Midlife and Aging Parents of Adults With Intellectual and Developmental Disabilities: Impacts of Lifelong Parenting

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Abstract
Using population data, this study included parents of individuals with intellectual and developmental disabilities \( n = 220 \) and parents of individuals without disabilities \( n = 1,042 \). Parents of individuals with intellectual and developmental disabilities were further divided into those who co-resided with their adult child and those whose adult child lived elsewhere, and the 3 groups were compared regarding parental patterns of attainment, social participation, psychological functioning, and health in midlife and early old age. In midlife, parents of individuals with intellectual and developmental disabilities were similar in general to comparison parents. However, by early old age, these parents had poorer health and mental health. Co-residence between the adult with intellectual and developmental disabilities and the parent was prevalent during midlife (51.4%) and in the early years of old age (38.6%), and there were different patterns of parental outcomes, depending on the residential status of the adult with intellectual and developmental disabilities.

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In general, parents of children with intellectual and developmental disabilities serve as supports and caregivers for their children throughout their lives. A great deal of research has been conducted about the impacts of parenting a child with intellectual and developmental disabilities on mothers and, to a lesser extent on fathers, with a focus on the impacts during early childhood (Baker et al., 2003; Crnic & Low, 2002), the school years (Floyd & Gallagher, 1997), and adulthood (Ha, Hong, Seltzer, & Greenberg, 2008; Lloyd & Hastings, 2009; Miodrag & Hodapp, 2010). Overall, parents of children with intellectual and developmental disabilities show patterns of resilience and effective coping with their parenting responsibilities (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001), although they also have been shown to have greater difficulties in psychosocial functioning than the general population (Fidler, Hodapp, & Dykens, 2000). Our purpose in the present study was to extend the developmental perspective to examine long-term outcomes for these parents through midlife and into the early years of old age.

Parents of children with intellectual and developmental disabilities have been shown to
differ in a number of important dimensions from similarly aged parents of children without disabilities. For example, previous research has shown that their patterns of employment may differ, due to lower rates of labor force participation among mothers (Baldwin & Glendinning, 1983; Hirst, 1985) and less involvement by fathers with childcare and housework (Bristol, Gallagher, & Schopler, 1988; Crnic, Arbona, Baker, & Blacher, 2009; Floyd, Costigan, & Phillippe, 1997). There is evidence that this is a lifelong pattern (Essex, Seltzer, & Krauss, 1999; Grant, 1986), extending well into the son or daughter’s adulthood. These parents also may be at somewhat greater risk of divorce. According to a recent meta-analysis, there are relatively small but significant elevations in marital distress and divorce rates compared with couples with typically developing children (Risdal & Singer, 2004), although certain subgroups may be more vulnerable to marital disruption (e.g., parents of individuals with autism spectrum disorders; Hartley et al., 2010).

In a prior publication based on a subgroup of the sample reported on here, we examined the life-course impacts of parenting a child with intellectual and developmental disabilities or mental illness (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001) for a cohort of adults from the Wisconsin Longitudinal Study (WLS; described below), a probability-sample study that first recruited participants when they were age 18 years in 1957 and followed them through midlife and early old age. 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, 1998). A unique feature of the WLS is that the participants were randomly selected for the study prior to the time when they became parents, and, thus, their involvement in the WLS is independent of the event of later having a child with a disability. In our prior analysis (Seltzer et al., 2001), we used reports of family caregiving, children’s educational attainment, and receipt of disability benefits to identify a subgroup of parents who had children with intellectual and developmental disabilities. Although the lack of direct questioning about children’s disabilities meant that some appropriate cases were not identified, this data source provided a sample that was not biased by the self-selection process, which is characteristic of most volunteer samples of parents of children with identified disabilities or those recruited through treatment settings.

In our prior analysis of WLS parents in adulthood (M age = 36 years) and midlife (M age = 53 years), those with children and young adults with intellectual and developmental disabilities were similar to a comparison group of parents who did not have any children with disabilities with respect to parents’ educational attainment, marital status, physical health, and psychological well-being (Seltzer et al., 2001). However, they had lower rates of employment and social participation than the comparison group. Additional analyses clarified the divergent patterns of employment for WLS mothers of children with intellectual and developmental disabilities (Parish, Seltzer, Greenberg, & Floyd, 2004), who returned later than their age peers to the labor market after the birth of their child and were less likely to work full time. As a result, these families had less savings and investments in midlife.

Another characteristic that distinguished this sample of parents from their age peers who did not have children with disabilities was the continued co-residence of the child with the parent well past the time when most children leave home and establish an independent residence. We found a higher rate of co-residence of adult children with intellectual and developmental disabilities when their parents were in midlife than was characteristic of the comparison group (57% vs. 16%). In population studies, when parents are in midlife and early old age, having an adult child live at home is generally associated with poorer well being for parents, particularly mothers (Pudrovská, 2009). However, the situation likely is more complex for parents of children with intellectual and developmental disabilities, because launching often does not result in complete independence for the adult child and some parenting responsibilities continue. In a longitudinal study tracking 117 families from before to after residential relocation of an adult son or daughter with intellectual and developmental disabilities, Seltzer, Krauss, Hong, and Orsmond (2001) found that although aging mothers maintained close relationships and had frequent contact after their adult child’s relocation, they had decreasing levels of direct caregiving and less frequent contact with residential staff during the first 3 years after their son or daughter moved away from home; thus, their daily lives were quite different than during the co-resident period. Therefore, in the present study, in addition to contrasts with the comparison group who did not have children with disabilities or chronic health problems,
we examined how parents whose child continued to live at home as an adult versus those whose child did not co-reside differed in terms of their profiles of attainment, social participation, psychological well being, and health.

Similar to the general population, the transition from midlife to the early years of old age likely brings an increased risk of health problems for these parents and transitions in employment and marital roles. In addition, there is an increased likelihood that adult children with intellectual and developmental disabilities will move away from the parental home during these stages of life (Seltzer & Krauss, 2001). Therefore, we examined family roles in midlife and the early years of old age as well as how co-residence between the parents and adult child with intellectual and developmental disabilities may be differentially associated with the physical and mental health of the parents.

**Present Study**

In the present study, our goal was to advance knowledge about the long-term impacts of parenting a child with intellectual and developmental disabilities, based on more thorough case finding, a broader range of health outcomes, and extension of our assessment of parental midlife functioning to the subsequent wave of data on WLS participants when they were in the early years of old age (i.e., in their mid-60s). The study is unique in examining how an unselected sample of parents at this stage of life differs from their age peers who do not have children with disabilities. The WLS data make it possible to examine the impacts of parenting a child with intellectual and developmental disabilities in a broad set of parental life-course outcomes, including educational and occupational attainment, marital status, social participation, psychological functioning, and health.

In this study, we compared three groups of parents: (a) those who had a co-residing grown child with intellectual and developmental disabilities, (b) those whose adult child with intellectual and developmental disabilities lived elsewhere, and (c) those whose children did not have disabilities or chronic health problems. Comparisons were made at two stages of life: midlife and the early years of old age. With the midlife comparisons, we sought to confirm the findings of our previous investigation (Seltzer et al., 2001) with a larger sample that was ascertained more systematically.

The comparisons during the parents’ early years of old age extend our investigation of the life-course impacts of nonnormative parenting during a period of potentially increased health vulnerability. We also examined how patterns of co-residence were associated with different outcomes for parents. Our hypotheses were as follows:

1. We anticipated that our prior findings about functioning in midlife would be confirmed and would extend to the early years of old age. We hypothesized that the lower rates of social participation in midlife parents of adults with intellectual and developmental disabilities (Seltzer et al., 2001) would extend into old age when these parents would be less active socially than the comparison group. In particular, we hypothesized that parents of co-residing adults with intellectual and developmental disabilities would have lower rates of social participation than comparison-group parents.

2. In addition, we hypothesized that the relatively later return to the workforce and lower rates of employment for the mothers of individuals with intellectual and developmental disabilities would be associated with lower rates of employment in the early years of old age, again particularly among mothers whose son or daughter with intellectual and developmental disabilities continued to live at home. However, based on past research indicating more traditional gender roles in families who have children with intellectual and developmental disabilities (e.g., Crnic, Arbona, Baker, & Blacher, 2009; Floyd et al., 1997; Parish et al., 2004), we hypothesized that during midlife and the early years of old age, fathers would be more likely to remain in the labor force than fathers in the comparison group.

3. Based on findings from earlier stages in the family life course indicating that there was a somewhat higher rate of divorce in couples who were parenting a child with intellectual and developmental disabilities (e.g., Hartley et al., 2010; Risdal & Singer, 2004), we hypothesized that parents of grown children with intellectual and developmental disabilities would be less likely to be married in the early years of old age than the comparison group.

4. Although past research has been mixed regarding the physical and mental health impacts through midlife of parenting a child with intellectual and developmental disabilities (e.g.,
Fidler, Hodapp, & Dykens, 2000), we hypothesized that such parents (both those whose son or daughter continued to live at home and those whose son or daughter lived elsewhere) would have poorer physical and mental health during the early years of old age than the comparison group (Clark, Bond, & Hecker, 2007; von Kanel, Dimsdale, Patterson, & Grant, 2003).

5. We hypothesized that midlife and older parents whose adult children with intellectual and developmental disabilities continued to co-reside with them would differ in several respects from parents whose adult children with intellectual and developmental disabilities did not live with them, in part as a result of having experienced a longer period of caregiving demands and currently having ongoing daily caregiving responsibilities. Specifically, we expected that these circumstances would accentuate the expected effects of raising a child with intellectual and developmental disabilities, such that mothers of co-residing adult children with intellectual and developmental disabilities would be less likely to be employed outside of the home and that parents of co-residing children with intellectual and developmental disabilities would have lower levels of social participation and greater physical and mental health difficulties than parents of adults with intellectual and developmental disabilities who did not live with them.

Method

Wisconsin Longitudinal Study

The WLS is composed of a random sample of 10,317 women and men who graduated from Wisconsin high schools in 1957 (Hauser, Sheridan, & Warren, 1998). Follow-up surveys were conducted in 1975 with 9,138 (90.1%) surviving members of the original sample when they were, on average, 36 years old; in 1992 with 8,493 (87.2%) of the surviving original respondents when they were in their early 50s; and again in 2004 with 7,265 (80.0%) of the surviving respondents when they were in their mid-60s. In addition, parallel data-collection procedures were conducted with one randomly selected sibling of the respondents in 1977, 1994, and 2006, with 5,823 siblings participating in one or more of these data-collection points. Family background data in 1957 and high school IQ scores were available for both the respondents and their randomly selected siblings. Data from three of the four rounds of data collection (1957, 1992–1994, and 2004–2006) were used in the present analyses. The 1992–1994 and 2004–2006 points were conceptualized as the parents’ midlife and the early years of old age, respectively.

Participants

To be included in the present analysis, parents in both the intellectual and developmental disabilities and the comparison groups had to have participated in both the 1992–1994 and 2004–2006 surveys. Parents of individuals with intellectual and developmental disabilities were identified through a series of screener questions asked of all parents during the 2004–2006 survey. The screener consisted of a maximum of 31 questions that began by asking parents if any of their children (living or deceased) had an intellectual or developmental disability and the specific diagnosis. If the parent indicated that the son or daughter had a specific intellectual and developmental disabilities condition (e.g., Down syndrome, fragile X syndrome, autism spectrum disorder), or used terms such as developmental disability, mental retardation, or cognitive disability, he or she was included in the intellectual and developmental disabilities sample. In 12 cases (5.4%), the parent did not know the specific diagnosis given to his or her child, but indicated that the child had difficulties in school. In such cases, branching follow-up questions asked if the child was below-average in intelligence, attended special education classes, and/or had difficulty performing activities of daily living (ADLs). If so, he or she was included in the intellectual and developmental disabilities group. In addition, when a parent indicated that the child had epilepsy or seizures, the question about intelligence was asked, and only if the epilepsy was accompanied by below-average intelligence was the child included in the intellectual and developmental disabilities sample. A total of 220 WLS respondents who met inclusion criteria for the present study had children with intellectual and developmental disabilities conditions out of a total of 28,305 biological or adopted children in the WLS. This translates into a prevalence of intellectual and developmental disabilities of nearly 1% (0.8%).

Parents in the comparison group met the following criteria: None of their children had an
intellectual and developmental disability or a mental health condition or required ongoing care for a chronic health problem. In addition, none of the parents in any of the groups had experienced the death of a child. To take full advantage of the WLS data and to obtain the best estimates of the effect of having a child with intellectual and developmental disabilities, instead of selecting one comparison-group case for each individual with intellectual and developmental disabilities, we selected at a ratio of 5:1, resulting in 1,100 potential comparison-group cases.

These 1,320 respondents in the intellectual and developmental disabilities or comparison groups included 58 sibling pairs. To avoid the dependence in the data that could have emanated from the inclusion of sibling pairs in the analysis, one member of each sibling pair was dropped from the analysis. In cases where one sibling had a child with intellectual and developmental disabilities and the other did not \( (n = 10 \text{ pairs}) \), we selected the respondent who had a child with intellectual and developmental disabilities for inclusion in the sample, to maximize the size of that group. In cases where both siblings were in the comparison group \( (n = 48 \text{ pairs}) \), one member of each pair was randomly selected for inclusion in our sample.

Thus, participants in the present analysis were 220 WLS respondents (112 men and 108 women), drawn from both the original and sibling samples, who became parents of individuals with intellectual and developmental disabilities, and 1,042 WLS respondents (533 men and 509 women) who had children without chronic health problems or disabilities and who constituted the comparison group. Note that these men and women were not married to each other (i.e., the unit of analysis was the individual WLS respondent, about half of whom were men [fathers] and half women [mothers]).

Of the 220 adult children with intellectual and developmental disabilities conditions, 28 had cerebral palsy, 28 had an autism spectrum disorder, 25 had Down syndrome, 47 had a variety of other specific intellectual and developmental disability diagnoses or conditions, and 92 had an intellectual and developmental disability of unspecified cause (generally, these parents said that their child had mental retardation or developmental disability). There was a significant association between the son or daughter’s diagnosis and current living arrangements in 1992–1994 and in 2004–2006; adults with Down syndrome were more likely to live at home with their parents than the other adults with other intellectual and developmental disabilities, \( \chi^2(4, N = 220) = 16.15, \quad p < .01, \) for 1992–1994; and \( \chi^2(4, N = 220) = 21.31, \quad p < .001, \) for 2004–2006. Specifically, whereas more than 75% of adults with Down syndrome lived with their parents at these two time points, about 45% of the adults with the other diagnoses lived at home in 1992–1994, and between 28% and 38% of the other groups lived at home in 2004–2006.

Table 1 presents the characteristics of both groups of respondents in 1957, when they averaged 18 years of age (prior to becoming parents). We adjusted for respondents’ age in these analyses of covariance (ANCOVAs) because, whereas all of the original WLS respondents were the same age, the participants from the sibling sample varied in age. However, although the ANCOVAs were adjusted for respondent age, the unadjusted means are presented for descriptive purposes. As shown in Table 1, respondents who later had a child with intellectual and developmental disabilities had early family backgrounds that were mainly similar to comparison-group respondents; the two groups did not differ with respect to father’s education, father’s occupational socioeconomic status (SES), family income, number of siblings, and IQ. However, respondents who later had a child with intellectual and developmental disabilities grew up in communities with significantly larger sized populations than the comparison group.

In the analyses reported below, we further divided the sample of parents of grown children with intellectual and developmental disabilities into those who co-resided with their child with intellectual and developmental disabilities and those whose child lived elsewhere. The background characteristics of these two groups did not differ.

**Measures**

The measures included in this study cover three domains: (a) attainment (educational, occupational, income, marital), (b) social participation, and (c) psychological functioning and physical health. Unless otherwise specified, measures were obtained from parents at both time periods: midlife and the early years of old age.

**Attainment.** Measures of attainment included years of education, employment status \( (0 = \text{not employed}, \quad 1 = \text{employed}) \), occupational SES, the number of years in the present job, family
income, current marital status (0 = not married, 1 = married), and whether currently married to the first spouse (0 = no, 1 = yes). Occupational SES was measured using Duncan’s Socio-Economic Index (Stevens & Featherman, 1981), which is a weighted composite of occupational and educational attainment. Scores ranged from 4.10 to 92.30; higher scores indicate higher SES (e.g., a score of 75 indicates a professional job, a score of 57 is associated with a manager or official, a score of 17 indicates a service worker). Years of education, occupational SES, and number of years in the present job were reported for the 1992–1994 point of data collection only, because education remained stable between midlife and old age and because by 2004–2006, approximately half of the sample had retired and the occupational status and stability variables were no longer relevant.

Social participation. Measures of social participation included the number of organizations in which the respondent was a member (endorsed from a list of 17 organizations), the number of visits in the past 4 weeks with friends and relatives, and a measure of emotional support. The measure of emotional support asked whether the respondent had a confidante (i.e., a friend “with whom you can really share your very private feelings and concerns” [0 = no, 1 = yes]).

Psychological functioning and physical health. Depression 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). For each of 20 depression symptoms, 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 = never, 1 = 1–2 days, 2 = 3–4 days, and 3 = 5–7 days), consistent with the conventional scoring of the CES-D. The total score was the sum of the ratings for the 20 items (zfs = .85 for both the 1992–1994 and 2004–2006 rounds of data collection), with higher scores indicating more depression symptoms. A score of 16 or greater indicates the risk of clinical depression.

In addition, a modified version of Ryff’s Psychological Well-Being Measure (Ryff, 1989) was available, covering six dimensions of well being: Self-Acceptance, Positive Relations With Others, Autonomy, Environmental Mastery, Purpose in Life, and Personal Growth. All subscales
consisted of three items, which were the same across both the 1992–1994 and 2004–2006 rounds of data collection. Each item was rated on a scale of 1 to 6 (1 = agree strongly to 6 = disagree strongly). For the present analyses, the items were reverse coded so that a higher score reflected higher levels of well being. Next, each subscale was averaged to obtain a subscale score, and the six subscale scores were summed for an overall well-being score (z = .89 for both the 1992–1994 and 2004–2006 rounds of data collection).

Measures of physical health included self-rated health (measured on a 5-point scale ranging from 1 = very poor to 5 = excellent); body mass index (BMI), measured as (weight in pounds ÷ height in inches$^2$); and self-reports of somatic symptoms, consisting of musculoskeletal problems (muscle ache, stiff–swollen joints, back pain–strain, and diagnosed serious back trouble), and cardiovascular problems (including chest pain and shortness of breath). The sensitivity of these latter two health measures to life stress was supported by earlier research that demonstrated that, in midlife, both musculoskeletal and cardiovascular problems were associated with low socioeconomic status and job stress (Warren, Hoonakker, Carayon, & Brand, 2004), and cardiovascular problems were related to the experience of child death (Rogers et al., 2008).

Limitations in activities of daily living (ranging from 0 to 6), measured only in 2004–2006, were assessed by difficulties with (a) bathing or dressing; (b) climbing stairs; (c) bending, kneeling, stooping; (d) lifting or carrying groceries, (e) moving around, moderate physical activity, and (f) vigorous physical activity.

Health-related quality of life (HRQoL) was measured in 2004–2006 by the Health Utilities Index Mark 3 (HUI-3; Feeny, Furlong, Boyle, & Torrance, 1995). This is a multidimensional self-report measure of overall health status (Boyle et al., 1995; Feeny et al., 2002; Feeny, Huguet, McFarland, & Kaplan, 2009; Maddigan, Feeny, Majumdar, Farris, & Johnson, 2006), and the measure has been used extensively in national population health studies (Feeny, Furlong, Boyle, & Torrance, 1995; Fryback et al., 2007; Kaplan et al., 2008; Robert et al., 2009).

Co-residence status. We divided the group of parents of individuals with intellectual and developmental disabilities into those whose son or daughter continued to live with the parent respondent and those whose son or daughter lived away from the respondent’s home. At midlife (1992–1994), 51% of the sons and daughters with intellectual and developmental disabilities lived at home, and by the early years of old age (2004–2006) the rate of co-residence was 39%. Patterns of co-residence were complex, because some of the sons and daughters with intellectual and developmental disabilities moved away from home between 1992–1994 and 2004–2006, and a few moved back. Thus, the composition of the co-resident and non–co-resident groups differed at the two time points. Note that when we refer to co-residence or living at home, we are referring to the son or daughter with intellectual and developmental disabilities living in the home of the WLS respondent parent.

In contrast, co-residence of the child with the parent was rare in the comparison group, with rates of 15% and 2% at the two time periods, respectively. According to our selection criteria, these adult children who lived at home did not have disabilities and did not receive care from their parents. Because of the relatively low rates of co-residence in this group, we did not separate co-resident and non–co-resident families in the comparison group.

Data Analysis

Two approaches were used to compare the three groups (parents of co-residing adults with intellectual and developmental disabilities, parents whose adult child with intellectual and developmental disabilities moved away from home between 1992–1994 and 2004–2006, and parents whose adult child with intellectual and developmental disabilities lived at home between 1992–1994). Each attribute is assessed by five or six levels of health status or functionality. For example, vision is evaluated from Level 1 (able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street) to Level 6 (unable to see at all). Emotion is assessed from Level 1 (happy and interested in life) to Level 5 (so unhappy that life is not worthwhile). Corresponding weights are assigned to each level of each attribute by a standardized scoring system, resulting in a multiattribute summary HUI-3 score (see Feeny et al., 2002), ranging from 0 to 1, where 0 means poorest health status and 1 means perfect health. The test–retest reliability and predictive as well as construct validities of the HUI-3 have been demonstrated in many studies (Boyle et al., 1995; Feeny et al., 2002; Feeny, Huguet, McFarland, & Kaplan, 2009; Maddigan, Feeny, Majumdar, Farris, & Johnson, 2006), and the measure has been used extensively in national population health studies (Feeny, Furlong, Boyle, & Torrance, 1995; Fryback et al., 2007; Kaplan et al., 2008; Robert et al., 2009).
developmental disabilities lived elsewhere, and parents in the comparison group). Logistic regression was used to test group differences with respect to dichotomous variables (employment status, marital status, whether the respondent was still married to the first spouse, and whether the respondent had a confidante). ANCOVAs were used to test group differences on the remaining continuous variables. Post hoc tests were used if the overall test statistic was significant; these post hoc tests contrasted (a) co-residing intellectual and developmental disabilities group versus the comparison group, (b) non–co-residing intellectual and developmental disabilities group versus the comparison groups, and (c) co-residing intellectual and developmental disabilities group versus non–co-residing intellectual and developmental disabilities group. In all of these analyses, gender (mothers vs. fathers) was entered as a factor—because of the known pattern of gender differences in the key dependent variables (e.g., employment, income, depression symptoms, health). However, because the main effect of gender was not the focus of our hypotheses, gender effects are included in the tables but not discussed in the text. We tested Parental Status × Gender interaction effects for all variables; only two effects were significant, and these effects are described in the text and noted as footnotes to the tables. Respondents’ age was controlled in the logistic regressions and the ANCOVAs because, whereas all of the original WLS respondents were the same age, participants from the sibling sample varied in age.

Although the design of the WLS was longitudinal, we were unable to use a repeated measures approach in these analyses because some measures (e.g., occupational SES, number of years in present job, ADLs, and HRQoL) were available or pertinent only at one of these time periods and because, as noted, the composition of the co-residing and non–co-residing groups changed from 1992–1994 to 2004–2006.

Cohen’s $d$ (Cohen, 1992) was used to calculate effect size for all significant differences in ordinal or interval level variables, and odds ratios were calculated for dichotomous variables. Effect sizes and odds ratios are reported in the text. The formula for calculating Cohen’s $d$ is $[M_1 - M_2]/[(SD_1 + SD_2)/2]$, where $M$ is the mean of each group and $SD$ is the standard deviation of each group. Cohen defines a small effect as $.2–.3$, a medium effect as approximately $.5$, and a large effect as $.8$ or higher.

Results

Patterns of Attainment

Table 2 presents data regarding patterns of attainment (educational, occupational, income, marital) in 1992–1994 (the midlife period). Unadjusted means are presented in the table for six subgroups (mothers and fathers of co-residing adults with intellectual and developmental disabilities, mothers and fathers of non–co-residing adults with intellectual and developmental disabilities, and mothers and fathers in the comparison group). As shown in Table 2, midlife parents of grown children with intellectual and developmental disabilities, whether co-residing or not, did not differ from the comparison group in the number of years of education they completed (approximately 14), employment status (approximately 80% were employed), or the number of years they were employed in their present job (approximately 12–13). Unexpectedly, parents whose adult child with intellectual and developmental disabilities continued to live at home had significantly lower levels of occupational SES than those whose adult child with intellectual and developmental disabilities lived elsewhere (effect size = .36) or than the comparison group (effect size = .27). This finding differed from our hypothesis of divergent patterns for mothers and fathers. There also was a significant difference in income, with midlife parents of co-residing grown children with intellectual and developmental disabilities earning significantly lower annual incomes (annual income $\sim$ $44,000$) than those whose adult child with intellectual and developmental disabilities lived elsewhere (effect size = .25).

Although parents of children with intellectual and developmental disabilities (co-resident and non–co-resident) and parents in the comparison group did not differ in marital status in midlife (>80% of all three groups were currently married), there was a significant difference in the proportion still married to their first spouse. Respondents who did not co-reside with their son or daughter with intellectual and developmental disabilities differed significantly from both the comparison group (odds ratio = .50) and from parents with co-resident adult children with intellectual and developmental disabilities (odds ratio = .43). Whereas about three fourths of the midlife parents in the comparison group and of those whose son or daughter with intellectual and developmental disabilities co-resided were still married to their first
Table 2. Patterns of Attainment in Midlife (1992–1994)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Intellectual and developmental disabilities/ co-residing group</th>
<th>Intellectual and developmental disabilities/ non–co-residing group</th>
<th>Comparison group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men (n = 54)</td>
<td>Women (n = 59)</td>
<td>Total (n = 113)</td>
</tr>
<tr>
<td>Years of education</td>
<td>14.6 (3.0)</td>
<td>13.0 (1.6)</td>
<td>13.8 (2.5)</td>
</tr>
<tr>
<td>Employment status (1 = employed)</td>
<td>.92 (.27)</td>
<td>.69 (.47)</td>
<td>.81 (.39)</td>
</tr>
<tr>
<td>Occupational SES</td>
<td>54.2 (24.6)</td>
<td>42.8 (21.0)</td>
<td>48.9 (23.5)</td>
</tr>
<tr>
<td>Years in present job</td>
<td>14.1 (10.3)</td>
<td>11.2 (9.1)</td>
<td>12.6 (9.8)</td>
</tr>
<tr>
<td>Income</td>
<td>$58,700</td>
<td>$33,000</td>
<td>$44,435</td>
</tr>
<tr>
<td>Marital status (1 = married)</td>
<td>.96 (.19)</td>
<td>.82 (.39)</td>
<td>.89 (.31)</td>
</tr>
<tr>
<td>Still married to the first spouse (1 = yes)</td>
<td>.85 (.36)</td>
<td>.69 (.47)</td>
<td>.78 (.42)</td>
</tr>
</tbody>
</table>

Note. The covariate was age of the respondent. Means are presented with $SD$s in parentheses. Means for dichotomous variables are proportions. The median incomes are reported in the table, although the $F$ ratios were based on the natural log of mean income. For the group differences, $F$ was presented for continuous variables and chi square was presented for dichotomous variables.

$^a$Significant difference between the co-residing IDD and comparison groups. $^b$Significant difference between the non–co-residing IDD and comparison groups. $^c$Significant difference between the co-residing IDD and non–co-residing IDD groups.

$p < .05$. **$p < .01$. ***$p < .001$. 
spouse; only about half of the parents whose son or daughter with intellectual and developmental disabilities was living away from home were still married to their first spouse. Thus, it was not marital status but rather marital stability that differentiated the groups.

We further explored this difference in marital stability to determine whether it reflected divorce or widowhood, and we found that there was an elevated rate of both divorce and widowhood in midlife among those whose son or daughter with intellectual and developmental disabilities had moved away from the respondent’s home, \( \chi^2(4, N = 1,201) = 20.64, p < .001 \). Nearly one third (33.0%) of this group was divorced from the other biological parent of the son or daughter with intellectual and developmental disabilities, and 6.8% had experienced the death of the other biological parent. In contrast, the rates for the co-resident parents of adult children with intellectual and developmental disabilities were 13.6% divorced and 5.5% widowed, and, for the comparison group, the rates were 20.0% divorced and 2.7% widowed.

Table 3 presents group comparisons in patterns of employment and marital status in 2004-2006, the early years of old age for these parents. When they were in their mid-60s, only about half of the sample members were still employed, and parents of grown children with intellectual and developmental disabilities had levels of employment and incomes that did not differ from the comparison group. Similar to patterns already evident in midlife, current marital status did not differ among the three groups; however, respondents whose grown children with intellectual and developmental disabilities lived away from home were about half as likely (odd ratio = .54) to be married to their first spouse than parents in the comparison group and about 60% less likely (odds ratio = .39) to be married to their first spouse as parents co-residing with their adult children with intellectual and developmental disabilities. Again, the probability of being divorced (32.3%) and widowed (12.8%) was considerably higher in this group of parents than the other two groups, \( \chi^2(4, N = 1,201) = 21.00, p < .001 \).

Thus, parents of grown children with intellectual and developmental disabilities showed normative profiles with respect to their level of education, employment status, and marital status in midlife and the early years of old age. However, in midlife, those who were co-residing had substantially lower incomes than the comparison group and those whose son or daughter lived elsewhere had higher occupational SES. By the early years of old age, the income differences were no longer evident, likely reflecting retirement of about half of all sample members. The most notable differences at both midlife and the early years of old age in this sample were in the realm of marital stability, particularly among parents whose grown children with intellectual and developmental disabilities no longer lived at home with them; these parents were considerably more likely to be divorced from the other biological parent of the child with intellectual and developmental disabilities and also more likely to have experienced the death of the other biological parent than the other two groups.

### Social Participation

Table 4 summarizes data for social participation in midlife. The patterns of social participation of parents of children with intellectual and developmental disabilities in midlife were similar to the comparison group with respect to the number of organizations to which parents belonged, the frequency of visits with friends and relatives, and their likelihood of having a confidante.

Table 5 presents the social participation comparisons reflecting the early years of old age for these parents. At this stage of life, parents of grown children with intellectual and developmental disabilities did not differ from the comparison group in the number of organizations to which they belonged. However, parents of co-residing grown children with intellectual and developmental disabilities were considerably less likely to visit with friends and relatives during the past month than the comparison group (effect size = .53). In addition, parents of non-co-residing adults with intellectual and developmental disabilities were considerably less likely to report having a confidante than comparison-group parents (odds ratio = .58) or than parents of co-residing adult children with intellectual and developmental disabilities (odds ratio = .49).

Thus, with respect to life-course patterns of social participation, parents of grown children with intellectual and developmental disabilities were similar in most respects to the general population during midlife, but by the early years of old age those whose son or daughter with
Table 3. Patterns of Attainment During the Early Years of Old Age (2004–2006)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intellectual and developmental disabilities/ co-residing group</th>
<th>Intellectual and developmental disabilities/ non–co-residing group</th>
<th>Comparison group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men (n = 40)</td>
<td>Women (n = 45)</td>
<td>Total (n = 85)</td>
</tr>
<tr>
<td>Employment status (1 = employed)</td>
<td>.55 (.50)</td>
<td>.38 (.49)</td>
<td>.46 (.50)</td>
</tr>
<tr>
<td>Income</td>
<td>$75,300</td>
<td>$25,400</td>
<td>$50,770</td>
</tr>
<tr>
<td>Marital status (1 = married)</td>
<td>.98 (.16)</td>
<td>.76 (.43)</td>
<td>.86 (.35)</td>
</tr>
<tr>
<td>Still married to the first spouse (1 = yes)</td>
<td>.85 (.36)</td>
<td>.67 (.48)</td>
<td>.75 (.43)</td>
</tr>
</tbody>
</table>

Note. The covariate was age of the respondent. Means are presented with SDs in parentheses. Means for dichotomous variables are proportions. The median incomes are reported in the table, although the F ratios were based on the natural log of mean income. For the group differences, F was presented for continuous variables and chi square was presented for dichotomous variables.

*Significant difference between the non–co-residing intellectual and developmental disabilities and comparison groups. **Significant difference between the co-residing intellectual and developmental disabilities and non–co-residing intellectual and developmental disabilities groups.

*p < .05. **p < .01. ***p < .001.
Table 4. Patterns of Social Participation in Midlife (1992–1994)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intellectual and developmental disabilities/ co-residing group</th>
<th>Intellectual and developmental disabilities/ non–co-residing group</th>
<th>Comparison group</th>
<th>Parent status</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men (n = 54)</td>
<td>Women (n = 59)</td>
<td>Total (n = 113)</td>
<td>Men (n = 58)</td>
<td>Women (n = 49)</td>
</tr>
<tr>
<td>No. of organizations</td>
<td>4.0 (2.4)</td>
<td>4.0 (3.1)</td>
<td>4.0 (2.8)</td>
<td>4.8 (2.8)</td>
<td>3.4 (2.4)</td>
</tr>
<tr>
<td>No. of visits with friends and relatives/ 4 weeks</td>
<td>5.6 (4.9)</td>
<td>7.3 (4.6)</td>
<td>6.4 (4.8)</td>
<td>5.4 (3.5)</td>
<td>7.4 (7.4)</td>
</tr>
<tr>
<td>Having confidante (1 = yes)</td>
<td>.61 (.49)</td>
<td>.76 (.43)</td>
<td>.68 (.47)</td>
<td>.70 (.46)</td>
<td>.88 (.33)</td>
</tr>
</tbody>
</table>

Note. The covariate was age of the respondents. Means are presented with SDs in parentheses. Means for dichotomous variables are proportions. For the group differences, F was presented for continuous variables and chi square was presented for dichotomous variables. **p < .01. ***p < .001.
Table 5. Patterns of Social Participation During the Early Years of Old Age (2004–2006)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intellectual and developmental disabilities/co-residing group</th>
<th>Intellectual and developmental disabilities/non–co-residing group</th>
<th>Comparison group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men</td>
<td>Women</td>
<td>Total</td>
</tr>
<tr>
<td>No. of organizations</td>
<td>3.6</td>
<td>2.7</td>
<td>3.1</td>
</tr>
<tr>
<td>No. of visits with friends and relatives/4 weeks</td>
<td>3.9</td>
<td>4.9</td>
<td>4.3</td>
</tr>
<tr>
<td>Having a confidante (1 = yes)</td>
<td>.65</td>
<td>.84</td>
<td>.74</td>
</tr>
</tbody>
</table>

Note. The covariate was age of the respondents. Means are presented with SD in parentheses. Means for dichotomous variables are proportions. For the group differences, F was presented for continuous variables and chi square was presented for dichotomous variables.

*Significant difference between the co-residing intellectual and developmental disabilities and comparison groups. **Significant difference between the non–co-residing intellectual and developmental disabilities and comparison groups. ***Significant difference between the co-residing intellectual and developmental disabilities and non–co-residing intellectual and developmental disabilities groups.

*p < .05. **p < .01. ***p < .001.
intellectual and developmental disabilities still lived at home visited with friends and family less frequently than the comparison group and those whose son or daughter lived away from home were less likely to have a confidante than either the co-residing intellectual and developmental disabilities group or the comparison group.

**Psychological Functioning and Health Outcomes**

As shown in Table 6, with respect to psychological functioning, midlife parents of children with intellectual and developmental disabilities did not differ from the comparison group in depression symptoms or psychological well being, regardless of whether their son or daughter with intellectual and developmental disabilities lived at home or elsewhere.

Regarding physical health in midlife, the groups did not differ in self-rated health or in their number of musculoskeletal problems. However, there was a significant Parent Status × Gender interaction effect in BMI in midlife, with mothers of co-residing adult children having significantly higher BMIs than fathers in this group; in contrast, for parents of adults with intellectual and developmental disabilities who lived away from home and for the comparison group, fathers had higher BMIs than mothers (effect size = .24). The groups also differed significantly in cardiovascular problems in midlife, with parents of co-residing grown children with intellectual and developmental disabilities having higher rates of such problems than the comparison group (effect size = .24).

However, by the early years of old age, parents of children with intellectual and developmental disabilities had a greater number of health and mental health difficulties (see Table 7). Specifically, parents of co-residing adult children with intellectual and developmental disabilities had higher levels of depressive symptoms than the comparison group (effect size = .30). However, parents of children with intellectual and developmental disabilities (co-residing or not) did not differ from the comparison group in the measure of positive psychological well being.

In the early years of old age, parents of adult children with intellectual and developmental disabilities had health problems and functional impairments that set them apart from the comparison group. There was a significant Parent Status × Gender interaction effect for self-rated health, \(F = 4.65, p < .01\), which indicated that, although there was no mother-father difference in self-rated health in the comparison group or the co-residing intellectual and developmental disabilities group, mothers of grown children with intellectual and developmental disabilities who lived away from home were more likely to perceive that their health was compromised relative to fathers of such children. In addition, co-residing parents of adults with intellectual and developmental disabilities had elevated BMIs relative to both the comparison group (effect size = .35) and to parents whose adult child with intellectual and developmental disabilities lived elsewhere (effect size = .34); the average BMI score of 30 for the group of co-residing parents signified obesity, placing them at higher risk for poor health.

Aging parents of grown children with intellectual and developmental disabilities did not differ from the comparison group with respect to their likelihood of having cardiovascular problems. However, there was a significant difference in musculoskeletal problems, although the post hoc test was not significant. In addition, the three groups differed significantly with respect to limitations in ADLs. Parents of co-residing adult children with intellectual and developmental disabilities had more limitations in ADLs than the comparison group (effect size = .32). Furthermore, both groups of parents of adult children with intellectual and developmental disabilities had significantly poorer HRQoL than comparison-group parents (effect size for co-residing intellectual and developmental disabilities vs. comparison group = .40; effect size for not co-residing intellectual and developmental disabilities vs. comparison group = .24).

**Discussion**

The present study extends our understanding of the life-course patterns of attainment, social participation, psychological functioning, and health in parents of individuals with intellectual and developmental disabilities. In our prior analysis of a subset of the parents in the present study in which we focused on functioning in midlife (Seltzer et al., 2001), we concluded that midlife parents of individuals with intellectual and developmental disabilities were similar in general to their counterparts who did not have a child with a disability, with largely comparable general patterns of attainment, psychological well being, and health.
Table 6. Patterns of Psychological Functioning and Health Outcomes in Midlife (1992–1994)

<table>
<thead>
<tr>
<th></th>
<th>Intellectual and developmental disabilities/ co-residing group</th>
<th>Intellectual and developmental disabilities/non–co-residing group</th>
<th>Comparison group</th>
<th>Parent status F</th>
<th>Gender F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
<td>Men (n = 54) Women (n = 59) Total (n = 113)</td>
<td>Men (n = 58) Women (n = 49) Total (n = 107)</td>
<td>Men (n = 533) Women (n = 509) Total (n = 1,042)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>7.2 (6.3) 9.6 (8.8) 8.1 (7.6)</td>
<td>8.8 (8.2) 9.5 (7.6) 9.2 (7.8)</td>
<td>7.7 (6.7) 8.5 (7.4) 8.1 (7.1)</td>
<td>1.1</td>
<td>4.81*</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>29.1 (4.1) 29.0 (4.3) 29.2 (4.2)</td>
<td>29.3 (4.0) 29.5 (4.2) 29.3 (4.1)</td>
<td>29.0 (4.2) 29.4 (4.2) 29.2 (4.2)</td>
<td>0.02</td>
<td>2.86</td>
</tr>
<tr>
<td>Self-rated health</td>
<td>4.1 (0.68) 4.0 (0.66) 4.1 (0.68)</td>
<td>4.3 (0.59) 4.1 (0.52) 4.2 (0.57)</td>
<td>4.2 (0.63) 4.2 (0.64) 4.2 (0.64)</td>
<td>0.36</td>
<td>0.26</td>
</tr>
<tr>
<td>BMI</td>
<td>27.7 (4.8) 28.3 (6.1) 27.9 (5.4)</td>
<td>27.1 (3.4) 26.6 (4.3) 26.8 (3.8)</td>
<td>27.5 (3.9) 25.8 (4.9) 26.7 (4.5)</td>
<td>3.44**a</td>
<td>27.82***</td>
</tr>
<tr>
<td>Musculoskeletal condition (0–4)</td>
<td>0.78 (0.98) 0.89 (1.1) 0.81 (1.0)</td>
<td>0.49 (0.88) 1.0 (1.2) 0.73 (1.1)</td>
<td>0.59 (0.94) 0.69 (1.0) 0.64 (0.99)</td>
<td>1.97</td>
<td>5.39*</td>
</tr>
<tr>
<td>Cardiovascular impairment (0–2)</td>
<td>.13 (.44) .18 (.50) .15 (.46)</td>
<td>.13 (.33) .12 (.33) .12 (.33)</td>
<td>.07 (.30) .06 (.25) .06 (.27)</td>
<td>5.19**a</td>
<td>0.12</td>
</tr>
</tbody>
</table>

Note. The covariate was age of the respondents. Means are presented with SD in parentheses.

* p < .05, ** p < .01, *** p < .001.

a Significant difference between the co-residing IDD and comparison groups. 

Significant Parent Status × Gender interaction effect (F = 3.50, p < .05).
Table 7. Patterns of Psychological Functioning and Health Outcomes During the Early Years of Old Age (2004–2006)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intellectual and developmental disabilities/co-residing group</th>
<th>Intellectual and developmental disabilities/non–co-residing group</th>
<th>Comparison group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men</td>
<td>Women</td>
<td>Total</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>7.5 (7.3)</td>
<td>10.2 (10.2)</td>
<td>8.8 (8.8)</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>27.9 (4.0)</td>
<td>27.6 (4.9)</td>
<td>27.7 (4.4)</td>
</tr>
<tr>
<td>Self-rated health&lt;sup&gt;d&lt;/sup&gt;</td>
<td>3.8 (0.70)</td>
<td>3.7 (0.93)</td>
<td>3.8 (0.83)</td>
</tr>
<tr>
<td>BMI</td>
<td>29.6 (6.1)</td>
<td>30.4 (8.1)</td>
<td>29.9 (7.0)</td>
</tr>
<tr>
<td>Musculoskeletal condition (0–4)</td>
<td>2.0 (1.2)</td>
<td>2.3 (1.1)</td>
<td>2.1 (1.1)</td>
</tr>
<tr>
<td>Cardiovascular impairment (0–2)</td>
<td>.50 (.65)</td>
<td>.43 (.74)</td>
<td>.47 (.69)</td>
</tr>
<tr>
<td>ADL limitations (1–6)</td>
<td>2.4 (1.9)</td>
<td>2.8 (1.9)</td>
<td>2.6 (1.9)</td>
</tr>
<tr>
<td>Health-related quality of life</td>
<td>.78 (.24)</td>
<td>.72 (.28)</td>
<td>.75 (.26)</td>
</tr>
</tbody>
</table>

Note. BMI = body mass index. ADL = activities of daily living. The covariate was age of the respondents. Means are presented with SDs in parentheses.  
<sup>a</sup>Significant difference between the co-residing intellectual and developmental disabilities and comparison groups.  
<sup>b</sup>Significant difference between the non–co-residing intellectual and developmental disabilities and comparison groups.  
<sup>c</sup>Significant difference between the co-residing intellectual and developmental disabilities and non–co-residing intellectual and developmental disabilities groups.  
<sup>d</sup>Significant Parent Status × Gender interaction effect, F = 4.65, p < .01.  
<sup>*p < .05.  **p < .01.  ***p < .001.  

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and more circumscribed differences in social participation and employment patterns. The present analysis doubles the sample size of WLS parents with a child with intellectual and developmental disabilities (due to better ascertainment), adds another point of measurement approximately 12 years after the midlife assessment, and reveals new difficulties, notably poorer health and functional abilities, that only became evident in early old age.

At the most recent point of data collection, the parents were in their mid-60s. In contrast to our hypotheses, at this stage of life, parents of adult children with intellectual and developmental disabilities continued to manifest normative rates of employment and retirement. However, in agreement with our predictions, in the early years of old age there was less social involvement among those whose child remained living at home (less frequent contact with friends and relatives) and less emotional support from a confidante among those whose son or daughter lived away from home. Furthermore, although parents of adult children with intellectual and developmental disabilities were just as likely to be married in midlife and the early years of old age as their counterparts whose children do not have disabilities, more fine-grained analyses revealed differences in parental marital stability, with a lower likelihood of being married to the first spouse among those respondents whose adult child no longer lived at home. There were elevated rates of both divorce and widowhood among respondents whose son or daughter lived away from home when the parents were in their mid-60s.

Although it is not possible to determine the causal order of family life events from the present data, one interpretation is that single parenthood due to divorce or widowhood may be a factor propelling the move of the son or daughter with intellectual and developmental disabilities out of the parental home. However, it is certainly possible that, in some cases of divorce in which the adult child no longer lived with the parent respondent, he or she was still living with the other biological parent (i.e., the former spouse of the WLS respondent). It is also possible that some parents are willing to consider and pursue divorce only after the child with a disability is being cared for in a setting out of their home. Unfortunately, detailed data on residential arrangements and the relative timing of launching and marital disruption were not available on all cases where the adult lived away from the parent respondent, so these remain questions for future life-course research.

Although there was no evidence of divergent mental health patterns in midlife, by the early years of old age parents of co-resident individuals with intellectual and developmental disabilities showed significant elevations in depression symptoms relative to the comparison group. Thus, long-term co-residence may take a toll on parental psychological functioning, evident only after parents reach the early years of old age. Perhaps as parents grapple with the need to plan for their adult child’s long-term future, beyond the time when they can be the primary caregivers or overseers of their son or daughter’s services and care, and as they struggle with their own functional limitations, they become vulnerable to feelings of depression that were not problematic in midlife.

However, the most prominent profile of life-course divergence from the normative pattern was in the domain of parental health. In midlife, parents of coresiding individuals with intellectual and developmental disabilities were more likely to be overweight and had a greater likelihood of cardiovascular impairments, but, otherwise, they did not appear to be at elevated risk for poorer health. However, by the early years of old age, there was evidence of more pervasive health impacts, indicated by continued likelihood of being overweight, poorer self-rated health (among mothers whose adult child lived away from home, relative to fathers), more musculoskeletal conditions, and more impaired daily functioning and poorer HRQoL.

Thus, our earlier conclusion that parents of individuals with intellectual and developmental disabilities showed a pattern of outcomes similar to their counterparts who did not have a child with intellectual and developmental disabilities is an accurate assessment through midlife. However, a decade later, these parents had elevated rates of depressive symptoms, divorce, widowhood, poorer physical health, and functional impairments. These findings underscore the need for a life-course perspective to fully understand the impacts of parenting a child with intellectual and developmental disabilities. Past research, mainly conducted at earlier stages of the life course, has presented a more dichotomous set of conclusions, either landing on the side of vulnerability (e.g., Ha et al., 2008; Singer, 2006) or resiliency (e.g., Costigan, Floyd, Harter, & McClinton, 1997). However, the results of the present study suggest
that the profile is more nuanced, depending on
the stage of the life course, the living arrangement
of the adult child, and the particular indicator of
parental functioning. The cumulative effects of
parenting may take decades to be manifested. A
recent study by Yamaki, Hsieh, and Heller (2009)
agreed with these findings. These investigators
reported elevated health problems among family
caregivers of co-resident adults with intellectual
and developmental disabilities, both in midlife
and in old age, and symptoms worsened from
midlife to old age.

The prevalence of co-residence among adults
with intellectual and developmental disabilities
when the parents were in their 60s was notable
(39% still lived at home). Examination of the
specific diagnoses of the adults who continued to
live at home versus those who did not live with
their parents at this stage of life revealed that
adults with Down syndrome were considerably
more likely to live at home than adults with
autism spectrum disorders, cerebral palsy, or other
intellectual and developmental disability condi-
tions. Past research has also shown higher rates of
co-residence in adults with Down syndrome than
adults with autism spectrum disorders (e.g., Esbensen,
Bishop, Seltzer, Greenberg, & Taylor, 2010), and
our findings are consistent in this respect.

Some researchers have attributed this differ-
ence in co-residence to the lower level of parent-
ing stress experienced by parents of children with
Down syndrome than autism spectrum disorders
(Esbensen & Seltzer, 2011). However, our findings
did not suggest that parents of co-residing adult
children had less distress in their lives. Although
those whose adult son or daughter lived elsewhere
had lower levels of marital stability, the profile of
vulnerability among parents whose adult child
continued to live at home was pronounced; these
parents had significantly more depression, less
frequent visits with friends and family, greater
obesity, greater functional impairments, and poorer
HRQoL. Thus, the preponderance of adults with
Down syndrome among those who continued to
live at home versus those who lived elsewhere
probably did not account for the differences in
parents’ profiles of vulnerability in the early years of
old age; continued co-residence and daily caregiv-
ing may be a more parsimonious explanation.

The present pattern of findings regarding
poorer health profiles of parents of adult children
with intellectual and developmental disabilities
points to the need for future research that can
investigate the mechanisms by which these diver-
gent health profiles arise. There are many possible
psychological and physiological mechanisms that
warrant investigation. One possible mechanism,
based on findings from other studies of midlife
parents of adults with disabilities, is disregulated
cortisol levels (Hartley et al., 2010; Seltzer et al.,
2009, 2010). It is possible that biomarkers of stress,
such as salivary cortisol, are early indicators of the
impact of parenting a child with intellectual and
developmental disabilities, but it may take until
the early years of old age for such biomarkers to
manifest in health problems and functional limi-
tations. Of course, other mechanisms warrant inves-
tigation in future research, as we seek to understand
the elevated risk of mental health, physical health,
and functional impairments of parents of adults
with intellectual and developmental disabilities in
the early years of old age.

The public health implications of these find-
ings suggest the need for more services, including
in-home family support and out-of-home respite
care for individuals with intellectual and develop-
mental disabilities. That more than one third of
adults with intellectual and developmental dis-
abilities continued to live with their parents
through the time when the parents were in their
mid-60s underscores the high probability of
continued co-residence. It is possible that earlier
investment in services and supports might extend
the capacity of older parents to continue to
provide care without a negative effect on their
own health, marital functioning, and mental
health. However, calls for such services and sup-
ports imply the need for research on how best to
meet the needs of families across the life course;
very little experimental intervention research has
been conducted that can point to specific services
that might result in less of a deleterious outcome
for parents over the long run. The parents in the
present study are from the first generation to
reach old age during the era following the elimi-
nation of institution-based services, and, hence,
they may provide a benchmark against which to
measure the impacts of subsequent expansions
and contractions of the service system.

An unexpected finding of the present study
was the lack of differential effects for mothers and
fathers of individuals with intellectual and devel-
opmental disabilities; there were only two signif-
ificant Parent Status × Gender interaction effects.
Most past research has focused on mothers, and
it has been assumed in general that the effects
of nonnormative parenting are stronger for mothers than for fathers. However, in the present population-based sample, there did not appear to be substantial differential gender differences, at least not in midlife or in old age. It is possible that this lack of difference may have been the result of the more representative sampling used in the present study than in past research or the long duration of caregiving; over time, the differential effects on mothers and fathers may diminish. This is an important question for future research.

The present study had some methodological limitations, notably the lack of racial and ethnic diversity in the sample of Wisconsin parents. In addition, parents who died before midlife were not included in this sample, nor were the parents of children who died before the 2004–2006 point of data collection. Ascertainment of respondents whose children had intellectual and developmental disabilities conditions was based on parent report. However, the series of branching questions that identified a child as having an intellectual and developmental disabilities condition was extensive, encompassing a total of 31 possible questions. We believe that the probability of false positives (i.e., a parent indicating that the child had intellectual and developmental disabilities when he or she did not have an intellectual and developmental disability condition) was very small, although false negatives remain a possibility. However, the prevalence of intellectual and developmental disabilities in the generation of children of WLS respondents was nearly 1%, which is consistent with population estimates and which bolsters confidence in the ascertainment of intellectual and developmental disabilities.

Among the strengths of the study are the long duration of the follow-up period, longer than any previous study, to our knowledge; the broad range of measures across multiple life domains; and, most important, the use of population-level data. The study’s findings indicate that in the early years of old age, the pattern of parental resilience that was evident through midlife was replaced by a more mixed profile of resilience and vulnerability. Resilience was evident with respect to participation in organizations and positive psychological well being, and they had similar patterns as their age-peers who did not have an adult child with a disability with respect to cardiovascular impairments. Vulnerability was evident by more marital disruptions, lower frequency of contact with friends and family, and greater likelihood of depression, obesity, musculoskeletal problems, and poorer HRQoL. The pattern of findings differed to some extent for parents whose adult child still lived with them and those whose adult child lived elsewhere, but both groups manifested substantial aspects of vulnerability. Ultimately, more research is needed about parenting a child with intellectual and developmental disabilities during old age. The findings of the present study call for services and supports to extend the pattern of resilience in aging parents of adults with intellectual and developmental disabilities.

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Midlife and aging parents

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