Later Life Impacts of Social Participation on Parents of Adult Offspring With and Without Intellectual and Developmental Disabilities

Darren L. Olsen, Frank J. Floyd, Marsha R. Mailick, and Jan S. Greenburg

Abstract

Social participation is an important resource for parents in old age, and may be particularly important for parents living with adult offspring with intellectual and developmental disabilities. To evaluate whether socializing with friends and family and participating in social organizations protects against depression in old age, this study examined parents of adult offspring with disabilities ($n=164$) and without disabilities ($n=820$). As expected, more socializing with friends and more participating in organizations were associated with fewer depressive symptoms for all parents. However, socializing with family members predicted fewer depressive symptoms only for parents co-residing with their adult offspring with disabilities, suggesting that socializing with family is particularly important for parents providing direct care to adults with disabilities.

Key Words: developmental disabilities; intellectual disability; aging; social participation

Parenting children with intellectual and developmental disabilities can be stressful for parents throughout the life course (Seltzer et al., 2009). Sources of stress include the caretaking demands associated with the child's intellectual or developmental limitations (Dumas, Wolf, Fisman, & Culligan, 1991) and the child's behavioral difficulties, such as sleep problems (Allik, Larsson, & Smedje, 2006), emotional problems (Herring et al., 2006), and other challenging behaviors (Abbeduto et al., 2004; Beck, Hastings, Daley, & Stevenson, 2004; Plant & Sanders, 2007). As most aging parents no longer provide direct care for their adult offspring, parenting stress is generally overlooked as a concern in normative aging research. However, for parents of offspring with disabilities, the extent and severity of the child's difficult behaviors are important predictors of poor well-being for both mothers and fathers, and these effects persist after the child has reached adulthood (Ha, Hong, Seltzer, & Greenberg, 2008; Miodrag & Hodapp, 2010). Thus, it is important to understand the ways in which parents of adult offspring with disabilities manage parenting stress in old age.

The need to manage parenting stress is particularly relevant when the adult with a disability continues to live in the home as the parents enter old age. For all parents, the situation of having adult offspring live with them is associated with relatively poor well-being in both midlife and old age (Pudrovská, 2009), possibly related to financial stress and worry about the child's future (Arnett & Schwab, 2013). This stress is likely compounded for aging parents of offspring with disabilities, who report that disruptive behaviors and worries about the future care of their child are their most significant concerns (Heller, Hsieh, & Rowitz, 1997; Seltzer, Floyd, Song, Greenberg, & Hong, 2011). Accordingly, in a study of coping strategies (Piazza, Floyd, Mailick, & Greenberg, 2014), the use of effective coping skills buffered stress for all aging parents of adult offspring with developmental disabilities, but were especially important among aging parents with co-resident offspring. Thus, in...
addition to coping skills, other means for managing stress may also be particularly important for aging parents who care for adult offspring with disabilities at home.

Social participation is one of the most significant and consistent predictors of psychological well-being in old age (Charles & Carstensen, 2010). Social participation entails how frequently and actively a person takes part in formal and informal groups and other social activities (Hyypä, Maki, Alanen, & Impivaara, 2008). It requires both access to social contacts and the ability to maintain social involvements and nurture interpersonal relationships. Further, multiple forms of social participation have been shown to be important to the well-being of elderly adults, including participating in formal organizations and clubs, and informal forms of social involvement such as socializing with friends and family. These activities have been shown to predict positive well-being (e.g., Ritchey, Ritchey, & Dietz, 2001; Veenstra, 2000) and happiness for elderly adults (Leikes, 2006; Powdthavee, 2008). Those who experience high levels of social participation may gain knowledge of and access to helpful resources that could promote positive functioning and well-being and increase coping options (Liebler & Sandefur, 2002). In contrast, limited social participation may reduce access to important resources such as aid, information, and emotional support, which are important for coping with the stressors associated with aging (Kawachi, Kennedy, & Glass, 1999). Further, social participation with family members may be particularly relevant for elderly individuals under stress, as they tend to depend on family members to help manage stress (Morgan, 2014).

For older parents of adults with intellectual and developmental disabilities, social participation might guard against the onset or exacerbation of depressive symptoms. A meta-analysis by Bailey, Golden, Roberts, and Ford (2007) found that approximately 24% of mothers of children with disabilities passed the clinical threshold for current depressive symptoms. This rate is considerably higher than the national average of approximately 6.6% for 12-month and 16.2% for lifetime prevalence rates of the general adult population in the United States (Kessler et al., 2003). Furthermore, the high rates of depression in these parents have been found to continue into old age (Seltzer et al., 2011). High-quality participation and ties to family have been found to provide supportive coping resources that buffer individuals from depression (Holtfreter, Reisig, & Turanovic, 2015). For elderly individuals experiencing negative effects of aging, supportive family members can facilitate positive coping, such as by promoting regular exercise and other forms of healthy behaviors (Coyle & Dugan, 2012).

The purpose of the present study is to examine whether social participation can help to protect aging parents of adults with intellectual and developmental disabilities from experiencing depressive symptoms. The current study follows up on an earlier report about the impacts of lifelong parenting for aging parents of offspring with intellectual and developmental disabilities (Seltzer et al., 2011). This research draws on participants in the Wisconsin Longitudinal Study (WLS). The original goal of the WLS was to describe the transition from high school to adult life among young adults in Wisconsin (Hauser, Sheridan, & Warren, 1999). As such, the WLS is a probability sample study of 18-year-old graduating seniors in Wisconsin in 1957, who were followed in adulthood through early old age. Like any cohort, some went on to have a child with a disability. A unique feature of the WLS is that the participants were randomly selected for the study prior to becoming parents. As such, their involvement in the WLS is independent of later having a child with a disability. Using this unselected sample, the present study examines the vulnerability of aging parents of offspring with intellectual and developmental disabilities as compared to parents with similar backgrounds who did not raise children with disabilities. The earlier report on this sample (Seltzer et al., 2011) showed that, although the parents of offspring with disabilities generally had positive functioning through midlife, by early old age they reported less social participation and greater depressive symptoms, along with other health problems, than matched controls. Poorer functioning was particularly the case for parents who co-resided with their offspring, presumably because of the added burden of providing direct care and worrying about future care. Furthermore, the parents with co-resident adult offspring scored lowest on a combined index of visits with friends and family. Thus, the combination of having co-resident offspring with disabilities and limited participation with family members and friends may create a context for particularly poor functioning for these parents. The purpose of
the present study was to address this idea by examining within-group variation and its association with depressive symptoms.

**Current Study**

The current study examines how social participation may protect against depressive symptoms for aging parents, especially in those still co-residing with their adult offspring with disabilities. In the current study, we separated the group of parents with offspring with disabilities into two subgroups—those who currently co-resided and those who did not co-reside with their adult offspring with intellectual and developmental disabilities. Both subgroups were compared to a comparison group of parents whose adult offspring did not have disabilities or chronic health problems and, with few exceptions, did not co-reside with the parents. The goal was to identify how each of the two family contexts within the intellectual and developmental disabilities samples might differ from normative patterns. We also assessed multiple forms of social participation to determine if participation with family, close friends, or organizations were each predictive of better functioning for these parents.

The hypotheses for the current investigation were that (1) overall, higher levels of each of the forms of social participation would predict fewer depressive symptoms, and (2) social participation with family members, with friends, and in organizations would serve as moderators of the stressful effects of having children with intellectual and developmental disabilities on depressive symptoms, such that social participation would buffer the negative effects of parenting children with intellectual and developmental disabilities.

**Method**

**Wisconsin Longitudinal Study (WLS)**

The WLS is a public data set consisting of information obtained from a random sample of 10,317 men and women who graduated from Wisconsin high schools in 1957 (Hauser et al., 1999) and who were subsequently contacted to obtain follow-up information in 1975. Further follow-up interviews were conducted in 1992–1994, 2004–2006, and 2011, and included the graduates and a randomly selected sibling of those who had at least one brother or sister. A total of 5,823 siblings participated in one or more of these data collection points in addition to the original respondents. For the present study, we focused on the period when parents were entering old age. Thus, data were drawn from the 2004–2006 wave, when nearly all of the original graduate participants were approximately 64 years old, and the average age of the sibling participants also was approximately 64 years old (SD = 4.6 yrs; Range: 47 yrs – 85 yrs).

**Participants**

The parents of children with intellectual and developmental disabilities and a comparison group of parents of children without disabilities were selected for the current investigation. The group of parents with children with disabilities was identified and used in previous analyses (e.g., Seltzer et al., 2011). Specifically, the participants were identified in the 2004–2006 data collection wave as having a child with an intellectual or developmental disability. During this wave, a “child screener” was administered over the phone and consisted of a series of questions (maximum of 31) that began by asking parents if they had any children (living or deceased). If yes, the parent was asked if any of those children had an intellectual or developmental disability, as well as the specific diagnosis. For inclusion in the disability group, the parent needed to have indicated that the identified child had a specific intellectual or developmental disability, or in describing the child the parent needed to use terms such as “developmental disability,” “mental retardation,” or “cognitive disability.” If a parent did not know the specific diagnosis, yet also reported that the child had experienced difficulties in school, follow-up questions were asked about issues such as whether the child had below-average intelligence or participated in special education classes. If so, they were included in the intellectual and developmental disabilities group. Furthermore, for the current analyses, participants were included only if they also indicated whether or not their son or daughter was currently living with the parent respondent or away from the respondent’s home. A total of 15 participants in the intellectual and developmental disabilities group were excluded due to missing co-residence data. In total, 164 of the living WLS respondents as of 2004–2006 met inclusion criteria for the intellectual and developmental disabilities group. The group consists of 85 fathers (51.8%) and 79 mothers (48.2%), 91
(55.5%) of whom were original graduates and 73 (44.5%) of whom were from the sibling sample. The identified disabilities of the children are 59 with intellectual disability, 22 with Down syndrome, 23 with cerebral palsy, 19 with an autism spectrum disorder, six with traumatic brain injury, 14 with learning disability including low IQ, and 21 with other specific intellectual and developmental disability diagnoses or conditions.

Participants in the comparison group had at least one child, and no child could be identified as having an intellectual or developmental disability or any mental health condition or condition requiring ongoing care for chronic health problems. Parents with a deceased child were not included. Stratified random sampling was used to randomly select the comparison group from the larger pool of eligible participants. Specifically, in order to ensure that the disability and comparison groups had equal representation of mothers and fathers and were similar in age, the groups were stratified by sex and graduate/sibling respondents, in order to account for age variation among the siblings. No sibling pairs were included in the samples to avoid the dependence in the data associated with non-independent cases, with one sibling randomly eliminated from the possible comparison group prior to stratification. Subsequently, the remaining qualified WLS participants who met exclusion criteria ($N = 5798$) were divided into four subgroups of men and women who were either graduates or siblings. As in previous research using this sample (Seltzer et al., 2011), in order to maximize the use of information from the larger data set, comparison cases were randomly selected from these subgroups at a ratio of 5:1 comparison to disability cases. The stratification procedure produced a group of 820 parents in the comparison group, including 425 fathers (51.8%) and 395 mothers (48.2%), with 455 graduate (55.5%) and 365 sibling (44.5%) respondents.

In terms of residence status, respondents were asked the residence status of their child with intellectual and developmental disability. Subgroups of these parents were created. One group consisted of parents whose son or daughter was currently living with the parent respondent and the other consisted of those parents whose son or daughter lived away from the respondent’s home. In total, 37.2% of the sons and daughters with intellectual and developmental disabilities lived at home, consistent with previous research using this sample (Seltzer et al., 2011). Co-residence was not used to distinguish subgroups of the comparison sample due to the relatively low rates of co-residence in the group (8%). Further, according to our selection criteria, the typically developing adult offspring living at home did not have disabilities and did not receive care from their parents.

Due to the ethnic composition of Wisconsin in the mid-20th century, virtually all of the participants in WLS are White. Table 1 shows the personal and family background characteristics of the participants for the current report, assessed during their junior year of high school in 1957, and later life sociodemographic variables assessed in 2004. The disability and comparison groups were comparable with respect to all 1957 personal and family background variables, including high school IQ scores, household income, father’s education, mother’s education, father’s occupational status, and community size. The two groups were also comparable with respect to all of the 2004 sociodemographic variables including age, number of children born, total personal income, total household income, years of education, and current marital status.

**Measures**

**Social participation.** Social participation was measured using multiple indices. These included the level of involvement in organizations in which the respondent was a member (endorsed from a list of 17 organizations such as charity or welfare organizations, civic groups, labor unions, neighborhood organizations, sports teams (1 = very little, 2 = some, 3 = quite a bit, 4 = a great deal; $M = 7.57$, $SD = 5.85$, Range = 0–35), the number of visits in the past 4 weeks with friends ($M = 3.34$, $SD = 3.62$, Range = 0–28), and the number of visits in the past 4 weeks with relatives ($M = 3.06$, $SD = 3.41$, Range = 0–28). An earlier report (Seltzer et al., 2011) found that the organization measure and a composite of the friend and family measures successfully discriminated levels of social participation in parents of children with intellectual and developmental disabilities and parents of typically developing children. For the current study, we used the friend and family participation variables separately to examine how each of these types of social participation independently affects individuals in old age. Additionally, we conducted one-way ANOVAs to evaluate mean group differences in the social participation variables. There were
significant group effects for family participation scores, $F(2,981) = 4.42, p < .05$, and friend participation scores, $F(2,981) = 2.85, p < .05$. No significant differences were found in organization participation scores, $F(2,981) = 0.19$. Duncan’s post-hoc multiple range test at $p = .05$ revealed that the parents of co-resident offspring with disabilities had significantly less participation with family members ($M = 2.27, SD = 2.04$) than the comparison group ($M = 3.51, SD = 3.51$). Similarly, the co-resident group had significantly less participation with friends ($M = 2.22, SD = 2.15$) than the comparison group ($M = 3.45, SD = 3.65$). The non-co-resident group had mid-range scores for both family participation ($M = 3.18, SD = 2.73$) and friend participation ($M = 3.26 SD = 3.59$) that did not significantly differ from either of the other two groups.

**Depressive symptoms.** Depressive symptoms were measured by the Center for Epidemiological Studies–Depression Scale (CES-D; Radloff, 1977), which has been used extensively in samples of midlife and older adults (Gatz & Hurwicz, 1990), including studies on midlife and later life parenting (Barker et al., 2011; Floyd, Seltzer, Greenberg, & Song, 2013; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008; Taylor, Greenberg, Seltzer, & Floyd, 2008). For each of 20 symptoms of depression, the respondent was asked to indicate how many days in the past week the symptom was experienced. The data were recoded into four categories ($0 = \text{never}$, $1 = 1–2 \text{ days}$, $2 = 3–4 \text{ days}$, and $3 = 5–7 \text{ days}$), consistent with the conventional scoring of the CES-D. The total score was the sum of the ratings for the 20 items. Scores could range from 0 to 60 with higher scores indicating more depressive symptoms, and a score of 16 or greater indicating the risk of clinical depression. The CES-D had adequate internal consistency in the present sample ($\alpha = .86$).

**Analyses.** To retain sample sizes, multiple imputation (MI) was used to estimate social participation and depressive symptoms data for participants with partial data. Multiple imputation is a preferred technique for handling missing data and has numerous advantages over other approaches (Azur, Stuart, Frangakis, & Leaf, 2011). The multivariate imputation regression method was used to generate five datasets with complete information for individuals with at least one point of data. Missing scores were replaced with the mean of the estimated values. Of the 164 respondents in the intellectual and developmental disabilities group, data were imputed for nine (5.5%) missing friend participation, 14 (8.5%) missing family participation, four (2.4%) missing

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**Table 1**

<table>
<thead>
<tr>
<th>Variable</th>
<th>IDD</th>
<th>Comparison</th>
<th>$t$</th>
<th>df</th>
</tr>
</thead>
<tbody>
<tr>
<td>IQ score</td>
<td>104.73 (15.19)</td>
<td>102.55 (14.59)</td>
<td>1.69</td>
<td>905</td>
</tr>
<tr>
<td>Household income in 1957 in $100$ dollars</td>
<td>96.19 (84.15)</td>
<td>96.41 (68.21)</td>
<td>-0.03</td>
<td>621</td>
</tr>
<tr>
<td>Father Years of Schooling 1957</td>
<td>10.81 (3.25)</td>
<td>10.49 (3.11)</td>
<td>1.15</td>
<td>911</td>
</tr>
<tr>
<td>Mother Years of Schooling 1957</td>
<td>10.87 (3.15)</td>
<td>10.86 (2.93)</td>
<td>0.03</td>
<td>928</td>
</tr>
<tr>
<td>Father Occupational Status Duncan SEI Score 1957</td>
<td>32.45 (23.14)</td>
<td>31.64 (22.93)</td>
<td>0.41</td>
<td>982</td>
</tr>
<tr>
<td>Community Population Size in Thousands 1957</td>
<td>141,471 (185,506)</td>
<td>134,685 (182,335)</td>
<td>0.43</td>
<td>982</td>
</tr>
<tr>
<td>Age in 2004 (Rounded)</td>
<td>64.89 (4.75)</td>
<td>64.51 (4.58)</td>
<td>-0.98</td>
<td>981</td>
</tr>
<tr>
<td>Number of Children Ever Born</td>
<td>3.20 (2.38)</td>
<td>3.23 (2.39)</td>
<td>-0.17</td>
<td>978</td>
</tr>
<tr>
<td>Respondent Total Personal Income in dollars 2004</td>
<td>56,735 (212,581)</td>
<td>42,246 (58,872)</td>
<td>1.59</td>
<td>914</td>
</tr>
<tr>
<td>Respondent Total Household Income in dollars 2004</td>
<td>82,663 (216,025)</td>
<td>68,354 (112,774)</td>
<td>1.21</td>
<td>914</td>
</tr>
<tr>
<td>Respondent Years of Schooling 2004</td>
<td>14.03 (2.68)</td>
<td>13.74 (2.33)</td>
<td>1.38</td>
<td>907</td>
</tr>
<tr>
<td>Marital Status in 2004$^a$</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Currently married</td>
<td>131 (79.9%)</td>
<td>679 (83.5%)</td>
<td>1.28</td>
<td>0.26</td>
</tr>
<tr>
<td>Not currently married</td>
<td>33 (20.1%)</td>
<td>134 (16.3%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Means are presented with SDs in parentheses. IDD = intellectual and developmental disabilities. SEI = Socioeconomic Index.

$^a$Chi squared.
organization participation, and three (1.8%) missing depressive symptoms data. Of the 820 respondents in the comparison group, data were imputed for 29 (3.5%) missing friend participation, 51 (6.2%) missing family participation, 14 (1.7%) missing organization participation, and 13 (1.6%) missing depressive symptoms data. Data were not imputed for co-residence status or background characteristics. Analyses indicated that the initial response data for the family and friend participation variables were significantly skewed. To address the skewness and reduce the influence of outliers in the data, outlier analyses were run. The analyses identified 13 (0.01%) friend participation and 9 (0.01%) family participation scores as extreme outliers. These individual responses were re-assigned the highest numerical value within 1.5 interquartile ranges above the third quartile. This correction resulted in acceptable levels of skewness in the family and friend participation variables. To assess multicollinearity, variance inflation statistics were run on the social participation variables. Variance inflation factor (VIF) scores ranged from 1.08 to 1.11 indicating very little collinearity between the social participation variables.

A linear regression analysis was conducted to examine the prediction of depressive symptoms in early old age from the social participation variables, disability group, and the interactions of disability group with social participation. The comparisons of the disability subgroups with the nondisability group were coded on two dummy coded orthogonal contrast vectors. One vector contrasted the parents with co-residing offspring with intellectual and developmental disabilities versus the comparison group of parents with typically developing offspring. The other vector contrasted the parents of non-co-residing offspring with intellectual and developmental disabilities versus the same comparison group. Sex (mothers vs. fathers) was included in order to account for the known pattern of sex differences in depressive symptoms and social participation. The group and sex vectors were entered in step one of the analysis. The social participation predictors (organizational, family, and friend participation) were mean centered and entered in step two of the analyses. At step 3, the cross-product interaction terms of each of the two group vectors with each of the social participation variables were tested for stepwise entry in order to evaluate whether social participation moderated the effects of group on depressive symptoms. Only interactions that significantly contributed to the regression were entered at step 3. In addition, we tested whether sex interacted with other group effects, but none were significant so they were not reported.

**Results**

Table 2 presents the results of the regression. The variables entered at step 1 accounted for significant variance in depressive symptoms scores, $F(3,980) = 7.01, p < .001$. The vector representing the group effect for the co-resident parents was significant, with the co-resident parents of offspring with disabilities reporting higher levels of depressive symptoms ($M = 8.64, SD = 9.17$) than the comparison sample ($M = 6.79, SD = 6.91$). The vector contrasting the non-co-residing parents with the comparison group was not significant. Thus, there was no significant difference in depressive symptoms scores between the non-co-residing parents of offspring with disabilities ($M = 7.51, SD = 7.06$) and the comparison group. The main effect of sex also was significant, with the women ($M = 7.92, SD = 7.98$) reporting higher depressive symptoms scores than the men ($M = 6.11, SD = 6.02$). These differences concurred with the group and sex differences identified by Seltzer et al. (2011).

Regarding the hypothesis that greater social participation would predict fewer depressive symptoms, the addition of the social participation variables at step 2 accounted for significant additional variance in depressive symptoms, $F(3,977) = 6.22, p < .001$. Table 2 shows that, as hypothesized, both organizational participation and friend participation significantly predicted depressive symptoms for the sample overall, with higher levels of both types of participation associated with fewer depressive symptoms. There was not a significant main effect of family participation.

Regarding the hypothesis that social participation would moderate the effects of disability group on depressive symptoms, at step 3 there was a significant interaction between family participation and the group vector for parents with co-residing offspring, $F(1,976) = 5.91, p < .001$. None of the interactions for the non-co-residing parents were significant and entered the equation. Figure 1 portrays the mean depressive symptoms scores for the co-resident and comparison groups, with the
median score on family participation for the entire sample used to subdivide the groups according to high or low levels of family participation. Consistent with hypothesis 2, the parents who co-resided with their adult offspring with disabilities and also engaged in low levels of social participation with family members reported the most depressive symptoms overall ($M = 10.32, SD = 10.43$), which was significantly greater than the comparison parents with low family social participation ($M = 7.31, SD = 7.10$). However, when parents had high levels of social participation with their families, the parents co-residing with their offspring with disabilities reported relatively lower levels of depressive symptoms ($M = 5.19, SD = 4.20$) that did not significantly differ from the comparison parents with high family participation ($M = 6.28, SD = 6.67$). Thus, the pattern is consistent with the hypothesis that social participation with family members would be protective of depressive symptoms for the parents living with offspring with disabilities in early old age.

### Discussion

The purpose of this study was to extend our understanding of the role of social participation in old age for parents of adult offspring with intellectual and developmental disabilities by examining how participation is linked to depressive symptoms. A prior analysis using the subset of parents in the present study showed that parents of offspring with disabilities generally reported both less social participation and greater depressive symptoms in early old age than matched controls, particularly when they co-reside with the adult offspring (Seltzer et al., 2011). Those findings did not address possible associations among the outcomes. Because limited social participation is a risk factor for depression in old age, the current investigation examined whether low levels of social participation would account, at least in part, for high

**Figure 1.** Family participation reduces the effect of disability status on depressive symptoms for co-resident parents.
levels of depressive symptoms among all older parents, and would amplify effects associated with parenting adult offspring with disabilities.

The findings show that both participation in formal organizations and informal socializing with friends were uniquely associated with fewer depressive symptoms, thus supporting the importance of multiple forms of social participation in old age. The significant main effects are consistent with other research that shows positive psychological outcomes for older adults who participate in organized clubs (Veenstra, 2000) and socialize with friends (Ritchey et al., 2001). Participation in these activities may allow for an intimate sense of belonging for older parents, including those with offspring who have intellectual and developmental disabilities.

The unique association of family participation with fewer depressive symptoms only for the parents who co-reside with their offspring with intellectual and developmental disabilities suggests that family contacts might play a unique role in managing stress for these parents. As with most adults in old age, social contacts with family members may build intimacy that is important to combat loneliness and maintain a sense of self-worth (Charles & Carstensen, 2010). The majority of parents had other children in addition to the child with a disability, and it is likely that social participation with family members involved contact with their other children in particular. In this way, social participation with family members may help to maintain a critical support system for managing ongoing day-to-day needs of the adult offspring with intellectual and developmental disabilities living in the home. This type of family involvement might become even more impactful as the parents age. Perhaps without family participation and the support that may come from it, parents may have difficulty meeting their adult offspring’s immediate needs and planning for long-term care at a time when the parents struggle with their own functional limitations. This burden may leave these parents more vulnerable and susceptible to additional stress and depressive symptomology. Thus, compared to organizational participation and social participation with friends, family social participation may be more directly linked to receiving physical and psychological support both for the parents and the offspring with disabilities living in the home.

The present study has both methodological limitations and strengths. In terms of limitations, there was a lack of racial and ethnic diversity in the sample, with a vast majority of the Wisconsin parents being White. Therefore, it is unknown whether the findings would generalize to ethnically/culturally diverse groups. The relative importance of family participation or participation in formal organizations, for example, might differ for families with different cultural values about social participation. Another limitation of the study was that information on the severity of disability was not available in the WLS and, thus, could not be taken into account in these analyses. The presence of relatively severe disability for the offspring may be the underlying reason for co-residence with parents into adulthood, and may also increase the parent’s depressive symptoms. Without a measure of disability severity, however, we were unable to determine whether this factor accounted for the findings in the co-resident group. A strength of the study was the use of population-level data, which reduces the potential effects of self-selection bias among the participants. The sample was not initially recruited because of their disability status and, thus, it was possible to examine the impacts of parenting a child with intellectual and developmental disabilities in a non-treatment seeking sample.

The study’s findings highlight the importance of social participation for all aging parents, and the specific importance of family participation for those co-residing with adult offspring with intellectual and developmental disabilities. Yet, more research is needed to understand the causal mechanisms of social participation. Future research may also examine other outcomes such as physical well-being or other mental health concerns in order to evaluate how they are related to depressive symptoms and other negative outcomes. In addition, future research could examine differences in parenting experiences with children with different levels of disability severity. Intellectual and developmental disabilities with varying severities that require lifelong care may render the parents more or less vulnerable to limited social participation and depression. Also, the findings suggest that support services for these parents should continue to emphasize respite or other forms of support that allow parents to maintain social involvements out of the home. Furthermore, for aging parents who have become disconnected from their family members, counseling or support group services...
might focus on helping them to reinstate or develop closer family ties.

References


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