

Families and intellectual disability

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Purpose of review

This review includes recent research pertaining to family functioning when there is a child or adult offspring with intellectual disability. The purpose was to broaden the examination of families research from an adjustment/coping perspective to consideration of more contextual factors (environment, culture, service delivery).

Recent findings

Studies continue to focus on parental well being, with parents of children with intellectual disability still showing evidence of stress and depression. Increasing evidence is accruing, however, that child behavior problems or specific syndrome more directly relate to poorer parental well being. On the other hand, parenting behaviors also contribute to child behaviors, with studies highlighting the importance of parenting context and dynamics. Interventions focus on child behaviors as well as on stress reduction for parents. Finally, the continued involvement of parents across the lifespan of their young adult with intellectual disability is apparent from studies of quality of life and living arrangements.

Summary

The well being of family members continues to be an area of interest, with special emphasis on siblings and cultural context. Methodological rigor in families research also continues to increase, with diverse methodologies represented. There is still a need, however, for the development of theoretical models within which to frame future research on topics such as siblings, as well as both negative and positive impact on families.

Keywords

culturally diverse families, family context, family stress, quality of life, siblings and adjustment

Introduction

The domain of 'families' has become a substantive research area, encompassing studies across ages and stages of the lifespan [1]. No longer focused solely on issues of adjustment and coping in mothers, family research now includes siblings as well as parents, diverse cultural contexts, and service delivery perspectives. Studies that address 'impact' of a child or adult with intellectual disability on the family still represent a dominant theme in current research. We parsed that literature into more specific areas, however, including the broader family context, parenting practices, and sibling impact. Aspects of quality of life characterize the papers pertaining to adulthood and families, although the papers included that pertain to cultural diversity also focused on young adults. There is increasing realization that culture matters, with more consideration of culture in studies of impact, and in the context of service delivery.

Impact on the broader family context

A child with a developmental delay can affect the family as well as individual members in diverse ways. During our review period, White and Hastings [2^{*}], studying families of adolescents with severe intellectual disabilities, found high parental stress and psychopathology. On the Hospital Anxiety and Depression scale, fully 61% of parents were in the clinical or borderline range for anxiety and 36% for depression. Parental well being was negatively related to child behavior problems and positively related to child adaptive behaviors. These authors further examined the buffering role of formal and informal support, finding that parents who perceived greater helpfulness of informal supports reported lower stress, anxiety and depression. Abbeduto and colleagues [3^{**}], also studying adolescents as well as young adults with intellectual disabilities, found the extent and severity of the youth's behavior problems to be the best predictor of maternal well being. These authors examined the differential impact of diagnosis (autism, Down syndrome, fragile X syndrome) on maternal pessimism about the youth's future, relationships with him or her, and depressive symptoms. Mothers of youth with autism and Down syndrome experienced the most and least compromised well being, respectively, while mothers of children with fragile X generally fell in between.

In addition to parents' individual psychological well being, researchers also explored how a child with intellectual disabilities in the family affects the marital relationship.

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Risdal and Singer [4[•]] conducted an historical review of studies from 1975 through 2003, as well as a meta-analysis that included 13 studies meeting inclusion criteria of families with and without disability: quantitative measurement of marital satisfaction, adjustment, and divorce/separation rates; and sufficient statistical information. There was a difference in marital adjustment in studies that met the criterion for 'small effect size', though considerably less than the impact that would have been expected from the historical review. The authors noted that, viewed in the context of marriages that end in divorce, there was an average increase in divorce of only about 6% among families with disabilities, and even lower in the better designed studies.

A child's disability will also have implications for family life as a whole. A study of adult children with intellectual disabilities by Parish *et al.* [5^{••}] found lower average household income and lower levels of savings among their families. Moreover, mothers of children with developmental disabilities were less likely to have ever been employed full-time or to have been employed continuously for more than 5 years. Constraints may also exist for these families in areas like recreation, as leisure and recreational activities are more difficult to implement because of the need to accommodate children's skill deficits, planning demands, and services [6[•]].

Contextual factors

Contextual factors also affect the way in which children's disabilities impact the family. One such factor is poverty. Emerson *et al.* [7^{••}] conducted a study of caregivers in a socio-economically deprived area of England, and found that 47% of the caregivers of children and adolescents in their study scored in the clinical range of psychological distress. This was significantly greater than the percentage found in a nationally representative sample of caregivers of children with (35%) and without (25%) disabilities. Another contextual factor is stressful life events. In a study by Pruchno and Meeks [8^{••}], 932 women aged 50 years and older and living with a young adult with developmental disabilities were divided into two groups based on high versus low major life events associated with health decline. Mothers who experienced high health-stress also displayed lower positive affect, higher negative affect, and higher levels of depressive symptomatology.

Cognitions and coping

Contextual factors such as poverty, health, and culture may affect not only the resources available to families but also the ways in which parents think about disability. Several studies contributed further to the understanding of the impact of children with developmental disabilities on parents by examining parental beliefs and coping styles. Sara Green [9[•]], a sociologist and mother of a

child with multiple disabilities, set out to examine feelings about control over matters of health and health care. She used narrative accounts and interactive interviews to study health related beliefs and well being in 81 mothers of children with disabilities. Mothers with a high internal locus of control who also believed in chance reported less subjective burden of caregiving, causing researchers to suggest that these mothers used belief in chance as a way to avoid blaming themselves for their children's problems. On the other hand, belief in chance without a strong internal locus of control related to increased subjective burden, as mothers may have felt overwhelmed by the uncontrollable nature of life events.

In making sense of life events, like having a child with a disability, some parents take comfort in their spirituality, which helps them view their child as a blessing or a test of their faith, rather than as a burden [10]. Accommodative coping, by which people flexibly adjust their goals in response to a persistent problem, also has been shown to be helpful to parents in dealing with non-normative parenting experiences. In a study by Seltzer and colleagues [11^{••}], however, the benefits of this type of coping were not found to extend into mid-life, possibly because parents made accommodations to their child's intellectual disability earlier in the lifecourse, reducing the need for additional accommodations by the time they reached mid-life.

Despite the difficulties that some families face in raising children with developmental delays, parents reported that family quality of life can be enhanced through participation in recreation [6[•]] or church activities [12[•]], which may provide social outlets that are more accepting of children's disabilities. In describing her own experience raising a child with a developmental disability, Turnbull [10] noted how various domains of family life could be improved through the development of a better support infrastructure, better information for families, as well as the encouragement of self-determination and friendships for people with disabilities.

Siblings

Broadening the study of families beyond the study of mothers, researchers have increasing interest in siblings of people with intellectual disabilities. The primary question asked was whether such siblings are at risk for psychopathology, a hypothesis that has received little empirical support [13]. Short of clinical disorders, however, Guite [14[•]] noted that some researchers viewed siblings as a vulnerable population at increased risk for adjustment problems, as well as problems with peers. Other research offered support for the opposite outcome: that having a sibling with developmental disabilities may

offer opportunities for growth and maturation [15]. A study by Levy-Wasser and Katz [16**] found strong evidence that the attachment styles of siblings of children with intellectual disabilities were characterized as more secure and less insecure than the attachment styles of siblings of children without intellectual disabilities. Within the subdomain of autism, Pilowsky *et al.* [17**] also found that siblings were well adjusted socially and emotionally. This finding was especially interesting given the genetic loading that is characteristic of autism and environmental factors, such as communication deficits and changes in family roles that are a part of growing up with a child with autism.

With the growth of sibling research, it is important to have a valid measure of the impact of a person with a developmental disability on his or her siblings. Guite *et al.* [14•] studied 51 families of children with chronic illness/developmental disabilities. They compared parent and sibling (ages 8–13 years) reports of the impact of the child with developmental disabilities on the siblings. Overall, although group mean scores on the Sibling Perceptions Questionnaire were not significantly different, the sibling and parent reports in the same family were often ‘discordant’. The authors note that among these discordant dyads, parents typically reported higher levels of concerns for siblings than siblings reported for themselves. Though many previous studies have used parent reports to measure the effect of a person with developmental disabilities on siblings, the study by Guite *et al.* [14•] pointed out the importance of obtaining sibling self-report measures as well.

Parent adjustment

Parents’ and children’s functioning are inextricably linked, and considerable research has examined the relationship between parental well being and adjustment of the child with disabilities. One study [18•] comparing families of 8–9-year-old children with spina bifida versus no disability found that better parent psychological and marital adjustment were associated with better child functioning (especially with regard to externalizing behaviors), both concurrently and 2 years later [18•]. Another study assessed mothers’ expressed emotion (criticism, hostility, and overprotection during a 5-min speech sample about the mother’s relationship with the child). Expressed emotion was higher toward their children with disabilities compared with non-disabled siblings, and expressed emotion related significantly to the extent of child behavior problems [19**].

Parenting practices

Several studies during the period reviewed focused on specific practices in parenting children with intellectual disabilities. Parents of children with delays may employ a number of positive parenting strategies. Floyd *et al.* [20]

observed problem solving sessions in 162 two-parent families with children with intellectual disabilities, chronic illness, or a non-disabled comparison group. When interacting with children with intellectual disabilities, parents were more directive and persistent, accommodating to the child’s disabilities by greater use of leading questions, prompting, and helping in order to stimulate child behavior. These parents also avoided negative parent–child exchanges.

Although children with disabilities may be less likely to engage with parents than typically developing children, Kim and Mahoney [21•] found, in an observational study, that regardless of children’s developmental status, they are more likely to engage in activities necessary for development if parents are responsive. Even for children with autism, a meta-analysis of research examining autism and attachment by Rutgers *et al.* [22•] was encouraging. Although the authors predictably found that children with autism were less securely attached to their parents than were children without autism, these differences disappeared at higher levels of intellectual functioning, suggesting that attachment security was not incompatible with autism.

A major concern for children with intellectual disabilities is the increased incidence of problem behaviors over children without such disabilities [23]. Parent–child interactions can encourage or discourage these, as they can with any child. Two studies focused on inappropriate child behaviors and naturally occurring reinforcement contingencies. Passey and Feldman [24•] examined parent–child interactions between 47 parents and their 2–3-year-old children, with, or at risk for, developmental problems. A lack of parental attention or no activity were the most frequent antecedents for inappropriate behavior. Strikingly, fully 77% of inappropriate behaviors were followed by positive consequences (parent attention or tangible rewards), a contingency that increases the future likelihood of that problem behavior. In another study, Lucyshyn *et al.* [25**] observed 10 families of 4–8-year-old children with intellectual disabilities for over 1 year. This assessment of coercion in typical family routines found similar patterns, by which heightened child attention-seeking when parents were engaged in non child-centered tasks led to attention from parents. In other cases, parental demands led to problem behavior, which was then followed by a withdrawal or reduction of demand. The thrust of these observational studies is that many parents (inadvertently) reinforce children for inappropriate behavior.

Toward further understanding of parenting practices, Woolfson [26•] described a psychosocial model of disability that could help parents break away from the prevailing societal view of disability. The author

proposed that society views disability as a medical problem or a tragedy, and views disabled people as dependent and in need of help from others. When parents adopt these views, they may tolerate difficult behavior, viewing it as unchangeable. Parents may also develop lower expectations for their children's behavior or independence. The author suggested that parents who hold beliefs that differ from the prevailing societal view of disability would be more likely to encourage their children's independence and work toward improvement in behavior problems.

Adults' quality of life

Over the course of development, the disparities between people with moderate to severe intellectual disabilities and those without becomes more apparent. As these adolescents enter adulthood, options become much more limited. McIntyre *et al.* [27**] investigated the quality of life of young adults with severe intellectual disabilities. Overall, their mothers reported that sons and daughters had a good quality of life. They reported that the most important components of high quality of life were happiness, recreation, hobbies and activities, having basic needs met, and having a social network. Surprisingly, work and vocational opportunities were not commonly reported components of high quality of life. This is particularly interesting, as these have been the foci of the majority of transition planning programs and of many instruments to assess quality of life.

One central question regarding the quality of life of adults with intellectual disability centers on living arrangements: is it better for the adult to remain living at home with his or her parents or to live in a residential community setting? Rourke *et al.* [28*] examined the satisfaction of older adults (age 40 years or over) with their living arrangement, and found that compared with adults in residential accommodations, those living with their families were more likely to report being happy, but were also more likely to report being lonely. The main components of a satisfactory living arrangement were the physical features of the living arrangement (such as nice facilities, good meals), provision of activities, independence and staff. The main components of an unsatisfactory living arrangement were rules or activities that hindered personal independence and staff-related difficulties. In general, the reports of the adults did not differ from those of their parents or caregivers. Keogh *et al.* [29*] conducted a 20-year follow up study of 30 young adults with intellectual disabilities who had participated as children in a research study. A majority of participants were unemployed or underemployed, were dependent on their families, and were living at home. In this study there was only a slight correlation between parent and adult child report of quality of life. The young adults

were most concerned about too much parent involvement, being bored, and not having enough friends.

Cultural diversity

In recent years, researchers have made tremendous advances in understanding family processes when a child has intellectual disability. A limitation of this research, however, is that few investigators have examined these processes in non-Western cultures or in cultural subgroups within the same country. Several previous studies in the US have found, though, that Latina mothers report significantly more depression than non-Latina mothers. Magaña *et al.* [30**] examined factors that accounted for this difference, studying a sample of Puerto Rican-American mothers ($n = 66$) and non-Latina white mothers ($n = 161$), who lived in Massachusetts and were each the primary caregiver for an adult with intellectual disabilities. The immigrant mothers were born in Puerto Rico; despite living in the US for an average of 22 years, all but one preferred to be interviewed in Spanish. Findings indicated that family problems mediated the relationship between the adult child's behavior problems and maternal depressive symptoms. Furthermore, this relationship was different for the two groups. Among 'low problem' families, the two groups of mothers had nearly identical depression scores on the Center for Epidemiologic Studies-Depression Scale (CES-D). Yet among 'high problem' families, although depression was higher for both samples, Puerto Rican mothers reported significantly higher scores than non-Latina white mothers. Cultural group also had a significant effect on the relationship between maternal health status and maternal depressive symptoms. Mothers in both groups who were in good health reported lower scores on depressive symptoms. Puerto Rican-American mothers, however, who were in poor health had elevated levels of depressive symptoms, whereas non-Latina white mothers in poor health did not differ substantially from those in good health in their depressive symptoms. These findings indicate the importance of examining family processes in different cultural groups. Further research could examine possible protective factors for non-Latina white mothers in poor health that may have affected their psychological well being.

A large-scale survey study looking beyond depression [31*] found that white non-Hispanic and Hispanic families reported greater negative impact of childhood disability than African American families. This negative impact manifested in reduction in family members' ability to work, changes in sleep schedules, and financial strain. Other studies have explored how culturally diverse families function within the service system. Using focus groups in Los Angeles conducted in Spanish, Shapiro *et al.* [32*] found that Latina mothers of adolescents and young adults with intellectual disabilities felt isolated

from the educational and developmental disability service delivery systems with regard to transition planning. These mothers reported that professionals exhibited poor communication, a lack of effort, negative attitudes toward the child, and negative treatment of the parents. These mothers took an advocacy role in the service system, but often felt forced into alienating and adversarial roles due to the perceived non-responsiveness of some service providers.

Interventions and services

Families continue to be the focus of intervention efforts on behalf of children or young adults with intellectual disabilities. In the past year, two types of interventions for families appeared in the literature reviewed herein: those designed to educate parents to facilitate their child's development, and those designed to directly increase parents' well being.

Woods *et al.* [33[•]] evaluated the effectiveness of an intervention designed for toddlers (13–31 months) who qualified for early intervention because of delays in social communication. The investigators incorporated individualized caregiver-led teaching strategies (e.g. gesture, expansions, open-ended questions) into the play routines of the toddlers. With a single subject multiple-baseline design across four parent–child dyads, they demonstrated clear gains in each child's communication skills. In a randomized group design in India, Russell *et al.* [34] contrasted two parent education approaches: intervention, 'interactive group psychoeducation' designed to improve parental attitudes toward managing a child with intellectual disabilities; and control, didactic lectures with the same general aim. Children in both groups attended an adaptive behavior therapy program as well. Twenty-two of 29 children with parents in the intervention group showed significant acquisition of adaptive behavior, compared with only four of 28 control children. These two studies add to the large evidence base demonstrating that interventions with parents can result in improved behavior for their children with intellectual disabilities.

The second set of interventions targeted aspects of family well being, with the implication being that this will indirectly facilitate raising a child with intellectual disabilities. Hastings [33^{••}] conducted an extensive review of interventions designed to reduce stress in parents of children with intellectual disabilities, and found that cognitive behavior group interventions proved most effective, especially for mothers. Ergüner-Tekinalp and Akkök [36^{••}] conducted a randomized trial in Turkey for parents of adolescents with autism, comparing a coping skills training program with a no-treatment control. The intervention significantly reduced the helplessness experienced by the mothers and increased the

use of social support as a coping strategy. Although the two conditions did not differ on changes in mothers' stress, the group size ($n = 10$ each) resulted in limited statistical power.

Other investigators have focused on personal control, or empowerment. Dempsey and Dunst [37[•]] studied families receiving services in the US and Australia, assessing their feelings of empowerment with the Family Empowerment Scale (FES). In both cases the enabling practices of the service agency (parents' collaboration, comfort, and autonomy in their relationships with staff) contributed most strongly to empowerment, even after controlling for demographic and other variables. McCallion *et al.* [38^{••}] investigated the effectiveness of a support group intervention for grandparent caregivers of people with intellectual disabilities, using a randomized design with intervention and waiting list conditions. The intervention produced increases in sense of empowerment, again using the FES, and reductions in depression (CES-D) relative to controls; similar effects were found for controls when they subsequently received the intervention.

An important aspect of measuring the effectiveness of services is knowing who is using the services, and how the services are being used. Damiani *et al.* [39^{••}] conducted a survey of 468 caregivers of children with cerebral palsy in Ontario, Canada, to identify factors that contributed to use of respite services. Almost half of the caregivers had used respite services during the past year, with the most common reason for using services being a 'planned break'. Caregivers who had a child who was male, was lower functioning, or had multiple handicapping conditions were more likely to use respite services. While over 90% of caregivers indicated that respite use is beneficial for both their family and child, over 60% reported facing many barriers in accessing services.

One sentiment that appears frequently in the literature is the importance of developing a partnership between parents and service providers [40,41,42[•]]. One particular approach, Positive Behavior Support, received a great deal of attention in the past year [41,43[•]]. This intervention is a variant of applied behavior analysis, with a broader emphasis that includes collaboration between families and service providers, the development of a functional assessment of the problems of the individual with intellectual disabilities, and a person-centered value system. Correcting behavior problems is a central goal of the support plan, but there is an overarching interest in the quality of life of the individual with developmental disabilities. This approach emphasizes the importance of working with families to develop plans, and positive outcomes have been shown as the result of close collaboration and communication.

Conclusion

Research on families and intellectual disability now comprises a substantive and salient place in the literature. While most studies fit, in some way or another, under the rubric of 'impact on families', the field has grown much more specialized. Here we have also considered the impact on siblings, the role of cognitions and coping, the effects of parental adjustment and parenting practices on children, the quality of life of adults with intellectual disabilities, the cultural context of family adjustment, and the integration of families and the helping services. The predominant theme across categories was family well being, and while studies of stress and negative impact continue to be represented, there is a decided shift toward less pathology and reports of positive impact, even in families whose children have pervasive disorders such as autism. Missing from the literature this year is any overarching theory of family well being that spans ages, life-course stages, phenotypes, and culture. Investigators increasingly use more sophisticated research designs, however, incorporate appropriate control groups, and present a more expansive, contextual view of families and intellectual disability.

References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

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