

Impact of Youth with Intellectual and Developmental Disabilities on Families: Balancing Perspectives

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Abstract The study of the impact of children or youth with intellectual and developmental disabilities on their families has grown increasingly complex. This is due, in part, to the multiple perspectives represented in research (e.g., mothers, fathers, siblings) and to the myriad of outcomes examined (e.g., negative vs. positive impact on families). Basic tenets set forth include encompassing theoretical models that can be used to integrate family research on impact, an evaluative discussion of the importance of child problem behaviors, and family socioeconomic status as vital to the discussion of family stress. Parenting behaviors that influence impact are also identified, with attention to important moderators of family outcomes that further elucidate processes over and above main effects research. The article concludes with a discussion of promising directions that may alter the impact of youth with intellectual and developmental disabilities on the family.

Keywords Intellectual disability · ASD · Problem behaviors · Parental well-being · Review

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Theoretical Framework

Over the past few decades, research on families with children and youth with intellectual and developmental disabilities (IDD) has expanded, and new directions of focus have appeared. Greater emphasis has been placed on studying the whole family, rather than merely the child with a disability. Family system models holistically consider the individual with a disability, the parents/caregivers, as well as the interactional processes that exist (e.g., marital adjustment, parent-child relationships, sibling relationships) and the subsystems that affect them [1–4]. Bronfenbrenner’s framework [5] has been considered a theoretical model that transformed the way many researchers approach the study of human development. He conceptualized the person and the family as the center focus, bounded by interrelated layers or systems. These systems are defined by interactional contexts, such as school, work, and overall social structure. Through this lens, one must assess the broader family context and the environment in which members are involved in order to understand the child’s development. Although this emphasis was embodied in the seminal article by Crnic, Friedrich, and Greenberg [6], it remains relevant today and can help to integrate research on the multiple biological and environmental pathways that are reflected in the impact of a child with disability on the family [7, 8].

This paper utilizes the term “intellectual and developmental disabilities” because it incorporates individuals with an IQ in the intellectual disability (ID) range as well as other conditions, notably autism, whose intelligence may or may not be in the ID range but who continue to struggle developmentally across adaptive domains. Throughout, we make no distinction unless there is a disability-specific point to be made. Following Odom, Horner, Snell, and Blacher [9], the construct of developmental disabilities does not include severe sensory

impairments or psychiatric conditions, unless the latter are associated with ID or autism spectrum disorder (ASD).

Due to the dynamic relationships developing within the family over the lifespan, long-term studies across multiple contexts are needed for an interpersonal-transactional approach to the study of individuals with IDD. Yet, the majority of research in this area maintains a glaring focus, if not on the child, on the mother as the unit of analysis [10, 11]. Kanner's report in the 1940s on the causal relationship between mothers who lack warmth, or "refrigerator mothers" [12], and children diagnosed with ASD marks the early stages of such direct attention on the mother-child relationship. In addition, most data on the child is provided by reports from mothers, as they are often the primary caregivers for the child with a disability. However, trends in the characteristics of families—rise in fathers as primary caretakers, increase in single-family households—have stimulated researchers to explore previously unexamined relationships, such as the paternal role in families of children with IDD [e.g., 13•, 14, 15, 16•]. Given our appreciation of the family in its entirety, this report will divert from the limitations of a one-sided view of family functioning and will draw on recent findings from studies of *both* mothers and fathers of children with IDD.

Families who raise a child with an IDD often experience more daily stresses and burdens as well as greater general life demands than families with typically developing children [17, 18]. Not surprisingly, the majority of research in this population has concentrated on the negative effects of having a diagnosis on the family. Indeed, parents of children with IDD encounter more financial stressors (e.g., long-term medical and service costs), psychopathology (e.g., anxiety and depression), somatic complaints (e.g., headaches and fatigue), marital discord, and overall family dysfunction [e.g., 19–22] than families without a child with IDD. More recently, however, researchers have shed light on successful family adaptations and the positive impacts of having a child with IDD on family functioning [e.g., 23–26], such as greater resiliency in family members and gaining feelings of connectedness and closeness.

Model applications for studying such positive family processes, such as the double ABCX model [27–29, 30•], suggest that family outcomes depend on interrelations among several factors, including child characteristics, family stressors, family resources, social support, coping strategies, and family perceptions. This model has been used to examine risk factors that increase the likelihood of negative family outcomes, as well as protective factors that act as potential buffers to adversity and support successful adaptation. Through incorporations of the ABCX model, positive family outcomes and fluid processes of family members following a child's diagnosis are evident and accounted for.

There are other theoretical models that incorporate an ecological transactional perspective [31]. For example, studies of resilience consistently demonstrated that parental sensitivity

and warmth can be powerful buffers against childhood adversities [32]. Yet, the presence of developmental risk, such as ID or ASD, stresses caregivers' ability to consistently provide the structure and nurturance required to facilitate positive and effective parent-child interactions. Parenting behavior and values are also shaped by cultural beliefs and practices [33], as well as by genetic forces. A critical focus is the interplay of culture and genetic susceptibility in shaping risk and resilience [34], such that differential outcomes are likely to emerge depending on the complex interplay of influences operating at multiple levels (child-level biology as well as the broader context of family, culture, and services). Thus, the current review aims to call attention to recent findings of not only identified risk factors but also protective factors and positive gains throughout the trajectory of family outcomes.

Impact of Child Characteristics

Family outcomes vary considerably depending on a host of variables associated with the child's disability symptoms or impairments. These might include cognitive, language or social deficits, along with behavior problems. Moreover, a wide range in severity, specific diagnoses phenotypes and age further complicate the impact on parents. A strong association has been detected between symptom severity and behavior problems, suggesting that as severity increases, so do incidences of problem behaviors [11]. Parents of children with high incidences of behavior problems, including externalizing and internalizing behaviors, often experience greater negative physical and mental well-being, poor marital happiness, and less family cohesion as compared to families of children with typical development [35–39]. These relationships have been confirmed with larger scale population-based studies [40, 41], and lead to the general conclusion that behavior problems matter.

Indeed, the extant literature supports the premise that the level of problem behaviors, not the core symptoms or type of disability, strongly impacts family outcomes. Thus, these maladaptive externalizing and internalizing behaviors contribute to increased levels of negative family experiences above and beyond the disability, *per se* [42]. For example, when child problem behaviors and diagnosis were entered into the same analyses, the level of problem behaviors was the significant predictor of family outcomes [16•, 18, 43]. Furthermore, the addition of problem behaviors to a significant diagnosis, such as ID or ASD, can result in dramatic increases in stress, depression, and other mental health symptoms in mothers [44, 45].

The impact of child problem behaviors differs between mothers and fathers [46] with such behaviors having a greater long-term negative effect on mothers. Problem behaviors predict poorer physical and psychological maternal well-being [37], while a similar effect has not been detected on father well-being [47]. Indeed, disruptive behaviors have an initial

impact on paternal psychological symptoms, but growth curve modeling indicated that these predictive effects do not maintain over time [13•]. These differences have been hypothesized to reflect the traditional family structure of mothers as primary caretakers and fathers as job-holders, thus suggesting that mothers have more exposure to child problem behaviors than fathers, which underscores the lasting impression that these behaviors have on mothers. In light of these recent findings, further investigations on mother-father differences is needed to examine child impact, and greater attention should be paid to the methodological limitations (e.g., sample sizes in mother and father groups) in these studies.

Though the negative impact of maladaptive behaviors in youth with IDD on their typically developing (TD) siblings has been less widely studied, research has also shown that child problem behaviors do affect the well-being in siblings of children with IDD [48–50]. Interestingly, in Neece et al. [50], mothers and fathers reported that their TD siblings were negatively impacted by the child with IDD (assessed at ages 5 through 8), more so than a control sample of TD children and their TD siblings. However, when child behavior problems were controlled, the disability status difference (IDD vs. TD) disappeared, suggesting once again that child behaviors influence family dynamics, rather than the fact that there is a child with IDD, per se.

Research on siblings of children with ASD is particularly complex. Ross and Cuskelly [51] examined the sibling relationship in families of children diagnosed with ASD and a normative sample of siblings. According to mother reports, 40 % of siblings in the ASD group fell within the borderline or clinical range on the *Child Behavior Checklist* [52], with the most commonly reported problem behaviors being aggression. In comparison, a national survey study found that 13 % of siblings in the normative sample are in these categories [53]. Although the contributing factors in Ross and Cuskelly's study are unknown, a possible explanation is that siblings of children with ASD are at an increased genetic risk for developing such difficulties [e.g., 54]. These sibling studies further illustrate the heightened stress placed on families raising a child with IDD, as well as the importance of studying family outcomes when more than one child may exhibit clinically elevated problem behaviors. Notably, there are many infant sibling studies in the field of ASD underway, but their focus is on early aspects of diagnosis [e.g., 55–57]. On the other hand, many studies indicate a lack of negative impact of a child with IDD on the psychological well-being of his or her siblings, although this literature is fraught with methodological difficulties [58]. Additionally, investigators have yet to demonstrate the positive impact that typically developing siblings might have on their brothers and sisters with IDD, as emphasized by Blacher and Begum [58].

In addition to behavioral problems, socio-emotional and communication impairments are highly related to levels of

familial stress. For example, children with a diagnosis of ASD are characterized by pervasive social and communication deficits, as well as stereotyped, repetitive behaviors, and interest [59]. Although substantial variability exists within the symptomology of ASD, studies have shown that these core impairments of ASD are related to higher levels of parental stress compared to parents of children with developmental disabilities without autism and of neuro-typical children [e.g., 60, 61]. Specifically, Dabrowska and Pisula [36] found that parents of children with autism are significantly more stressed by the child's dependency, need for behavior management, restrictions on family opportunities, and need for child care over much of the lifespan. However, this does not preclude recognizing the need to focus on positive family outcomes in the area of ASD [16•].

Impact of Parent Characteristics and Parenting

Several demographic risk and protective factors have been investigated among families of children with IDD. Olsson and Hwang [62] found that unmarried mothers of children with IDD were at greater risk for depression, as assessed by the *Beck Depression Inventory* [63], than mothers living with a partner. Greater income serves a protective function for maternal well-being and depressive symptoms [64]. When considered together, the protective roles of marriage and employment on maternal mental health have been shown to be mediated by socio-economic status [65]. Higher socio-economic status (SES) is associated with lower risk for psychiatric disorders [66] and fewer symptoms of depression, anxiety, and despair among parents of children with ID [67]. However, even when SES is controlled, mothers of adolescents with ASD report greater financial stress than mothers of typically developing adolescents. Furthermore, when youth with ASD have a co-morbid mental health disorder (e.g., ADHD, ODD), mothers' stress increases and mental health decreases even more [45]. These findings regarding SES are less robust in culturally diverse samples. For example, SES was not found to be protective for Latina mothers' perceptions of family quality of life, in part because there was less variance in SES [68]. Findings from Eisenhower and Blacher [65] suggest that the specific components of SES might have different effects across cultural groups, with income more important for Latina mothers' well-being, and education more important for non-Latino White mothers' well-being [65].

Parent factors have been examined as predictors of poor parent-child interactions. The acceptance, or denial, of diagnosis significantly influences parenting styles. For example, mothers who are unresolved regarding their child's diagnosis show less sensitivity to their child's signals [69, 70], and greater resolve has been correlated not only to positive parenting behavior but also to less parental stress [e.g., 70]. These

resolutions support the need for parent interventions targeted toward addressing the common stages of adjustment experienced by parents of children with disabilities such as various forms of shock, denial, acceptance [e.g., 71], and to move parents quickly to acceptance and to more active, positive coping [e.g., 72, 73].

Parenting behavior has been widely studied within families of children with IDD, and parent-child relationships can be negatively affected by the presence of IDD. Observational studies have found that while children with IDD tend to be more socially withdrawn, specifically displaying less eye contact and vocalizations and more independent play than control groups [74], mothers can be intrusive, as evident by greater frequency of commands and physical manipulations of the child [75, 76]. Interactions appear to be different for fathers vs. mothers. Costigan and colleagues [77] found that fathers of children with disabilities tended to be less controlling than mothers, which the investigators attributed to the more playful nature between father and child [78]. Parental mental health, too, is significantly associated with the functioning of the child with IDD. In a cross-sectional study of young children with Down syndrome, lower maternal sensitivity was linked to increased child aggression in home and school settings [79]. However, these early parent-child interactions function as important experiences for fostering positive outcomes [80, 81]. For example, Fenning and Baker [82] examined mother-child interactions at age 3 and found that maternal technical scaffolding and dyadic pleasure decreased the likelihood that children would meet criteria for ID later (age 5).

In order to understand how parenting behaviors differed across contexts and time, Blacher and colleagues [75] observed 183 parent-child dyads during structured (e.g., three problem-solving tasks plus clean-up) and unstructured (e.g., free play) interactions across the child ages of 3, 4, and 5 years. Child status groups included typically developing children and those with ASD, undifferentiated developmental delay, Down syndrome, and cerebral palsy. Context definitely mattered. In activities with greater task demands, mothers of children in the four disability groups demonstrated more negative parenting behavior (expressed by negative affect, hostile nonverbal behavior, an adult-centered agenda) than did mothers of the control children. More positive parenting was found in the unstructured setting than in the structured one. Furthermore, mothers of children with Down syndrome demonstrated more positive parenting behavior than mothers of children with other disabilities (e.g., cerebral palsy, autism, undifferentiated developmental delay) and mothers of typically developing children.

Despite stressful events related to the care of a child with a disability, many parents report experiencing positivity alongside negative states. Several coping mechanisms have been identified, which allow families to manage the mix of positive and negative emotions [24], including benefit-finding wherein

positive outcomes are recognized within the context of highly negative events [25, 83]. These positive outcomes can be considered therapeutic or simply aspects of resilient parenting [84, 85]. This idea of resilience can be conceptualized in many ways, but in literature pertaining to IDD, it includes domains such as dispositional optimism [24, 86, 87], hopefulness [88, 89], hardiness [90, 91], and sense of coherence [92, 93]. Ellingsen et al. [85] demonstrated how mothers' dispositional optimism moderated parenting skills. For example, coded mother-child interactions indicated a decrease in positive parenting as child risk level (determined by several variables, including clinically significant behavior problems) increased. However, positive parenting was lowest when children were at the highest risk levels and mothers were low in optimism, suggesting that dispositional characteristics of the mother make a difference in parenting.

In a study of parents of children with ASD, parents identified feelings of appreciation for the uniqueness of their child with a disability and for the enriched and strengthened relationships in their spiritual life, marriage, and family [94]. Thus, positive views can also derive from domains other than personality, such as spirituality or sense of family. Cultural differences of positive perceptions have also been examined in samples of young children with developmental delays, as well as in young adults with severe ID [95]. With regard to the younger children, when behavior problems were low, Latino and Anglo mothers and fathers expressed comparable positive perceptions. However, when behavior problems were high, Anglo mothers and fathers each expressed lower positive perceptions, whereas Latino mothers and fathers each expressed higher positive perceptions. There is much to be gained from additional research on factors that can influence how parents cope with a child's disability, since we know that culture is not a static variable, but rather, a dynamic process tied to the social context [96]. There is also relatively little known about the cultural context relevant to parenting children and youth with ASD.

Altering the Impact of Youth with IDD on the Family: Promising Directions

There is an expression in French: *Plus ça change, plus c'est la même chose* (i.e., the more things change, the more they stay the same). This saying is quite apt for describing the current literature on the impact of children or youth on their parents, as illustrated by the following three points. (1) *Behavior matters*: children and youth with disabilities do have an impact on their families—one that in most empirical reports has a negative component. For example, children with ASD and the behavioral/self-regulatory deficits that are core to the disorder especially challenge families. Indeed, evidence suggests that parents of children with ASD experience greater stress and lower levels of psychological well-being than parents of

children with typical development or other developmental disabilities [97]. (2) *It matters to be on the sunny side of the street*: there are increasingly more robust efforts being made to focus on the positive, demonstrated by both research and clinical approaches [30•]. Contextual factors, specifically social support and quality of marital and co-parenting relationships, are also associated with greater parent well-being [98] and family quality of life [68, 78]. (3) *The earlier the better*: coping with child behavior problems continues to require environmental adjustments, whether in the form of behavioral intervention for the child and family members or cognitive coping programs for parents. Family-oriented early intervention practices may lead to greater feelings of cohesion in the family, overall better individual and family well-being, and overall improvement in family outcomes [39]. It would be hard to argue against providing services to these families as soon as possible.

Conclusions

Although this review suggests that palpable advances have been made in studies of families of children with IDD, there is still pressing need for better understanding of the family response to children or youth with IDD. More complex and transactional relations, perhaps including new knowledge about gene expression and gene-by-environment interactions, should be studied. There is growing demand for effective early intervention programs, especially those with systemic approaches that include larger family perspectives. These are simply necessary because without them, the potential for escalation of adverse developmental and health outcomes is substantial.

Compliance with Ethical Standards

Conflict of Interest Yasamine Bolourian and Jan Blacher declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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