long-lasting relationships (for a review see Hartley, Seltzer, Barker, & Greenberg, 2011).

In part, the discrepancy between and within studies in marital quality reflects differences in family characteristics as well as in the nature of various IDDs. There are vast differences in functioning, symptoms, and co-occurring behavior problems among individuals with IDD, such that some types of IDD appear to be more taxing on parents’ marital quality than others. Indeed, differences in risk of divorce and level of marital satisfaction vary by type of IDD (Hartley et al., 2010; Risdal & Singer, 2004; Urbano & Hodapp, 2007). For example, using population data on adults in their midlife in the United States, parents who had an adult child with IDD (due to mixed etiologies) were not more likely to have divorced than parents whose adult children did not have disabilities (Seltzer et al., 2011). In contrast, in a sample of 391 mothers of adolescents and adults with ASD, Hartley et al. (2010) found an increased risk of divorce for this ASD group compared to a matched sample of mothers of adolescents and adults without disabilities. Compared to the stress of parenting offspring with other types of IDD, having a son or daughter with ASD has been found to be especially stressful for parents (eg, Abbeduto et al., 2004; Hartley, Seltzer, Head, & Abbeduto, 2012); parenting offspring with ASD (versus with other types of IDD) may also take a greater toll on marital quality.
2.2 Present State of Research

Current research has begun to shift from examinations of group differences by disability type, and instead to focus on when couples might be most at-risk, as well as understanding why some couples fare better than others. There is also emerging research that takes a family systems perspective, examining how multiple relationships in the family act on and are influenced by each other. Each of these ideas, with representative studies, is further explained in the following discussion.

Pinpointing when in the life course couples are most at-risk. There is evidence that risk of divorce varies across the life course of the individual with IDD, and periods of greatest vulnerability differ for different types of IDD. In the Hartley et al. (2010) study, parents of individuals with ASD did not evidence an increased risk of divorce relative to parents whose children did not have a disability when the child was young (ie, prior to age 9 years). However, beginning in older childhood and continuing into the offspring’s adolescence and adulthood, mothers in the ASD group had a higher risk of divorce than mothers in the comparison group. It may be that marital strain from negative couple interactions accumulates over time to eventually take its toll, leading to marital disruption. Alternatively, transitions and changes during adulthood (eg, exit out of high school) have been found to be particularly challenging for individuals with ASD and their parents (Taylor & Seltzer, 2010, 2011a, 2011b), and individuals with ASD have relatively poorer outcomes in adulthood than individuals with other types of IDD (eg, Levy & Perry, 2011). Thus, challenges that occur during adulthood may add new stressors to the marital relationship. In contrast, in a population study of parents of children with Down syndrome in Tennessee, the overall risk of divorce was equal to and even slightly less than that of parents whose children did not have a disability (Urbano & Hodapp, 2007). However, risk of divorce was heightened during the first 2 years of life of the child with Down syndrome. The authors hypothesized that this was because stress may be particularly high during these first few years as this corresponds to the timing of diagnosis (eg, prenatally or after birth) and often medical problems. Thus, different behavioral phenotypes and diagnoses patterns between disability types likely not only impact overall marital quality, but also when in the life course marital relationship might be the most vulnerable. Working to further understand life course patterns of marital risk and resiliency is an important area for continued research.
Examining the mechanisms by which some couples fare better than others. As in the parent—child literature, there has been a move away from between-group differences to understanding why some marital relationships might be at-risk. Hartley, Seltzer, et al. (2011) have proposed a modified version of the vulnerability-stress-adaptation model (Karney & Bradbury, 1995) to guide inquiry into the factors shaping marital quality in the parents of young and grown children with IDD. In this model, vulnerability factors (stable or long-standing parent or family factors) make some parents susceptible to poor marital quality, independent of having a son or daughter with IDD. Moreover, these vulnerability factors interact with stressors related to the challenges of parenting a son or daughter with IDD. Finally, the adaptation processes that parents use to manage and cope with these stressors influence the extent to which they experience negative couple interactions. Over time, the accumulation of negative couple interactions leads to poor marital quality.

Over the last several years, several vulnerability factors have been identified as being related to poor marital quality in parents of individuals with ASD. These include parents’ personality traits or broader autism phenotype symptoms (i.e., mild autism-like traits), parental age when their son or daughter with IDD was born, parental education, household income, and presence of multiple children with special health needs in the family (e.g., Ekas, Timmons, Pruitt, Ghilain, & Alassandri, 2015; Hartley et al., 2010; Namkung, Song, Greenberg, Mailick, & Floyd, 2015). While some of these vulnerability factors (e.g., parental education, household income) are not unique to parents of individuals with IDD, there are also differences in vulnerability factors between parents of individuals with IDD and parents of individuals without disabilities. For example, in a study of 190 parents of adult children with IDD and a comparison group of 7251 parents of adult children without disabilities, the number of children in the family was positively associated with risk of divorce through parents’ midlife in the comparison group but was not associated with divorce in the IDD group (Namkung et al., 2015). There also appears to be mother—father differences in vulnerability factors for poor marital quality (Hartley, Papp, Blumenstock, Floyd, & Goetz, in press), that are in need of further study. For example, in a study of 176 couples who had a child with ASD (aged 5—12 years), household income and presence of multiple children with special health care needs served as vulnerability factors for having more frequent negative couple interactions only in fathers of children with ASD.
In terms of the stress components, the severity of the child-related stress predicts, in part, differences in marital quality among parents of young and grown individuals with ASD. Indeed, cross-sectional studies indicate that severity of co-occurring behavior problems is related to differences in level of marital satisfaction in parents of children with intellectual disability (eg, Baker, Blacher, Cnic, & Edelbrock, 2002) and parents of adolescents and adults with ASD (eg, Hartley, Barker, Seltzer, Floyd, & Greenberg, 2011). Moreover, at a within-person level across an 8-year period, fluctuations in maternal level of marital satisfaction were found to co-vary across time with fluctuations in the severity of the adolescent or adult with ASD’s co-occurring behavior problems (Hartley, Barker, Baker, Seltzer, & Greenberg, 2012). Thus, even in adulthood, the challenges of the individual with ASD are intertwined with mothers’ level of marital satisfaction. Presence (or level) of intellectual disability has been generally found not to be linked to marital satisfaction or risk of divorce among parents of young or grown children with ASD or other types of IDD (Baker et al., 2002; Hartley et al., 2010; Hartley, Barker, et al., 2012), nor has the lifetime severity of ASD symptoms in parents of adolescents and adults with ASD (Hartley et al., 2010). The severity of co-occurring behavior problems has been found to be a stronger predictor of parenting stress than intellectual functioning and severity of ASD symptoms in parents of both young and grown children with IDD, and thus it makes sense that the severity of co-occurring behaviors would also have a greater association with marital satisfaction (eg, Abbeduto et al., 2004; Lecavalier, Leone, & Wiltz, 2006).

There is also a need to better understand the mechanisms through which stressors related to the individual with IDD lead to negative couple interactions and eventually poor marital quality. In part, negative couple interactions may be the direct result of experiencing a higher level of couple disagreements about parenting the individual with IDD, as parents may simply be faced with a higher level of child-related challenges to solve. Indeed, evidence from a 14-day daily diary study of 176 couples who had a child with ASD (aged 5—12 years) found that daily couple problem-solving interactions were frequently about the child with ASD (average of 25% of the days during a 14-day daily diary), and the child with ASD was more frequently the topic of couple problem-solving interactions than were other children in the home (Hartley, Papp, Blumenstock, et al., in press). However, couple problem-solving interactions about the child with ASD were not associated with high levels of parental negative affect. Instead, couple problem-solving interactions about the couple relationship (ie, closeness) and
partner behaviors (eg, communication, personality, and habits) were reported to be the most distressing interactions. Thus, while they may frequently occur, couple disagreements about the child with ASD do not necessarily lead to negative couple interactions. It is not clear if this pattern of findings would remain true for parents of adults with ASD and/or for parents of young and grown children with types of IDDs.

Alternatively, poor marital quality in some parents of individuals with IDD may reflect an indirect process of stress spillover from parenting challenges. Indeed, evidence of a spillover process was also found in the aforementioned daily diary study, in which the tension, affect, and behaviors originating from stressful parenting experiences carried into marital experiences, after accounting for couple problem-solving interactions about the child with ASD. Specifically, for mothers, experiencing a day with a higher level of parenting stress predicted a lower number of positive marital interactions (eg, meaningful conversations with partner, joking with partner, and kissing and hugging partner) the following day (Hartley, Papp, & Bolt, 2016). Thus, at a daily level, a higher level of parenting stress may reduce emotional resources, leaving mothers of individuals with ASD less likely to engage in positive marital interactions. Over time, a low number of positive marital interactions is problematic for marital quality, as such interactions are needed to offset the impact of negative couple interactions to maintain healthy relationships in studies on the general population (Gottman, 1993).

Unfortunately, little research has examined couple-level adaptation processes in parents of individuals with IDD. From studies on parents of children with ASD, partner support has strong associations with positive and negative daily affect (eg, Ekas et al., 2015; Pottie, Cohen, & Ingram, 2009). Thus, partner support may be a critical adaptation process for successful marital quality in the context of having a young or grown child with IDD. Future studies should focus on understanding dyadic coping processes (ie couple-level ability to offer and receive support and jointly deal with stress) and couple conflict processes (ie, factors related to how couples handle disagreements or problem-solving issues), as how couples handle conflict is arguably one of the most robust predictors of long-term marital outcomes in studies on the general population (eg, Finkel, Slotter, Luchies, Walton, & Gross, 2013; Gottman, 1993; Park & Unutzer, 2014). To better understand how couples navigate conflict (eg, avoidance, demand–withdrawal patterns, and stalemate), we need to perform observational studies of actual couple interacting.
Considering the interactive effects of multiple relationships. In the field of IDD, there is a tendency to attribute parent outcomes, including marital quality, to the individual with IDD. Indeed, the majority of research on marital quality has focused on the impact of the individual with IDD on parents’ marital outcomes. However, it is also important to understand how parents’ marital quality influences the functioning of the individual with IDD and/or parenting experiences. In the Hartley et al. (2016) study involving a 14-day daily diary study, for mothers, experiencing a day with a higher number of negative marital interactions (eg, made a critical comment to partner, avoided partner, and expressed frustration with partner) predicted a higher level of parenting stress the following day. In other words, the negative affect, tension, and behaviors originating from negative marital interactions also spilled over into parenting experiences for mothers of individuals with ASD. Thus, at least in this study, the link between marital quality and parenting stress was found to flow bidirectionally.

In sum, the current research reflects a significant increase in knowledge about marital relationships of families of individuals with IDD, particularly in considering the unique experiences of families of adults as distinct from families of children. Research has progressed from studies of between-group differences to understanding the varied and interactive factors that allow some couples to thrive and place others at-risk; this has been a considerable advance and one that should continue in future research.

In the next section, we discuss the research on siblings of adolescents and adults with IDD. This family member is less often included in research, yet plays a very important role in the lives of individuals with IDD, particularly in adulthood.

3. RELATIONSHIPS AND WELL-BEING AMONG SIBLINGS OF ADOLESCENTS AND ADULTS WITH IDD

Although most family research focuses on parents of individuals with disabilities, it is important to recognize the roles of other family members such as siblings. Regardless of whether or not a disability is present, siblings have the longest lasting familial relationship (Cicirelli, 1982). When a disability is present, the sibling without a disability may fulfill unique roles such as advocate (Burke, Arnold, & Owen, 2015), supporter (Kramer, Hall, & Heller, 2013), and eventual caregiver (Burke, Taylor, Urbano, & Hodapp, 2012; Orsmond & Seltzer, 2000). As we review the past and present of sibling research, note that we refer to the typically developing
member of the sibling pair as the “sibling” and the individual with IDD as the “brother or sister.”

3.1 Past Research

Similar to both the parent—child and marital literature, many past studies of siblings tended to focus on group differences, examining whether psychological functioning and the sibling relationships differed between siblings of individuals with IDD versus those without disabilities. Although adult siblings generally report frequent phone and in-person contact with their brothers and sisters with IDD (Krauss, Seltzer, Gordon, & Friedman, 1996), Zetlin (1986) found substantial variability in the types of relationships between siblings and their brother/sister, ranging from frequent contacts and very warm feelings, to hostile feelings with little to no contact.

Just as Zetlin (1986) found variability in sibling closeness and contact within her sample, there is also variability between studies regarding the impact of having a brother or sister with IDD on sibling relationship closeness. For example, Begun (1989) examined relationship closeness of siblings to their brother or sister with IDD and to a typically developing brother or sister (thereby controlling for family effects). She found that siblings reported less closeness with their brother/sister with IDD (relative to their brother or sister without a disability). On the other hand, McHale, Sloan, and Simeonsson (1986) found no difference in the quality of sibling relationships among siblings of individuals with ASD, intellectual disability, and without disability. More recent research has continued this theme. Using a population-based cohort of siblings (the Wisconsin Longitudinal Study), Taylor, Greenberg, Seltzer, and Floyd (2008) found that siblings of adults with mild intellectual deficits tended to have more contact with family members than siblings of typically developing adults, but reported less affective closeness.

Other adult sibling studies have moved beyond the impact of having a brother or sister with versus without a disability, to instead examine whether the type of disability infers a differential impact on sibling well-being and the sibling relationship. These studies have suggested that having a brother or sister with a mental illness or with an ASD might infer the greatest risk. For example, Seltzer, Greenberg, Krauss, Gordon, and Judge (1997) found that, relative to siblings of adults with a mental illness, siblings of adults with IDD reported greater psychological well-being including feelings of self-acceptance, autonomy, and personal growth. Their study also suggested that siblings of individuals with IDD (versus mental illness) reported closer
sibling relationships and were more likely to report that their brothers/sisters positively impacted their lives across many areas (eg, professions, partners). In a more recent study in this same vein, Hodapp and Urbano (2007) found that, relative to siblings of adults with Down syndrome, siblings of individuals with ASD reported less close and warm sibling relationships, fewer contacts with their brothers and sisters, as well as worse health and more depressive symptoms. Thus, although findings appear mixed about whether siblings of adults with IDD have poorer quality of sibling relationships compared to typically developing sibships, the type of disability seems an important contributor to sibling well-being and the sibling relationship.

Although most early sibling studies focused on children, another theme in earlier studies examined the characteristics of adult siblings who would become primary caregivers for their brother/sister with IDD. Because individuals with IDD are living longer lives, with more adults outliving their parents (Braddock et al., 2005), studies of future caregiving began to gain traction in the 1990s. As one example, Greenberg, Seltzer, Orsmond, and Krauss (1999) examined the factors associated with siblings’ expectation to assume primary caregiving, using a sample of 61 siblings of individuals with mental illness and 119 siblings of individuals with IDD. They found that those siblings most likely to anticipate future caregiving were sisters, siblings who did not have minor children living at home, and siblings who lived in closer proximity and who felt emotionally closer to their brother/sister with disabilities. Similarly, Krauss et al. (1996) examined the factors associated with siblings’ expectation to coreside with their brother or sister with IDD in the future. They found that 19% of siblings anticipated living with their brother/sister with IDD. Predictors of anticipated coresiding mirrored predictors of anticipated primary caregiving: female (versus male), having more shared activities with the brother/sister with IDD, living in closer proximity to the brother/sister, and feeling emotionally closer to him/her. Additionally, siblings of individuals with less severe disabilities and less problem behaviors were more likely to report anticipating coresidence. A more recent study corroborated many of these earlier findings: in a large survey (N = 757) of siblings of adults with IDD, female (versus male) siblings and those who were closer to their brother or sister (both physically and emotionally) were again more likely to anticipate future caregiving roles (Burke et al., 2012). Burke et al. (2012) also found a significant role of the number of siblings in the family on the likelihood of caregiving. Specially, they found that those siblings who had no other typically developing brothers or sisters in the sibship (ie, they were the only nondisabled
sibling) were more likely to expect to provide future caregiving than siblings who had other typically developing brothers or sisters in their family.

### 3.2 Present State of Research

In alignment with the larger family literature, recent sibling research has tended to move beyond a focus on between-group differences, toward examining the specific factors that might promote better relationship quality with the brother/sister with IDD or improved sibling well-being. Studies are also beginning to incorporate a family systems perspective by considering multiple relationships simultaneously as well as the impact of multiple family members (parents, typically developing siblings) on the sibling relationship. Finally, current sibling caregiving research is seeking to understand differences between anticipated caregiving and actual assumption of care. Each of these areas is explained further in the following discussion, with representative studies.

**Factors that impact the sibling relationship and sibling well-being.** Much of the current sibling research focuses on understanding how characteristics of the sibling, the brother or sister with IDD, and other family demographic variables affect sibling functioning and relationships. Consistent with other areas of family research, one characteristic of the brother or sister with IDD that consistently emerges as a predictor of sibling functioning and relationships is behavior problems. Studies using maternal report as well as sibling report have found that adolescent and adult siblings have better well-being and more positive sibling relationships when their brothers and sisters with IDD have fewer behavior problems (Orsmond, Kuo, & Seltzer, 2009; Pruchno, Patrick, & Burant, 1996; Shivers, Diesenroth, & Taylor, 2013; Taylor & Hodapp, 2012). As well, Taylor and Hodapp (2012) found that siblings of brothers and sisters with greater functional abilities reported feeling closer to that brother/sister. However, when their brothers or sisters with IDD had more unmet service needs, siblings reported less closeness in the sibling relationship as well as more depressive symptoms. Finally, Orsmond et al. (2009) reported that adult siblings of individuals with ASD who were older (eg, in their 30s or 40s) reported fewer shared activities with their brothers and sisters than siblings of younger individuals (eg, in their teens or 20s). This last finding is particularly interesting, and may be because older siblings are more likely to have their own family and work obligations, leaving less time for shared activities.

In terms of characteristics of the sibling himself or herself, the most consistent correlate of relationship quality with the brother/sister with IDD is gender. In addition to being more likely to assume primary care
for their brothers or sisters with IDD, female siblings report being (or are reported to be) closer to and more involved with their brother/sister with IDD than male siblings (e.g., Hodapp, Urbano, & Burke, 2010; Orsmond & Seltzer, 2000; Seltzer, Begun, Seltzer, & Krauss, 1991). Interestingly, Orsmond and Seltzer (2000) found that the sex of the adult with IDD was also an important determinant of the sibling relationship, but only for male siblings. That is, male siblings of sisters with IDD reported fewer positive feelings and greater negative feelings about their involvement in the sibling relationship relative to male siblings of brothers with IDD. For female siblings, however, the sex of the brother/sister with IDD did not affect the sibling relationship.

Although the body of research is quite small, a few family demographic characteristics have been implicated in sibling well-being and the sibling relationship. Having more brothers and sisters in a family might serve as a protective factor; Pruchno et al. (1996) found that mothers reported closer sibling relationships when there were more typically developing siblings in the family, and Orsmond et al. (2009) found greater psychological well-being among adolescent siblings with larger sibships. Furthermore, Taylor and Hodapp (2012) found that physical distance between siblings was important to the sibling relationship, with siblings reporting a closer affective relationship when there was less distance between their residence and the residence of the brother or sister with IDD.

*Interplay between parents, siblings, and the brother/sister with IDD.* In addition to focusing on how the characteristics of the sibling dyad might influence well-being and the sibling relationship, more recent research has also examined the role of parental support, characteristics, and relationships. These studies generally find that, when parents provide emotional and instrumental support to both the sibling and the brother/sister with IDD, siblings report greater closeness in the sibling relationship as well as better psychological functioning. For example, Orsmond et al. (2009) considered the role of a number of family background characteristics and sibling resources in the relationships of adult siblings to their brother/sister with ASD. The only predictor of sibling relationship quality was the level of social support provided by parents, with siblings feeling closer to their brother or sister when their parents were more supportive. Finally, the extent to which parents are capable of providing care to the brother or sister with IDD seems to be important for both sibling well-being and the sibling relationship, particularly in adulthood. Specifically, siblings whose parents are more able to care for the brother/sister with IDD tend to have fewer depressive symptoms (Taylor & Hodapp, 2012). Given the interwoven lives of parents, siblings, and
individuals with IDD—particularly as parents age and consider transitions of care—it will continue to be important to understand how each of these different aspects of the family unit impacts sibling functioning and relationships.

*Anticipating caregiving versus actual caregiving.* Sibling caregiving remains an important area of research. As already mentioned, individuals with IDD often outlive their parents (Braddock et al., 2005). However, it has become clear that the adult service delivery system is unable to meet the needs of all adults with disabilities. Over 75% of adults with IDD live with their families while waiting for services (Braddock, Hemp, & Rizzolo, 2008). Due to the inadequacy of the service delivery system and the longer lives of individuals with disabilities, adult siblings are increasingly fulfilling formal caregiving roles.

As noted previously, earlier studies on this topic tended to focus on siblings’ expectations to fulfill future caregiving roles as opposed to examining siblings who are current caregivers. However, not all siblings who expect to become primary caregivers end up doing so. Freedman, Krauss, and Seltzer (1997) found that, at least in terms of coresidence, twice as many siblings expected to coreside with their brother or sister with IDD than actually ended up doing so (19% vs 10%).

Thus, it is important to examine the differences between anticipatory and current sibling caregivers. To this end, Burke, Fish, and Lawton (2015) conducted a qualitative study comparing anticipatory and current sibling caregivers. Both caregiver groups were knowledgeable about and invested in their brothers and sisters with disabilities. Yet, each caregiver group had different challenges related to their roles. Current caregivers reported struggling to understand and navigate the service delivery system. In contrast, anticipatory caregivers were concerned about future planning. Mixed viewpoints were expressed about receiving pay for providing care, although more current (versus anticipated) caregivers were receptive to paid caregiving as a means to supporting their own families.

Given that many siblings anticipate fulfilling future caregiving responsibilities, we need to understand the transition of caregiving from parents to siblings. Coyle, Kramer, and Mutchler (2014) conducted interviews with siblings who had recently transitioned to caregiving roles. Siblings reported struggling to meet the aging-related needs of their brothers and sisters. Also, siblings reported that their transitions to caregiving roles were facilitated when future planning occurred and support was available. Although recognized as important, future planning seems to be infrequently practiced
among families of individuals with IDD. Notably, future planning is more likely to occur when the sibling is older in age, more involved in disability activities, and provides more support to the brother or sister (Heller & Kramer, 2009). As individuals with IDD continue to live longer lives in the paucity of appropriately funded adult disability support, it is critical to better understand the characteristics of siblings who assume primary caregiving for their brother/sister, as well as the reasons why anticipated caregiving does not come to fruition. Perhaps most importantly, we need to know how best to support siblings before, during, and after assuming care.

4. SUMMARY OF PAST AND PRESENT RESEARCH

There are a number of overlapping themes in family research when there is an adolescent or adult with IDD. Past research across all areas (parent—child, marital, and sibling) has moved from considering adult relationships as an extension of relationships in childhood, to recognizing that families of adults with IDD are important to study in their own right. Across all relationships, research has also moved from descriptions of group differences to understanding the interplay of multiple factors that place family relationships or members at-risk or that lead them to thrive. Furthermore, perhaps one of the most consistent findings across all types of family relationships is the detrimental impact on all family members of high levels of behavior problems among adolescents and adults with IDD. Behavior problems lead to parental stress, problems in the parent—child relationship, marital strain, sibling distress, and less likelihood that siblings will feel close to their brother or sister and expect to provide care for them in the future. Furthermore, it is worth noting that the effect of family size seems to work differently in families of individuals with disabilities. In contrast to the typical idea of larger family sizes resulting in the dilution of resources and thus worse outcomes among children (eg, Downey, 1995), findings among sibling of individuals with IDD suggest that larger families serve as a protective factor, likely because (at least in part) there are more individuals to distribute caregiving. We now turn to recommendations for future research.

5. DIRECTIONS FOR FUTURE RESEARCH WITH FAMILIES OF ADOLESCENTS AND ADULTS WITH IDD

Many of the recommendations for future research on families of adolescents and adults with IDD are issues that are important to address for
families across the lifespan (and not just families of adolescents/adults). We have outlined in the following sections six key directions for future research for families of individuals with IDD, and we highlight how each of these areas might be particularly relevant for families of adolescents and adults.

5.1 Moving Beyond Group Differences

Looking forward, the field needs to continue to move beyond identifying average group differences (ie, IDD versus comparison group) in broad markers of the parent—child relationship (eg, parenting stress), marital quality (eg, global marital satisfaction or divorce/separation), and sibling relationship (eg, sibling contact, closeness). Instead, we need to elucidate the specific dyad- and family-level processes through which having a son or daughter with IDD contributes to difficult relationships in some families, while other families thrive. Modified versions of the vulnerability-stress-adaptation model appear to offer a useful framework, not only for the marital relationship but also for family relationships more generally. But more work is needed to identify relevant vulnerability, stressors, and adaptation processes.

5.2 Including More Representative Samples

Although a handful of studies have examined families who have a member with IDD using population-based samples (eg, Namkung et al., 2015; Piazza et al., 2014; Taylor et al., 2008), most family research relies on samples of convenience. Studies that use convenience or clinical samples run the risk of being nonrepresentative, meaning that the experiences of families that chose to participate in studies or that have access to the clinic are likely different than those who do not. Often times, it is families that have the highest level of need—particularly economic need—that are not included (Shattuck et al., 2012). It is unclear to what extent findings and recommendations generated from convenience samples will generalize to families of lower socioeconomic position, and thus it is important to conduct family research with samples that represent the entire population of individuals with IDD. This is particularly crucial for studies that are attempting to characterize the amount and types of need, as well as the most effective ways to support families.

Similarly, future research also needs to include culturally and linguistically diverse families. To date, most studies of individuals with IDD and their families primarily include white families (Hodapp, Glidden, & Kaiser, 2005; Shattuck et al., 2012). It is important to understand how family member functioning and family relationships might differ across different
racial/ethnic groups. Specifically, culturally and ethnically diverse families are likely to have greater difficulty accessing services (e.g., Liptak et al., 2008; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Taylor & Henninger, 2015) and thus their needs and the corresponding appropriate supports are likely different from those of white families. To conduct research with culturally and linguistically diverse populations, research should be culturally responsive. Thus, to recruit such participants, researchers may need to alter their methods to be more aligned with different populations. For example, with respect to Latino families of individuals with intellectual disabilities, Magaña (2000) outlines several ways to make research more culturally responsive in the development of a study, participant recruitment, measures, data collection, and analysis. Additionally, Bal and Trainor (2015) developed a rubric to help researchers conduct culturally responsive intervention studies. These tools may be helpful in facilitating research with diverse families.

However, future research needs to go beyond just including culturally and linguistically diverse families, by specifically addressing the associations between cultural values/backgrounds and family relationships. This may be particularly important to consider as it relates to care decisions of aging parents and siblings. Although past studies have shown differences across cultural groups in the meaning of disability and the impact of disability on the family (Neely-Barnes & Marcenko, 2004), our understanding of these factors and how services and supports should be informed by them is still rather limited, particularly among older families, with much of the work being qualitative in nature. For example, McCallion, Janicki, and Grant-Griffin (1997) conducted focus groups with a wide range of cultural groups and found multiple differences across groups including the definition of disability and family, family roles and expectations, family cultural values, and willingness to access services. Subsequent qualitative studies with African-American and Latino parents of children with disabilities have also shown cultural differences, suggesting that to best support families and parent-child interactions, service providers need to be aware of unique worldviews and how they impact service utilization (Blanche, Diaz, Barretto, & Cermak, 2015; Terhune, 2005). For example, for Latino parents, important predictors of lower stress include increased levels of acculturation (Long, Kao, Plante, Seifer, & Lobato, 2015; Magaña, Schwartz, Rubert, & Szapocznik, 2006) and familism (i.e., a belief in the commitment of family members to their family relationships; Steidel & Contreras, 2003). Among African-American families of individuals with IDD, lower parental stress...
and depression are predicted by greater religious connectedness (Rogers-Dulan, 1998). More work is needed to fully understand the range of diverse family experiences and attitudes, particularly about family care, transitions, and the aging process, as these differences should inform our theoretical models and guide intervention development.

Beyond racial/ethnic or socioeconomic diversity, other types of family diversity may also impact relationships and caregiving. For example, most studies of couples parenting an individual with IDD have focused on heterosexual married partnerships. While many findings are likely to extend to same-sex partnerships and/or longstanding partnerships outside of a legal marriage, there is a need for future studies to include these families. Other examples of family diversity are the presence of extended family members in the household, parental marital status, or the number of siblings (particularly whether there is one sibling without a disability in the family vs. more than one; Burke et al., 2012). How each of these factors impacts family member well-being, family relationships, and future caregiving is not fully understood and should continue to be the focus of future research.

5.3 Understanding the Experience of All Members of the Family

Nearly all research on families of individuals with IDD focuses on the experience of one family member, mostly the mother, sometimes the sibling, and rarely the father or the person with IDD. Yet family systems theory suggests that family relationships and dynamics are interactive, and each relationship depends on the others. Furthermore, each person in the relationship likely experiences it differently and is differentially impacted by that relationship. Thus, we need to conduct research that includes multiple family members’ perspectives—the parent, sibling, and the individual with IDD.

Including the adult with IDD, in particular, might be daunting for researchers. However, there are some examples of how this can be effectively accomplished. Kramer et al. (2013) overcame some of the potential barriers by having an interviewer establish rapport, rephrase questions, allow more time for the individual with IDD to respond, and allow that person to choose a support person to be present during the interview (Mactavish, MacKay, Iwasaki, & Betteridge, 2007). Dyadic interviewing (ie, interviewing an individual with an intellectual disability and a support person chosen by that individual) may be an effective way to include individuals with IDD in qualitative research (Caldwell, 2013). Regardless of potential difficulty, it
is important that the experiences of individuals with IDD themselves are considered in future research on family functioning and relationships.

Another critical area for future family research in IDD is understanding the unique experience and contribution of fathers. As with the general parenting literature (Pleck, 2012), the role of fathers in the lives of adolescents and adults with IDD is currently understudied. Although some work has examined the impact of having a son or daughter with a disability on paternal well-being (e.g., Hartley, Seltzer, et al., 2012), little work has applied a transactional perspective to fathers. What is known is that fathers of children with IDD have heightened levels of depression and stress compared to fathers of children without disabilities and that, like mothers, child behavior problems are a significant predictor of well-being (Giallo et al., 2015). To more fully understand the role and impact of fathering, the field will likely need new measures specifically designed to assess fathering for adolescents and adults with IDD (Ly & Goldberg, 2014), particularly when considering the unique, nonnormative aspects of father involvement in the lives of their adult children and as families age.

In addition, many studies have only included mothers’ ratings of marital quality and thus much less is known about the marital experiences of fathers of individuals with IDD. Studies that have included individual ratings of marital quality of both mothers and fathers suggest important differences in both the vulnerability factors and links between parenting experiences and marital functioning (Hartley et al., 2016; Hartley, Barker, et al., 2011; Hartley, Papp, Blumenstock, et al., in press). In a cross-sectional study, Hartley, Barker, et al. (2011) found that global marital quality was more strongly related to the parenting experiences of fathers than mothers of adolescents and adults with ASD. However, when parents of children with ASD (aged 5–12 years) were studied at a daily level, the association between parenting stress and positive and negative marital interactions was stronger for mothers than for fathers (Hartley et al., 2016). Thus, mechanisms linking parenting and marital experiences may operate differently for mothers and fathers, and their effects might differ depending on the stage of the lifespan of their son or daughter (e.g., early childhood, adolescence, adult).

Relatedly, in sibling research, studies often focus on the perspectives of the most involved siblings, usually sisters of individuals with IDD. Although important, the perspectives of the most involved siblings may not represent the perspectives of all siblings. One way to collect a more representative sample is to randomly choose the sibling to be included in a given research
study or to choose siblings based on a characteristic other than their relationship involvement (eg, choosing the sibling closest in age to the brother/sister with IDD). However, a more holistic way to have a representative sibling sample is to include the perspectives of each sibling in a given family in a research study. In this way, we could better understand how each individual perceives his or her sibling relationship, well-being, and responsibilities as siblings.

Finally, the children of typically developing siblings who have a brother or sister with IDD have been virtually ignored in research studies. Siblings of adults with IDD have been referred to as the “club sandwich generation” (Meyer & Holl, 2015), simultaneously providing care for their aging parents, brothers and sisters with IDD, and their own children. Thus, research may need to consider the effects of multiple caregiving responsibilities on the children of these siblings. For example, do children of siblings become more empathetic because they are watching their parents provide care for their aunts and uncles with IDD? So far, such questions have been left unanswered, yet they have important implications for the types of supports needed by typically developing siblings and their children.

5.4 Longitudinal Studies That Consider Key Turning Points and Directions of Effects

Longitudinal research can aid in identifying predictors, mediators, and moderators of family relationships, well-being, roles, and responsibilities. Although there have been a fair number of longitudinal studies of parents and the parent—child relationship, most studies of the marital or sibling relationship have been cross-sectional. Cross-sectional studies provide a jumping off point to understanding the influence of, for example, the type of disability of the brother/sister on the sibling relationship (Bagenholm & Gillberg, 1991; Hodapp & Urbano, 2007; Roeyes & Mycke, 1995). They cannot, however, accurately identify how these relationships will change or what predicts relationships that improve versus worsen over time. Only with longitudinal datasets can we observe and predict how family relationships unfold while individuals with IDD progress through adolescence and adulthood.

Furthermore, adults with IDD experience several life transitions (eg, exit out of high school, navigating employment and/or adult disability services, transition out of the family home, and transition of guardianship). There is a need to better understand how these changes impact and/or are impacted by parents and siblings (including parental and sibling well-being, the
parent—child relationship, parents’ marital quality, and the sibling relationship). For example, in a study of parents of youth with ASD, Taylor and Seltzer (2011a) found evidence for a negative effect of high school exit on the parent—child relationship. Specifically, improvements in relationship quality, parental burden, and parental warmth slowed and even stopped (and in the case of burden, worsened) after their son or daughter left high school. In their study of 199 continuously married mothers of adolescents and adults with ASD across 8 years, Hartley, Barker, et al. (2012) found that having the adult with ASD transition out of the family home was not associated with a change in marital satisfaction. However, in another study, parents who coresided with their adult child with IDD (mixed etiology group) were less likely to be divorced than were parents whose adult child with IDD lived elsewhere (Seltzer et al., 2011). As time-order pathways could not be teased out in this study, it is not clear if following a separation/divorce the adult child with IDD was more likely to transition out of the house or if this transition occurred prior to the separation/divorce. Moreover, third variables (eg, physical or psychological health of the parent) may have triggered both parental separation/divorce and the transition of the adult with IDD out of the family home. This topic deserves more attention.

Given the longer lives of individuals with IDD, longitudinal research is also needed to understand how sibling and parent well-being, relationships, roles, and responsibilities change as individuals with IDD age, and especially as caregiving shifts from parents to another person (likely siblings). Parents and siblings are often not able to anticipate how caregiving and shifts in responsibility of care will unfold over time (see Burke et al., 2012; Burke Fish, et al., 2015; Krauss et al., 1996). Furthermore, virtually nothing is known about the impact of providing care on the well-being and marital quality of the sibling or other relative caregivers. Longitudinal studies can help to answer important questions about predictors of shifts in caregiving, the needs of parent caregivers both before and after relinquishing care, as well as the needs of sibling caregivers before and after assuming care.

Finally, and perhaps most importantly, longitudinal studies allow for the determination of directions of effects, which is critical for designing and delivering effective interventions. Examining bi-directional relations are becoming more common when examining associations between parents and their adolescent/adult offspring with IDD (eg, Greenberg, Seltzer, Hong, & Orsmond, 2006; Smith, Greenberg, et al., 2008; Woodman, Smith, et al., 2015), but they rarely occur in studies of siblings of individual
with IDD or in studies of the marital relationship. There is a need to better understand the impact of marital quality and of the sibling relationship on the functioning of adults with IDD. This direction of effects has been largely overlooked in IDD research.

5.5 Considering Positive Outcomes

Although research on parent–child relationships and sibling relationships has begun to consider the positive ways that parents and siblings might be impacted by having a family member with IDD, to date research on the marital relationship has focused on negative marital quality and the child and parent factors associated with these negative outcomes. However, it is equally important to understand aspects of positive marital quality and factors associated with why some couples thrive, and may even become closer, in the face of having a young or grown child with IDD. Studies have examined positive couple processes in parents of children with ASD (Ekas et al., 2015) and this work should be expanded on and extended to parents of adults with IDD. Furthermore, with very few exceptions (eg, Taylor & Shivers, 2011), studies of adult sibling psychosocial outcomes focus on the potential negative impacts of having a brother/sister with IDD. Although many studies have examined predictors of positive sibling relationships, research on siblings’ own personal development tends to have a lens of psychological risk instead of the ways that siblings might benefit from having a brother or sister with IDD. Future research should move toward a holistic view of the lives of these siblings and all family members, including the factors that might put them at-risk (in order to provide appropriate supports) as well as the unique advantages that might be afforded to them by their experiences.

5.6 Developing and Implementing Effective Supports for Families

Finally, another key future direction in family research during adolescence and adulthood is to better understand how to support families, as well as the societal costs and implications for failing to do so. For instance, research suggests that parenting a son or daughter with a disability negatively impacts employment patterns and income for mothers (Heller et al., 2007; Parish, Seltzer, Greenberg, & Floyd, 2004), as mothers often must cease employment or adjust work to care for their child in the absence of adequate supports. This care continues well past the age when most parents of typically developing offspring are providing active caregiving. Compared to families
of children without disabilities, families of children with disabilities also have significantly more material hardship such as food insecurity and housing instability (Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008). There is a need for improved methods of data collection on the specific supports that families naturalistically provide to their family members with IDD, particularly as increasing numbers of individuals continue to live with family members as they age (Rizzolo, Hemp, Braddock, & Schindler, 2009). In the coming decades, documenting formal and informal supports, and the contexts and timing in which they are most advantageous, will be critical for guiding policies and practices to improve quality of life for families of individuals with IDD.

This information must then be used to develop and pilot interventions to better support families. To date, there are few interventions that have been developed specifically to support families of adolescents/adults with IDD (Burke, Patton, & Taylor, in press), but promising models have recently emerged. For example, mindfulness-based stress reduction approaches have been shown to lower stress and anxiety for parents of individuals with IDD (Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014). Other approaches include psychoeducational programs for parents of adults with ASD, focused on sharing information and problem solving (Smith, Greenberg, & Mailick, 2014), and trainings specifically targeted at helping parents of youth and adults with IDD develop advocacy skills and navigate the adult disability service system on behalf of their son/daughter (Taylor, Hodapp, Burke, & Rabideau, 2016). In terms of potential sibling interventions, past research suggests that future planning interventions might be particularly fruitful. One current intervention for future planning is called the “Future is Now” (Heller & Caldwell, 2006). An intervention which includes parents and the individual with IDD, the Future Is Now has been shown to increase future planning and reduce caregiving burden. Such an intervention may need to be adapted to include siblings of individuals with IDD in the future planning process. Relatedly, other interventions should also be created and tested for siblings to address sibling well-being, relationships, roles, and responsibilities.

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