Economic Implications of Caregiving at Midlife: Comparing Parents With and Without Children Who Have Developmental Disabilities

Susan L. Parish, Marsha Mailick Seltzer, Jan S. Greenberg, and Frank Floyd

Abstract
We compared the economic well-being and maternal employment of parents whose children did or did not have developmental disabilities. This prospective study is a secondary analysis of data from the Wisconsin Longitudinal Study, collected when respondents were aged 18, 36, and 53, on average. Although the two groups were similar at age 18, income and savings differed markedly by age 53, but statistically significant differences were not found on other measures. Mothers of children with disabilities were less likely to have job spells lasting more than 5 years and had lower earnings when they were 36 years old. Further, there was a trend for them to be less likely to have full-time jobs as their children grew older.

Families comprise the largest group of caregivers for people with developmental disabilities in the United States, as 60% of Americans of all ages with such disabilities live with their families (Fujiura, 1998). Because the vast majority of public financial resources for developmental disabilities is devoted to residential services, families receive very limited financial support to care for their child with developmental disabilities (Parish, Pomeranz-Essley, & Braddock, 2003). Psychosocial consequences of parenting children with developmental disabilities have been examined in some detail (e.g., Pruchno & Patrick, 1999; Seltzer, Greenberg, Floyd, Pettée, & Hong, 2001), but these families’ long-term economic outcomes are less clear.

A great range of needs is associated with caring for children with developmental disabilities, including specialized therapies, respite care, lengthy diagnostic tests, home modifications, adaptive equipment, medication, and educational services. Supplemental Security Income payments (SSI), which are provided for individuals who meet strict income and disability eligibility criteria, are usually insufficient to cover these expenses (General Accounting Office, 1999).

Few researchers have conducted empirical studies of the economic implications of having a child with disabilities. In order to accommodate the needs of their child with disabilities, many families experience opportunity costs or forego earnings because they spend less time in paid employment. Previous researchers have only examined disability-related outlays, including attempts to estimate the incremental costs attributable to the care needs of children with disabilities in excess of the care needs of children without disabilities who are the same age (e.g., Newacheck & McManus, 1988). Others have examined the out-of-pocket costs for children with disabilities or chronic health conditions (e.g., Birenbaum, Guyot, & Cohen, 1990; Fujiura, Rocofforte, & Braddock, 1994).

However, these studies have largely been cross-sectional or have spanned short intervals. In addition, studies of the economic consequences of parenting a child with disabilities have been focused on the direct costs associated with caregiving. The effects of caregiving on other aspects of economic well-being, such as home equity, savings, and investments, have not been examined. We do not know how families respond to the added expenses of caring for their child with disabilities over the course of their life. Do parents boost employment
to meet the added expenses they incur? Or do caregiving responsibilities erode families' economic well-being?

Researchers on the economic consequences of parenting children with disabilities have focused on maternal labor force participation because fathers tend not to diverge from the norm in their employment rates (Seltzer et al., 2001). American women's employment has steadily increased since the beginning of the 20th century (Moen, 1992), and for mothers of children with no disabilities, a number of factors have influenced the extent of their workforce participation. Having either younger or a greater number of children reduces maternal employment (Connelly, 1991; Waldfogel, 1997), and women who earn higher wages have generally elevated rates of labor force participation (Blau & Robins, 1991; Connelly, 1989).

Some analysts have argued that the dual roles women occupy—mother and worker—have inherent conflicts (Moen, 1992). From the 1940s through the 1980s, as women's employment rates rose, women used three mechanisms to meet the demands of their caregiving responsibilities for their children, in addition to arranging for paid child care: reduction of their hours at their jobs, complete cessation of employment, and/or shifting to less involved or demanding work (Moen, 1992). All of these strategies result in significant reductions in women's earnings. The role conflict between mother and worker may be particularly acute for mothers of children with developmental disabilities because their child's care needs frequently extend beyond early childhood into adolescence and adulthood.

Having a child with disabilities likely has a similar effect on maternal employment as having very young children who do not have disabilities: diminished maternal workforce participation and reduced hours. Mothers have reported that the time demands associated with providing care for a child with disabilities and a lack of affordable and adequate child care limit their employment opportunities (Shearn & Todd, 2000). Caregiving demands were the most commonly cited reason for unemployment by mothers of adults with disabilities in a study by Eiman and Cuskelly (2002), who also found lower employment rates and fewer hours worked per week among employed mothers of children with disabilities (Eiman & Cuskelly, 2002). In other research, mothers of children with severe impairments reported an array of employment problems associated with their caregiving responsibilities: the need to reduce work hours, take time off from work, and change jobs. The majority of nonworking mothers of children with chronic health conditions attributed their unemployment to their child's care needs (Thyen, Kuhlthau, & Perrin, 1999).

In the earliest investigations of maternal employment when a child has disabilities, researchers used data from the 1970s, when women's employment was dramatically increasing. Between 1970 and 1990, married women with children in the United States increased their labor force participation by 27%, and participation for mothers of children under age 6 rose from 30% in 1970 to 64% in 1990 (Kamerman, 1995). In an early study, Salkever (1983) found that mothers of children with disabilities were 10% less likely to be employed than were other mothers. Other early researchers, however, found that having a child with disabilities negatively impacted maternal employment only in poor families; in high income families, mothers of children with disabilities were more likely to be employed than were mothers of children with no disabilities (Breslau, Salkever, & Staruch, 1982).

Studies conducted in the intervening decades have had similarly mixed results. Some investigators have found reduced maternal employment when a child has a disability or chronic health condition (e.g., Heck & Makuc, 2000; Kuhlthau & Perrin, 2001; Thyen et al., 1999) or reduced employment among parents of children with severe, but not moderate, disabilities (Lukemeyer, Meyers, & Smeeding, 2000; Wolfe & Hill, 1995). In contrast, in a large, nationally representative investigation of British women, Carmichael and Charles (1998) found that unpaid caregiving responsibilities actually increased the probability of employment, although the number of hours worked per week was reduced. To account for this unexpected finding, the researchers noted that the income and respite effects of employment provided strong incentives for mothers of children with disabilities to participate in the work force. Similarly, Lewis, Kagan, and Heaton (2000) noted that mothers of children with disabilities cited economic and psychological benefits associated with employment as their motivation for remaining in the paid work force. However, in another investigation no employment differences were found among mothers of children with mental retardation or
chronic illnesses and mothers of typically developing children (Walker, Ortiz-Valdes, & Newbrough, 1989). Finally, some researchers asking a somewhat different question evaluated the influence of characteristics such as education, severity of child’s disability, and maternal health and found that individual and family characteristics had stronger effects on maternal employment than whether the child had a disability (Booth & Kelly, 1999; Powers, 2001; Wolfe & Hill, 1995).

To summarize, the extant literature on maternal employment when a child has a disability has been cross-sectional; the employment of these mothers over their life course has not been examined. Several researchers have focused on employment immediately after the child’s diagnosis, but the findings cannot be generalized to other times in the women’s employment careers. Gaps in the existing research necessitate further analysis to elucidate women’s employment trajectories, particularly as they and their children grow older.

We conducted the present research to begin to bridge some of these gaps. Our two research questions were: (a) Are earnings, income, and wealth at midlife different for mothers and fathers of children with developmental disabilities than for parents of children without disabilities? (b) How does the employment trajectory compare for mothers of children with developmental disabilities and other mothers? Our analyses of these two questions were based, in part, by an economic framework. There is longstanding evidence that families are economic units. Decisions about consumption and allocation of home- and market-based production are typically shared by family members, who are interdependent (Becker, 1992; Mincer & Polacheck, 1974). For our purposes, this framework means that parents are best understood as sharing decisions and responsibilities for the care of their child with disabilities, including the employment they do or do not pursue.

Parents of children with developmental disabilities may jointly decide to forego savings, job promotions, and other opportunities to care for their child.

Thus, related to our first question, we hypothesized that cumulative measures of economic well-being, such as savings, income, home equity, and mortgage amounts, would be lower for parents of children with developmental disabilities than for parents of children with no disabilities. However, we did not expect pension participation or home ownership rates to be different. At mid-life, fathers of children with developmental disabilities have been found to have greater job stability and less job mobility than fathers of children without disabilities (Seltzer et al., 2001). These fathers’ longer tenure in their existing jobs at mid-life suggests that they accrue the requisite years of employment for pension or retirement savings plan participation. We also did not expect significant differences in home ownership rates among these groups because the cohort of adults at mid-life consists overwhelmingly of homeowners (U.S. Census Bureau, 2002).

Furthermore, for parents of a child with developmental disabilities, the costs of child care may be significantly higher than for parents of children without disabilities, which may offset, to some extent, the economic gain of maternal employment. Therefore, regarding Research Question 2, we hypothesized that mothers of children with developmental disabilities would have lower rates of employment across the life course, work fewer hours, and earn less than their counterparts with children without disabilities.

**Method**

**Wisconsin Longitudinal Study**

This study was conducted using data from the Wisconsin Longitudinal Study. The study began in 1957 with a random sample of one third of all Wisconsin high school seniors (N = 10,317). Survey data were collected from the respondents in 1957, 1975, and 1992 (Hauser & Sewell, 1985; Hauser, Sheridan, & Warren, 1998). By the 1992 wave of data collection, 87% of the surviving respondents (n = 8,493) participated in computer-assisted telephone interviews that averaged one hour in duration. Mail surveys were subsequently completed by 81% of the telephone respondents (n = 6,875).

Beginning in 1975, the Wisconsin Longitudinal Study team obtained a roster of the respondents’ siblings, and a stratified random sample of siblings (n = 2,429) was selected to participate in the study. The first sibling survey was conducted in 1977, when 2,133 of contacted siblings (88%) participated. The sibling survey contained a subset of the questions asked of original respondents. The siblings were again surveyed through telephone calls in 1994, 2 years after the original respondents’ telephone survey was conducted. In the 1994 sibling data-collection wave, 69% of the sib-
ling sample selected in 1977 participated again (n = 1,669). For the 1994 survey, study team members also attempted to contact siblings who were not surveyed in 1977, with 3,694 participating. As such, 5,363 siblings participated in the 1994 survey. In 1994, the siblings ranged in age from 35 to 67 years (mean = 53, the same as the original respondents).

**Sample**

In the present study we utilized a sample previously obtained from the Wisconsin Longitudinal Study to examine the life-course impact of parenting children with developmental disabilities or mental illness (Seltzer et al., 2001). Seltzer et al. employed a series of screening measures to identify respondents who had adult children with developmental disabilities or mental illness. The screening procedures, explained in detail in Seltzer et al. are briefly described here. Respondents whose offspring had mental illness were excluded from the present analysis.

Respondents who indicated that they had a child with a developmental disability were included in the present sample based on their response to a question about the provision of care to anyone in their household. In addition, four risk factors were used to identify other possible Wisconsin Longitudinal Study respondents: (a) having a child living in a supervised setting, such as a group home or foster care; (b) having a child with an atypical education pattern (e.g., delayed start of school, very few years of education); (c) having a child who received federal disability income transfers, such as SSI; or (d) the parental expectation, as reported in 1975/1977, that the child would not graduate from high school (Seltzer et al., 2001).

If a respondent reported any one of these risk factors, the entire interview protocol was reviewed, including margin notes made by the interviewers. Respondents were subsequently included in the sample only if they stated that their child had a developmental disability. These procedures, therefore, yielded a conservative identification of children with developmental disabilities because respondents were excluded if they had a risk factor but did not explicitly report that their child had a developmental disability. Using these procedures (Seltzer et al., 2001), we identified 165 parents of a child with developmental disabilities. A random sample of 13% of these respondents was selected for reliability checks of our sample identification procedures. These respondents were telephoned and asked a detailed set of questions regarding their child’s diagnosis and functional abilities. All 13% were confirmed as having a child with a developmental disability.

We employed stratified random sampling to select comparison parents from the Wisconsin Longitudinal Study (Seltzer et al., 2001). None of the comparison parents had children with disabilities, chronic illnesses, or any of the risk factors previously mentioned. In addition, none of the parents in either the developmental disabilities or comparison groups were siblings of each other. The comparison group was stratified by respondent’s gender and sibling/original respondent status in order to have the same proportionate representation as the group whose children had developmental disabilities. In comparison families, a target child was randomly selected. In the developmental disabilities families, the target child was the one with disabilities. Table 1 shows the distribution of the sample by gender (mothers or fathers), subgroup (original Wisconsin Longitudinal Study respondents or siblings), and whether the target child had developmental disabilities or was in the comparison group.

For some analyses, a subset of these parents was examined. Specifically, to study women’s employment, only the 61 mothers of children with developmental disabilities who were original Wisconsin Longitudinal Study respondents (i.e., not siblings) and their 61 counterparts in the comparison group were analyzed (see Table 1). We focused on this subgroup because of the availability of employment data. In an earlier Wisconsin Longitudinal Study (Sheridan, 1998), variables were constructed to provide a comprehensive set of measures of women’s employment, and we used these data for our analysis. Because these variables were not available for men or for female siblings, those subsamples could not be included in the analysis of the second research question.

Consistent with the composition of Wisconsin’s population and minorities’ lower high school graduation rates in the 1950s (Sewell & Hauser, 1975), nearly all respondents in the Wisconsin Longitudinal Study were non-Hispanic Whites. As high school graduates, Wisconsin Longitudinal Study respondents represent a somewhat advantaged subset of the population because the overall rate of high school graduation in Wisconsin was approximately 75% in the late 1950s (Sewell &
Table 1  Distribution of Sample by Gender and Wisconsin Longitudinal Study Original Respondent/Sibling Status

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>WLS a original</td>
<td>48</td>
<td>61</td>
</tr>
<tr>
<td>Sib of original</td>
<td>25</td>
<td>31</td>
</tr>
</tbody>
</table>

aChild has developmental disabilities. bNo children with developmental disabilities. cWisconsin Longitudinal Study.

Employment outcomes

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Table 2 presents descriptive data for the two groups of parents analyzed for Research Question 1, which is a subset of the sample employed by Seltzer et al. (2001), as described previously. Our findings regarding the differences between parents of children with developmental disabilities and comparison group parents replicate Seltzer et al.’s results. As is evident from the table, the groups were quite similar on all characteristics measured in 1957 and most characteristics measured in 1992/1994.

There were three points of significant divergence between the two groups of parents assessed in 1992/1994: number of children, birth order of the target child, and the target child’s living arrangement. Parents of children with developmental disabilities had significantly more children than did comparison parents (Ms = 3.4 and 2.9, respectively). Target children with developmental disabilities were significantly later in the birth order than target children who did not have disabilities, with mean birth orders of 2.4 and 2.0, respectively. Finally, children with developmental disabilities were significantly more likely to live at home than were their peers without disabilities (57% vs. 17%, respectively). This latter finding is consistent with national data; Fujiura (1998) found that 60% of all people with developmental disabilities lived with their families. We checked and confirmed that the subsample of 61 original Wisconsin Longitudinal Study mothers of children with developmental disabilities had patterns similar to those of comparison group mothers, as is evident in the larger group portrayed in Table 2 (data not shown).

Measure

Data regarding respondents’ family of origin characteristics, including the years of education for the respondents’ mothers and fathers, were obtained from the Wisconsin Longitudinal Study 1957 wave of data collection. Average income of the respondent’s family-of-origin for 1957–1960 was obtained from Wisconsin Longitudinal Study files containing the Wisconsin Revenue Department’s tax records.

Measures of economic well-being, the dependent variables for Research Question 1, were drawn from the 1992/1994 Wisconsin Longitudinal Study telephone interviews. Measures included income, savings and investments, home equity, mortgage amounts, home ownership, and pensions.

Parents’ income included income from all sources for both the respondent and his or her spouse (if he or she had one). This single income value was calculated by adding, for the respondent and his or her spouse, all reported wage income, salary income, self-employed income, farm income, pension payments, interest and investment income, and income transfer payments (e.g., Worker’s Compensation, SSI, and Aid to Families With Dependent Children). Each income value, therefore, represents the total earned and unearned income from all sources for the respondent and his or her spouse. This income is not total household income because other household members’ income was not included.

Savings and investments (summed for both spouses), home ownership, and equity were other indices of economic well-being measured in 1992/1994. Nonliquid assets (e.g., vehicles, boats) were excluded from the savings data analyzed here. Home ownership was drawn directly from the question “Do you own your home now, or are you renting?” This variable was dichotomously coded (0 = renting or other nonownership, 1 = ownership). Mortgage amounts for 1992/1994 were obtained directly from the respondent’s answer to the question “How much, if anything, do you owe on your home?” Home equity was calculated by subtracting the mortgage amount from the current estimated value of the home (obtained from the question “How much do you think your home would sell for now?”).

Our measure of retirement plan participation in...
Table 2 Description of Parent Groups in 1957 and 1992/1994

<table>
<thead>
<tr>
<th>Variable</th>
<th>DD (n = 165)</th>
<th>Comparison (n = 165)</th>
<th>Test statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Mean</td>
<td>Mann-Whitney</td>
</tr>
<tr>
<td>Family's income, 1957c</td>
<td>$5,500</td>
<td>$5,400</td>
<td>-0.03</td>
</tr>
<tr>
<td>Years of education, 1957</td>
<td>10.4</td>
<td>10.6</td>
<td>-0.14</td>
</tr>
<tr>
<td>Mother</td>
<td>10.1</td>
<td>10.6</td>
<td>-0.35</td>
</tr>
<tr>
<td>Father</td>
<td>13.3</td>
<td>13.4</td>
<td>-0.03</td>
</tr>
<tr>
<td>Respondent's years of educationd</td>
<td>53.1</td>
<td>53.0</td>
<td>-0.35</td>
</tr>
<tr>
<td>No. of children</td>
<td>3.4</td>
<td>2.9</td>
<td>-2.67**</td>
</tr>
<tr>
<td>No. living in householdd</td>
<td>2.9</td>
<td>2.7</td>
<td>-1.21</td>
</tr>
<tr>
<td>Target child's birth order</td>
<td>2.4</td>
<td>2.0</td>
<td>-2.83**</td>
</tr>
<tr>
<td>Marital status (%)e</td>
<td>87</td>
<td>85</td>
<td>0.22</td>
</tr>
<tr>
<td>Respondent's gender (%)f</td>
<td>56</td>
<td>56</td>
<td>0.00</td>
</tr>
<tr>
<td>Child living at home (%)g</td>
<td>57</td>
<td>17</td>
<td>55.20***</td>
</tr>
</tbody>
</table>

*aLast three entries are percentages. bChi-squares in boldface. cMedian income. d1992/1994. e1 married. f1 female. g1 yes.
*p < .05. **p < .01. ***p < .001.

1992/1994 was drawn from four Wisconsin Longitudinal Study questions: (a) Is respondent currently included in a pension plan or retirement plan offered by a current or former employer or union? (b) Does respondent have an individual IRA or Keogh Account? (c) Does spouse have a pension plan from any current or former employers? and (d) "Does respondent have any other retirement or pension plans? If the respondent answered affirmatively to any of these four questions, the parents were considered to be pension plan participants, and the measure was dichotomously coded (0 = no, 1 = yes). Although it would have been preferable to directly measure the level of retirement savings, these data were not available from the Wisconsin Longitudinal Study.

To ensure comparability of Wisconsin Longitudinal Study original female respondents but not siblings or men), which were the dependent variables for Research Question 2, were drawn from three Wisconsin Longitudinal Study data modules, including one constructed specifically for an earlier study of women’s occupations (Sheridan, 1998). Measures of women’s employment included employment status during 1957–1992, employment status transitions between 1957–1992, months of full-time and part-time employment between 1957–1992, occupational socioeconomic status (SES) for each job spell (defined below) between 1957–1992 and earned income in 1974 and 1991.

Employment status was defined as nonworking, part-time employment, or full-time employment (0, nonworking; 1, employed part-time, defined as working fewer than 35 hours per week; and 2, employed full-time, defined as working 35 or more hours per week). Employment status transitions were defined as the number of changes between full-time employment and part-time employment or between nonworking and being employed during the 1957–1992 period. Months of full-time and part-time employment were defined as the sum of months spent working either full-time or part-time during the 1957–1992 period. Occupational SES was...
scored using the Duncan Socioeconomic Index (SEI) and was obtained for each job spell from 1957–1992. A spell was defined as a period of uninterrupted nonworking time (occupational SES not coded), uninterrupted full-time employment, or uninterrupted part-time employment. When there was a change in employment status (e.g., moving from full-time employment to part-time employment), this would constitute two job spells and one transition.

Women’s earned income was collected during the 1975 and 1992 surveys, for 1974 and 1991, respectively, and for our purposes, was defined to include the sum of each woman’s own earned wages, salaries, self-employment income, and farm earnings. Women who reported no earnings were included in the analysis and coded as zero dollars. Interest and dividends were excluded from income analyzed for this component of the study because these income sources could have been derived from the women or their spouses. Women’s 1974 and 1991 earnings were transformed to constant 1993 dollars.

Item nonresponse for dependent measures with missing data (e.g., income, savings, home equity, and women’s 1974 income) was handled by multiple imputation, as recommended by Little and Rubin (1987) and Schafer (1997). Multiple imputation is a simulation-based approach wherein the missing values are simulated \( m \) \( \times \) times, producing \( m \) versions of the complete data. The results are then combined into a single set of estimates and standard errors (Rubin, 1987; Schafer, 1997). The statistical software NORM was employed for these imputation procedures (Schafer, 1999).

### Findings

In our first research question, we addressed economic well-being and examined the entire parents’ sample (165 parents of adult children with developmental disabilities and 165 comparison parents). To examine differences in income, savings and investments, home equity, and mortgage amounts, we employed ranked analysis of covariance (ANCOVA) because the nonnormal distribution of dependent variables violates the statistical assumptions necessary for parametric ANCOVA (Conover, 1999; Daniel, 1995). To examine differences in home ownership and retirement or pension plan participation logistic, we used regression because these measures had binary outcomes. The target child’s birth order and the family’s number of children were employed as covariates in all analyses to control for group differences.

We hypothesized that parents of children with developmental disabilities would have worse economic outcomes as measured by income, savings, home equity, and mortgage amounts. There was partial support for this hypothesis. The significant findings in Table 3 show that the parents of children with developmental disabilities had a mean annual income that was nearly $12,000 lower than the mean of comparison parents, and they had a

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**Table 3** Comparison of Parent Groups’ Economic Outcomes

<table>
<thead>
<tr>
<th>Variable</th>
<th>DD Mean</th>
<th>Comparison Mean</th>
<th>Test statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income(^b)</td>
<td>$38.2</td>
<td>$50.1</td>
<td>4.53*</td>
</tr>
<tr>
<td>Savings(^b,c)</td>
<td>$132.7</td>
<td>$181.0</td>
<td>7.67**</td>
</tr>
<tr>
<td>Home equity(^b,d)</td>
<td>$95.6</td>
<td>$97.6</td>
<td>0.20</td>
</tr>
<tr>
<td>Mortgage(^b,d)</td>
<td>$39.2</td>
<td>$31.3</td>
<td>0.13</td>
</tr>
<tr>
<td>Owns home(^e) (%)</td>
<td>90</td>
<td>91</td>
<td>0.04</td>
</tr>
<tr>
<td>Has pension(^*) (%)</td>
<td>81</td>
<td>81</td>
<td>0.13</td>
</tr>
</tbody>
</table>

*Note. Covariates include number of children & target child’s birth order. There were 165 in each group.*

\(^a\) Boldface indicates Wald statistic. \(^b\) Medians reported in $1,000s of constant 1993 dollars. \(^c\) Includes investments. \(^d\) Equity and mortgage analyzed only for 150 contrast and 149 DD homeowners.

\( *p < .05. **p < .01. \)
mean level of savings (excluding home equity) that was nearly 27% below the savings level of the comparison parents. However, counter to our predictions, the two groups were similar on other measures of mid-life economic well-being, including home equity and outstanding mortgage amounts. Furthermore, consistent with our expectations, we found no group differences in home ownership or the likelihood of participating in a pension or retirement savings plan. As shown in Table 3, both the rates of home ownership and the rates of retirement savings participation were very high in both groups.

In our second research question, we addressed differences in patterns of women’s employment by the child’s disability status. As previously noted, the sample for this question included the 61 mothers of adult children with developmental disabilities and the 61 comparison mothers, all of whom were original Wisconsin Longitudinal Study respondents (not siblings). We again used ranked ANCOVA tests to examine differences for continuous dependent variables and logistic regression for binary outcomes. Results of the analysis of employment outcomes are presented in Table 4.

One of the most striking differences between the two groups of mothers was annual earnings in 1974. During that year, mean annual income (expressed in constant 1993 dollars) was significantly lower for mothers of children with developmental disabilities than for the comparison mothers (see Table 4). To better understand this difference, we conducted a series of follow-up analyses, which revealed that the lower mean income of mothers of children with developmental disabilities was attributable, in part, to their lower rates of overall employment and to their greater likelihood of part-time employment. In 1974, 46% of these mothers were employed versus 64% of comparison mothers, $X^2(1, N = 122) = 4.78, p < .05$. In 1974, mothers of children with developmental disabilities were more likely to be employed part-time, while comparison mothers had a greater likelihood of full-time employment. In 1974, 12% of mothers of children with developmental disabilities were employed full-time as contrasted with 38% of comparison mothers; part-time employment rates were 34% and 28%, respectively, $X^2(2, N = 122) = 11.6, p < .01$.

Table 4 also shows that by 1992, the two groups of women were similar in earned income. Again, we conducted follow-up analyses, this time to explore the lack of difference between groups of

Table 4 Employment Contrast by Group

<table>
<thead>
<tr>
<th>Variable</th>
<th>Years</th>
<th>DD mean or %</th>
<th>Comparison mean</th>
<th>Test statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own earned income$^{b,c}$</td>
<td>1974</td>
<td>$4.9$</td>
<td>$9.4$</td>
<td>10.53**</td>
</tr>
<tr>
<td>Own earned income$^{b}$</td>
<td>1991</td>
<td>$14.6$</td>
<td>$18.8$</td>
<td>1.37</td>
</tr>
<tr>
<td>Occupational SES</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Job spell of longest duration</td>
<td>1957–1992</td>
<td>404</td>
<td>456</td>
<td>1.55</td>
</tr>
<tr>
<td>Mean for all job spells</td>
<td>1957–1992</td>
<td>426</td>
<td>451</td>
<td>0.05</td>
</tr>
<tr>
<td>Total months worked full-time</td>
<td>1957–1992</td>
<td>125</td>
<td>147</td>
<td>2.05†</td>
</tr>
<tr>
<td>Total months worked part-time</td>
<td>1957–1992</td>
<td>74</td>
<td>64</td>
<td>1.44</td>
</tr>
<tr>
<td>Total no. of transitions</td>
<td>1957–1992</td>
<td>2.8</td>
<td>3.4</td>
<td>4.02*</td>
</tr>
<tr>
<td>Ever had job spell $&gt;5$ years in duration</td>
<td>1957–1992</td>
<td>53</td>
<td>75</td>
<td>3.48*</td>
</tr>
<tr>
<td>Ever employed full-time</td>
<td></td>
<td>69</td>
<td>84</td>
<td>0.98</td>
</tr>
</tbody>
</table>

Note. Covariates include number of children and target child’s birth order. $N = 61$ in both groups. $^{a}$Boldface indicates Wald statistic. $^{b}$Median reported in $1,000$s of constant 1993 dollars. $^{c}$1974 income analyzed for 60 DD mothers and 59 comparison mothers whose target child was born before 1975.

$\dagger p < .10$. $^p p < .05$. $^{**}p < .01$. 

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mothers. These follow-up analyses revealed that in 1992, when the women were 53 years old and their children were 27 years old, on average, 82% of mothers of children with developmental disabilities and 89% of comparison mothers were employed, not a significant difference. They also did not differ in their rates of either full- or part-time employment (43% of mothers of children with developmental disabilities and 49% of contrast mothers were employed full-time in 1992, and approximately 39% of women in both groups were employed part-time).

In addition, the two groups of women had similar occupational SES, as measured by the Duncan SEI for both their longest duration job spell and the mean of all their job spells during the 35-year period between 1957 and 1992. As shown in Table 4, although there was a trend-level difference in the duration of full-time employment between 1957 and 1992, differences were not found between the two groups in their total months of part-time employment between 1957 and 1992. Table 4 also shows that during the 35-year period between 1957 and 1992, mothers of children with developmental disabilities had significantly fewer employment status transitions (between full-time employment, part-time employment, or not working) than did comparison mothers, likely signifying the later entry of mothers of adults with developmental disabilities into the labor force (which will be shown below). Also, mothers of children with developmental disabilities were less likely to have ever had a job spell that exceeded 5 years in duration.

Finally, to examine women’s employment trajectories as their child grew up, which was measured as maternal employment status at the target child’s ages of 0, 8, and 16 years, we computed inverse normal transformation of the aligned scores (Harwell & Serlin, 1988; Hettmansperger, 1984). Women’s employment status (full-time employment, part-time employment, or not working) was compared at three points in the target child’s life to assess change over time. The interaction effect of group (child’s disability status) by child age on employment status was also tested.

Results of these analyses are presented in Table 5. Both groups of women experienced a similar general trajectory: Their likelihood of full-time employment increased as their child grew older. However, there was a significant interaction effect of group by child’s age on employment status, F(2) = 3.25, p < .05. Controlling for a slightly higher

<table>
<thead>
<tr>
<th>Employment status</th>
<th>Age: 0</th>
<th>DD</th>
<th>%</th>
<th>n</th>
<th>Comparison</th>
<th>DD</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not working</td>
<td></td>
<td>36</td>
<td>59</td>
<td>47</td>
<td>41</td>
<td>26</td>
<td>45</td>
<td>30</td>
</tr>
<tr>
<td>Part-time</td>
<td></td>
<td>14</td>
<td>23</td>
<td>10</td>
<td>16</td>
<td>12</td>
<td>20</td>
<td>15</td>
</tr>
<tr>
<td>Full-time</td>
<td></td>
<td>11</td>
<td>18</td>
<td>8</td>
<td>13</td>
<td>14</td>
<td>23</td>
<td>19</td>
</tr>
</tbody>
</table>

Note: Covariates include target child’s birth order and number of children. N = 61 in each group.
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rate of employment in the year their target child was born, the likelihood of employment of mothers of children with developmental disabilities increased more slowly as the child aged than comparison mother's employment over time. As the comparison children grew up, their mothers were more likely to enter full-time employment. However, mothers of children with developmental disabilities increased their employment to full-time more slowly and were nearly as likely to be employed part-time as full-time when their target child was an adolescent.

Discussion

Parenting children with developmental disabilities has some, but not pervasive, negative effects on economic well-being as conventionally measured by earnings and savings. These parents have significantly lower savings and income by mid-life than do other parents, and mothers have a differential pattern of employment as their child grows up. For this comparatively well-educated cohort, however, statistically significant differences in other measures of economic well-being, including home ownership, home equity, and mortgage amounts, were not found. Further, differences in retirement plan participation were not detected, but we note that our measure (having or not having some form of retirement savings or a pension) is gross and does not offer information on the actual level of retirement savings.

We cannot be completely certain of the mechanisms underpinning these findings. Having a child with developmental disabilities is likely to result in greater expenditures for health care and child care but may also mean reduced expenses for college. If the person with disabilities is an adult and needs care or supervision, and if that supervision is not paid for by public agencies, then a member of the household, usually the mother, may be forced to forego full time employment in order to provide that care, or she might continue to work but outlay funds to pay for child care. The likelihood of being employed did increase for both groups of women as their children grew older, but comparison mothers moved more quickly into full-time employment than did mothers of children with developmental disabilities. Mothers of children with developmental disabilities were less likely to ever have been employed full-time and less likely to have ever had a job spell exceeding 5 years in duration. The considerable disparity in the two groups’ 1974 earnings and employment rates, when they were about 36 years old, is further evidence of these distinctive employment patterns. The care needs of a child with developmental disabilities likely impedes their mothers from pursuing full-time employment, even when the children are adolescents.

The lower earnings of mothers of children with developmental disabilities when they were in their 30s may have contributed to the diminished savings levels of their families by mid-life. These findings are consistent with other research suggesting that women's earnings are critical to the financial well-being of their families (Blau, 1998; Cancian & Reed, 1999). These findings are also consistent with longstanding evidence that earnings are dramatically influenced by human capital (e.g., education, workforce experience) (Mincer, 1974), and for mothers of children with developmental disabilities, many of whom spend long periods out of the workforce, their skills and experience may become obsolete or less valuable. Wisconsin Longitudinal Study parents of children with developmental disabilities had a somewhat atypical pattern of childbearing, which also might have contributed to their lower levels of income and savings. These parents had larger families, a factor we controlled in our preliminary analyses (though the effects were not significant). Further, there is some evidence from a previous Wisconsin Longitudinal Study investigation that when a child with developmental disabilities is born earlier in the birth order, his or her parents delay having their next child, whereas parents of a child with developmental disabilities born later in the birth order have subsequent children more quickly than the norm (Pettee, 2000). This disruption to the typical pattern of childbearing may account for some of our findings.

Do parents of children with developmental disabilities have increased debt? Do they reduce their consumption and spending patterns to compensate for the greater caregiving costs associated with their child’s needs? Or are the differences in savings we found attributable to the cost of paid caregiving? Our findings illustrate the need for more research in these areas. It seems possible that economically, as has been found psychologically (e.g., Costigan, Floyd, Harter, & McClintock, 1997; Seltzer, Greenberg, & Krauss, 1995), parents of children with developmental disabilities are resilient and adapt to
meet their families’ needs. However, the considerable difference we found in savings suggests that parents of children with developmental disabilities endure substantial economic sacrifices associated with their caregiving roles. These findings also may suggest particularly negative future financial outcomes. The differences in savings and income at mid-life may have a disproportionately deleterious effect on the mothers of children with developmental disabilities as they age, become widows, and can no longer rely on spousal support.

One notable strength of the present analysis lies in the fact that respondents began participating in the study in advance of the birth of their child with developmental disabilities; and as a prospective population-based probability sample, it overcomes some of the limitations associated with selection bias. Furthermore, the two groups were comparable on a host of background characteristics, indicating similar advantages in young adulthood. As a result, we can have greater confidence that the group differences in mid-life economic well-being are due to the added direct costs and foregone employment associated with parenting a child with developmental disabilities. Another strength of this study is our focus on a long stretch of the mothers’ careers, spanning 35 years in the lives of mothers of children with developmental disabilities, thereby highlighting the complexity of life course patterns of employment impacts, which cannot be detected with cross-sectional or even short-term longitudinal research.

The study has several limitations as well. We do not have data on the severity of the children’s disabilities. Previous researchers have found that the time and financial costs associated with caring for children and adults with severe impairments are more extensive than those for children with milder disabilities (e.g., Birenbaum et al., 1990).

A second limitation is the nature of the sample, all of whom were high school graduates, and 99.7% of whom were White. Although the racial composition of the sample is representative of Wisconsin high school graduates in the late 1950s, it is not a sample that can presently be generalized readily to the nation as a whole. This limitation points to important directions for future researchers. Will our results hold for more diverse groups? For less well-educated families? Further inquiry into economic outcomes for the broader population of parents of children with developmental disabilities would be instructive.

In addition, the small sample size analyzed for Research Question 2 might have contributed to an inconsistency in findings regarding our two research questions. Although the earned income of the two groups of women analyzed for Research Question 2 was not significantly different in 1991, the income of respondents and their spouses in the larger sample, which we analyzed for Research Question 1, was significantly different in 1991. The small sample size and consequent reduced power for the Research Question 2 analyses might have contributed to this inconsistency and to other instances in the present analysis of large, but not statistically significant differences between parents of children with and those without developmental disabilities. For example, mothers of children with developmental disabilities had substantially, but not significantly, lower incomes in 1991 than did comparison mothers ($14,600 vs. $18,800) and were considerably, but not significantly, less likely to have ever been employed full time (69% vs. 84%) between 1957 and 1992 than were comparison group mothers. Given the small sample size, the risk of Type II error should be considered when interpreting the findings reported in this paper.

We are cognizant of the fact that raising children with developmental disabilities clearly has great nonmonetary value to the child with the disability, the family, and the community. It is important to be cognizant of the fact that much of the economic activity occurring within families falls outside the marketplace (e.g., child rearing and child caring by parents, housework) and is not readily measurable with the dollar metrics we have employed. Finally, we must acknowledge that other costs associated with caring for a child with developmental disabilities could not be measured in the present study, such as foregone vacations, few promotions, and other benefits in order to care for their children with developmental disabilities.

An important direction for future researchers is to examine the effect of the Family and Medical Leave Act (FMLA) on maternal employment and, successively, on families’ economic well-being. The FMLA allows parents to take up to 12 weeks of unpaid leave per year in order to provide care to a family member with disabilities or other chronic health conditions (P.L. 103–3). The FMLA specifically allows caregivers to take leave intermittently and might enable some caregivers to meet their child’s episodic needs for more intense levels of care and maintain their employment. We were obviously
not able to assess this policy’s effects, as it was enacted in 1993, after it might have assisted these families. However, researchers have found that use of the FMLA to care for family members with disabilities is not widespread (Waldfogel, 2001), and, therefore, our results are likely still relevant for today’s younger mothers of children with developmental disabilities.

We conclude that some—but not all—families suffer adverse economic consequences associated with caring for a child with developmental disabilities. Nevertheless, reduced rates of employment for mothers who provide care to a child with developmental disabilities appear to have a long-term effect on family economic well-being by contributing to substantially lower savings and income for these families at mid-life and may signal increased economic vulnerability in old age. Our findings suggest the advisability of financial family supports. If many mothers of children with developmental disabilities pass up marketplace earnings and their associated health insurance and retirement savings, further analysis and reconﬁguration of health insurance, retirement savings, and Social Security policy may be in order. The notion of some form of “matched savings” plan involving government funds to help families of children with developmental disabilities survive economically and have better financial well-being in middle-age and senior years may well be warranted.

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