**Symposium Title:** The Ties of Adaptive Behavior of Individuals with IDD To Family Caregiving Over the Lifespan

**Chair:** Meghan M. Burke (University of Illinois at Urbana-Champaign)

**Discussant:** Robert M. Hodapp (Vanderbilt University)

**Overview:** Offspring characteristics often directly influence family caregiving, especially when the offspring has a disability. Adaptive behavior of a child with an intellectual and developmental disability (IDD) may directly influence parent and sibling caregivers, and these ties may occur from childhood through adulthood. Examining 110 parents of Chilean children with ID, authors of the first study examined the ties of educational levels on adaptive behavior and parent caregiving. In the second study, the authors examined the role of both adaptive and maladaptive behavior as it relates to a large ($N = 141$) sample of adult siblings of individuals with IDD. In the third study, the authors used a sample of 632 adult siblings of individuals with IDD to discern the role of adaptive behavior with respect to natural supports in employment, recreation, and housing. These studies extend findings on the correlates of adaptive behavior by showing how: (1) adaptive behavior connects to important caregiving variables across the lifespan; (2) the ties of adaptive behavior to certain caregiving variables may sometimes be non-linear; and (3) adaptive behavior not only relates to family caregiving, but also to specific services and supports received by individuals with IDD.

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**Paper Title:** Adaptive Behavior in Children with Intellectual Disability: Relation with Contextual Factors and Parenting Attitudes

**Authors:** Paulina Arango (Universidad de los Andes), Camila Sabat (Universidad de los Andes)

**Introduction:** Adaptive behavior is currently considered a central factor for the diagnosis of ID, as well as for establishing the supports needed to facilitate autonomy and social participation of people with ID (Tassé, Luckasson, & Schalock, 2016). Defined as the learned conceptual, social, and practical skills that are performed by people in their everyday lives (Tassé et al., 2012), adaptive behavior has been associated with several sociodemographic factors and characteristics of the parents (Sabat, Tassé, & Tenorio, 2019; Shogren, Luckasson, & Schalock, 2014). Although few studies have explored in depth parenting in families of children with ID, some parents show a tendency to overprotection and inconsistency in establishing limits and norms (Manjarrés, 2012; Peralta, 2008), as well as less sensitivity to the child’s needs (Fenning, Baker, Baker & Crnic, 2007). This study explored the relation between sociodemographic factors of the family and the main caregivers’ attitudes towards parenting, with the adaptive behaviors of children with ID.

**Methods:** Participants included 110 main caregivers (93.6% mothers; $M = 42.48$ years, $SD = 7.75$) of children with ID ($M = 9.05$ years, $SD = 3.41$). Participants completed a sociodemographic questionnaire, a Chilean adapted version of the Parent-Child Relationship Inventory (PCRI; Gerard, 1994), and the Adaptive Behavior Assessment System, second edition, Spanish version (ABAS-II; Harrison & Oakland, 2013). Family income, educational level of the main caregiver, and number of children were used as the sociodemographic variables for the analyses. Descriptive statistics, bivariate correlations, and ANOVAs were used to analyze relations among variables and differences across groups.

**Results:** Significant differences occurred in parent attitudes of satisfaction, autonomy, and role distribution between families with low, middle, and high incomes, $p$’s < .006. Similarly, autonomy and role distribution also showed differences when comparing educational levels. In all cases, caregivers with a higher income and higher educational level presented more positive attitudes. Domains of adaptive behavior also correlated with communication and autonomy; specifically, the child’s levels in the conceptual and social domains related to levels of parental support and satisfaction ($r$’s from -.21 to -.39), while the adaptive scale’s conceptual and practical domains related to role distribution ($r$’s -.23 & -.24, respectively). There were no significant
differences in adaptive behavior when considering the sociodemographic variables, except for self-care, which was lower for children of middle educational level caregivers compared to high educational levels.

**Discussion:** Consistent with previous research, the family’s educational and sociodemographic context influences parenting and, in turn, parenting influences the development of children (Letourneau, Duffett-Leger, Levac, Watson & Young-Morris, 2013), although few studies have explored this relation with adaptive behavior. The available evidence suggests that sociocultural variables such as socioeconomic status do not directly influence adaptive behavior, but that there is an indirect impact because it influences resource availability, which can in turn increase stress levels when resources are limited (Emerson, 2004). This, coupled with the higher stress levels associated with having a child with ID, can impact parents’ attitudes towards parenting and their behaviors (Hodapp, Ly, Fidler & Ricci, 2001; Miodrag & Hodapp, 2010). The characteristics associated with SES can also be related to the practices that are most valued in the cultural context of the family.

**References/Citations:**

Paper Title: Examining the Relation Between Adaptive and Maladaptive Behavior Among Older Adults with Intellectual and Developmental Disabilities (IDD) and Sibling Caregiving

Authors: Meghan Burke (University of Illinois at Urbana-Champaign), Chung eun Lee (Vanderbilt University Medical Center), Catherine K. Arnold (University of Illinois at Chicago)

Introduction: Given the longer lives of individuals with intellectual and developmental disabilities (IDD) and the increasing likelihood of siblings fulfilling caregiving roles, it is critical to identify correlates of sibling caregiving. Yet little research has examined the relation between adaptive and maladaptive behavior and sibling caregiving. From previous literature, we know that parents of individuals with the most significant support needs—defined as the lowest levels of adaptive behavior skills and/or the highest levels of maladaptive behavior—report significant caregiving burden and greater advocacy (McCann, Bull, & Winzenerg, 2012). It remains unknown, however, whether such a non-linear pattern applies to adult sibling caregivers. This study attempted to understand the relation between levels of adaptive and maladaptive behaviors and sibling caregiving, including advocacy and future planning.

Methods: Participants included 141 adult siblings of individuals with IDD who completed a national, web-based survey. Participants were primarily female (89.4%, n = 126), White (89.4%, n = 126), and had at least a college degree (96.4%, n = 136). The mean age of the sibling respondent was 55.87 years (SD = 8.48), with a range from 33 to 78 years. Half of the participants’ brothers or sisters with IDD were male (51.8%, n = 73); on average, they were 51.46 years of age (SD = 8.70), ranging from 44 to 76 years old. In addition, 27.7% (n = 39) of the brothers or sisters with disabilities lived in their family homes. To measure adaptive and maladaptive behavior, we used the Activities of Daily Living Scale (Lawton et al., 1982) and the Scales of Independent Behavior-Revised (Bruinink et al., 1996), respectively. With respect to dependent variables (DVs), the following measures were collected: extent of caregiving (Horowitz, 1985); caregiving demands (Perkins & Haley, 2010); number of caregiving supporters (Penrod et al., 1995); advocacy (Taylor et al., 2017); and future planning (Heller & Kramer, 2009). Analyses included inferential statistics. We also conducted linear and curvilinear regressions to determine the best fitting models for the relations between DVs and adaptive and maladaptive behavior, controlling for income and residential arrangement.

Results: Strong relations existed between the offspring’s (lower) levels of adaptive behavior and: caregiving, advocacy, and future planning. In most analyses, relations improved significantly when non-linear (as opposed to linear) regressions were performed. With respect to the extent of caregiving, adaptive behavior explained 18.6% of the variance, F = 10.03, p < .001, whereas in the curvilinear regression the amount of variance explained improved to 20.1%, F = 8.23, p < .001. With respect to caregiving hours, the linear regression explained 16.8% of the variance, F = 8.86, p < .00 whereas the curvilinear regression explained 17.4% of the variance, F = 6.91, p < .001. Similarly, curvilinear (versus linear) regressions explained more variance with respect to the relation between adaptive behavior and advocacy and future planning. Regarding advocacy and adaptive behaviors, the linear regression explained 13.6% of the variance, F = 6.90, p < .001, whereas the curvilinear regression explained 14.9% of the variance, F = 5.72, p < .001. Regarding future planning and adaptive behaviors, the linear regression explained 29.1% of the variance, F = 13.27, p < .001, whereas the curvilinear regression explained 35.2% of the variance, F = 13.04, p < .001. For example, offspring with the highest adaptive behaviors had: 1-2 hours of sibling caregiving hours per week, siblings engaged in advocacy activities often, and conducted three future planning activities. On the other hand, offspring with the fewest adaptive behaviors had: 5-14 hours of sibling caregiving hours per week, siblings engaged in very frequently, and conducted eight future planning activities. Only asocial maladaptive behaviors significantly related to caregiving demands. Notably, siblings of individuals with the most significant asocial behaviors had the most caregiving demands. Specifically, the linear regression explained 7% of the variance, F = 2.95, p = .03, while the curvilinear regression explained 7.5% of the variance with respect to caregiving demands, F = 2.36, p = .05.

Discussion: Overall, older adults with the lowest levels of adaptive behavior skills were significantly more likely to have siblings who engaged in greater amounts of caregiving, advocacy, and future planning. Future research is needed to examine the effect
of adaptive and maladaptive behavior of older adults with disabilities on the health and well-being of sibling caregivers and to identify other sources of variance with respect to sibling caregiving.

References/Citations:


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Paper Title: Getting by With A Little Help from My Friends: Siblings Report on The Relation Between Adaptive Behavior and The Amount of Informal Support Received by Adults with Intellectual and Developmental Disabilities (IDD)

Authors: Kelli A. Sanderson (California State University at Long Beach), Meghan M. Burke (University of Illinois at Urbana-Champaign), Richard C. Urbano (Vanderbilt University Medical Center), Catherine K. Arnold (University of Illinois at Chicago), Robert M. Hodapp (Vanderbilt University)

Introduction: With long waitlists for formal services (Braddock et al., 2015), many adults with IDD rely on informal, or natural, supports to meet their daily needs. Existing research on informal supports has found that family members, particularly parents and adult siblings, provide the bulk of the support and, to a lesser extent, family friends, acquaintances and neighbors (Duggan & Linehan 2013; Sanderson et al. 2017). But to effectively support adults with IDD, we also need to understand how informal supports are organized (i.e., by support activity or by life domain?), as well as determine the amount of informal support received in each major life domain (recreation, housing, and employment). Finally, we must establish if the amount of support received by adults with IDD relates to characteristics (e.g., adaptive behavior) of the adults with IDDs, their families, and/or their formal (or informal) service system.

Method: Participants included 632 adult siblings of individuals with IDD who responded to an online survey. The survey contained four sections about: (1) the sibling respondent; (2) the respondent’s family of origin, including the brother-sister with disabilities; (3) the sibling relationship; and (4) future planning. Most responses were categorical (yes-no) or on a Likert-type scale. For each of the three life domains (i.e., recreation, employment, and housing), respondents rated the extent to which their sibling received three types of informal support activities (i.e., referrals, opportunities, and help gathering information). To examine characteristics of adults with IDD, the following measures were used: race, residential status, and adaptive behavior (Lawton et al., 1982). To examine parent characteristics, the following measures were used: health, caregiving ability, and age. To examine formal supports, a composite variable was used summing whether the individual received formal financial, housing, and health assistance (e.g., Medicaid waiver services). Amounts of informal support were compared across domains using a repeated measures ANOVA. A factor analysis was used to determine how informal support is organized. Univariate analyses and regression analyses were conducted to analyze relations between the domains of informal support and characteristics of the adults with disabilities, their parents, their informal supporters, and their formal service system.
Results: Informal support was organized by the life domains of recreation, employment, and housing; together, these three domains accounted for 85.38% of the total variance. Adults with IDD received the most extensive informal support in the recreation domain and the least extensive support in the area of housing ($F = 15.69, p < .001$); however, low levels characterized all domains. In examining correlates of levels of informal supports in all three domains, we found that individuals with greater numbers of supporters in a domain experienced higher levels of support in that area. For recreational support, more extensive recreational support was found when parents were able to provide care and when greater numbers of informal supporters were present ($F = 9.60, p < .001, R^2 = .12$). In housing, more extensive support was found when adults lived apart from their families, had greater formal benefits, and had greater numbers of informal supporters ($F = 12.50, p < .001, R^2 = .16$). Additionally, adults with IDD residing with family and those who received more state-supported, formal benefits also received more extensive informal support. With respect to employment, more extensive support was noted for adults with limited adaptive behavior skills, adults who lived in the family home, and adults who received greater formal benefits and greater informal supports ($F = 27.59, p < .001, R^2 = .30$). Thus, on a scale of amount of informal support in the employment domain (range from 3-15), individuals with the highest levels of adaptive functioning averaged 5.40 ($SD = 3.51$), whereas those in the lowest quartile averaged 8.68 (3.76), $F = 20.49, p < .001$.

Discussion: Until now, studies of informal supports for adults with IDD have examined who provides such supports (Duggan & Linehan 2013). This study, in contrast, provides insight into the amount of informal support received by adults with IDD, how that informal support is organized, and correlates of having more extensive informal support. As noted above, both parent-family and individual offspring characteristics—including the offspring’s level of adaptive behavior (for employment)—relate to amounts of informal supports. Results from this study also highlight the need to increase access to both formal and informal supports for adults with IDD, and the need to examine in greater detail the connections between individual characteristics of the adult with IDD and the receipt of both informal and informal services.

References