An Unanticipated Life: The Impact of Lifelong Caregiving

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Why Conduct Research About Family Caregiving? (Example: DD)

- Increased life expectancy for persons with DD extends duration of family-based care
- Living with family is often the preferred option
- Both gratifications and challenges of family-based care
Prevalence of Family-Based Care (Example: DD)

- Roughly 60% of persons with developmental disabilities live with their families.
- Five times the number of people in other types of residential care.
- Over 83,000 individuals in the US now on waiting lists for residential services.
- Only 3% of approximately $22.8 billion spent on DD services is targeted toward family support services.
Figure 2.14

UNITED STATES:
DISTRIBUTION OF INDIVIDUALS WITH MR/DD
LIVING WITH FAMILY CAREGIVERS, FY 2000

Caregivers Aged <41
1,044,304

Caregivers Aged 41-59
927,955

Caregivers Aged 60+
672,994

Total Estimated Population: 2,645,253
**Parents of Disabled Kids Manage the Extremes Of Home-Job Pressures**

**FOR THE SECOND TIME** in the five years since her son was born, Christa Pardee is re-drawing her career path.

Though she loved her job as a social worker for a Maryland agency, she cut back to part-time hours after her son was diagnosed at age three with a genetic disorder that impairs his brain function. Her reduced paycheck pinched the family budget, but enabled her to take her son to therapy and respond to sitter's overmatched by his erratic behavior.

Last summer, her employer insisted she work full time just as her son was dismissed or refused by several childcare programs.

Reluctantly, she quit. Ever resourceful, she's planning to find another job, train to be a nurse and work nights so her husband, a salesman, can watch their son.

"When my son was born, I thought I was the luckiest mom in the world," she says. "Little did I know that five years later, I would be unemployed with a huge debt and no foreseeable answer."

In the great gamble that is parenthood, few parents face more extreme challenges than those with disabled children. Their kids' periods of heavy dependency don't wax and wane as typical children's do, but go on relentlessly. These parents face setbacks on the job, including discrimination or firing for time-off needs. Ms. Pardee has met several employers in her job search who praise her parental dedication, but can't provide the flexible hours she needs.

**BEYOND THE DIFFICULTIES**, the huge expenses and the marital strain that come with a disabled child, these parents bring inspiring energy to the task of transforming their work-life setups to meet their children's needs.

Linda Roundtree, of Seattle, jumped off the management track at American Airlines after her second child, Alex, now three, was born with Down syndrome, then developed a seizure disorder. American set her up to work from home as a human-resource manager, then raised the possibility of a promotion to Dallas headquarters.

Ms. Roundtree opted to stay in Seattle to maintain family, doctor, school and church ties for Alex. Amid airline turmoil, she moved last year to Ceridian, a Minneapolis-based provider of payroll and other services, as a vice president, account management, to head a virtual team of seven.

Alex never sleeps through the night and needs constant care, requiring the presence of both Ms. Roundtree and her husband, who quit his sales job to stay home. To cope, "you just grab onto that untapped resiliency that so many people have."

Another mother, a customer-service specialist whose son, 11, uses a wheelchair and has speech impairments, became an expert on flexible-work arrangements to get the job-sharing setup she needed. Though her employer had never offered such a thing, she patiently negotiated for a year, surmounting hurdle after hurdle, and won approval. Learning to advocate for her son taught her assertiveness, she says.

The resiliency of these families is drawing new attention. A study of 242 low-birth-weight children, published Jan. 17 in the New England Journal of Medicine, found that while they had more medical and educational problems, as young adults they used less alcohol and illegal drugs, and got in less trouble with the police, than other kids. An editorial suggests that parents' positive attitude, increased attention and protectiveness toward such children may produce a higher quality of life.

Support for these families is up for debate this year on Capitol Hill, as lawmakers weigh reauthorization of the Individuals with Disabilities Education Act.

Whatever the outcome, a core resource for many of these parents will be their own remarkable perspective. Steven Gendel and his wife set aside many dreams after their baby was born prematurely and developed cerebral palsy and epilepsy. He gave up hopes of starting a business. She quit a cherished career as a geriatric social worker. They forgot about buying a house.

As sales director for Cyanamid, a Port Hope, N.J., software concern where managers have been highly supportive, Mr. Gendel walks a razor's edge between performance and pain. He was in an important client-sales meeting when his son's neurosurgeon called to tell him the child's devastating seizure problems were inoperable.

"I returned to the meeting white as a ghost," he recalls. "My boss looked at me and said, 'Are you OK?' I looked at him and said, 'No, not really, but don't worry about it. Let's just do it.'"

Mr. Gendel says. He finished the meeting, walked back to his office, put his head in his hands and wept. A few weeks later, he closed the sale.

Amid setbacks, Mr. Gendel has learned to delight in small things. Though his son, now 2½, has trouble talking, he says, "sometimes he'll look at you and, clear as day, he'll say, 'I love you.' He took a step the other day, and I said, 'Hey, my kid can walk!' I'm going to savor every little win that I can."

Have a question about balancing work and life? E-mail me at sue.sellenbarger@wsj.com. You can read my responses tomorrow in the Work & Family Mailbox in The Wall Street Journal Online at WSJ.com/JournalLink.

Thanks to the readers who pointed out an error in last week's column. There are no wild tigers in the Serengeti.

**WEDNESDAY, JANUARY 30, 2002**
My Research Questions

- How well do older families adapt to the challenges of lifelong caregiving?
- What factors explain parental well-being in later life?
Study #1
Aging Parents of Adults with MR/DD: The Impact of Lifelong Caregiving
(with Marty W. Krauss, PhD and Jan S. Greenberg, PhD)

Funding:
1988-2000 Retirement Research Foundation, AARP
Andrus Foundation, March of Dimes Birth Defects Foundation
1990-2000 National Institute on Aging
R01 AG08768
Aging Parents of Adults with MR/DD: The Impact of Lifelong Caregiving

Central question:

What is the impact of the dual challenge for older mothers of dealing with the manifestations and consequences of their own aging while continuing to provide care for an adult son or daughter with MR/DD?
Research Design

- Sample Criteria (n=461)
  - mothers age 55 and over
  - Wisconsin and Massachusetts
  - son or daughter with MR/DD lives at home

- Sources of Data
  - mothers, fathers, siblings, adults with MR/DD

- Frequency of Data Collection
  - 8 waves of data collection (1988 - 2000)
  - every 18 months
Sample Characteristics at Time 1

- Average age of mothers: 66 years (55-85)
- 2/3 married
- 1/4 employed outside the home
- Average age of adults with MR: 33 years (15-66)
- 54% sons; 46% daughters
- 80% mild or moderate retardation
- 1/3 Down syndrome
- 90% in a day program
Question #1

How well have these families adapted to the challenges of lifelong caregiving?
## Maternal Well-Being

<table>
<thead>
<tr>
<th></th>
<th>Mothers in present study</th>
<th>Family caregivers</th>
<th>Older non-caregivers</th>
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<tbody>
<tr>
<td>% in good or excellent health</td>
<td>71%</td>
<td>67%</td>
<td>60%</td>
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<tr>
<td>Depression</td>
<td>10</td>
<td>8</td>
<td>10</td>
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<tr>
<td>Life satisfaction</td>
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<td>8</td>
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<td>Burden</td>
<td>30</td>
<td>31</td>
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<tr>
<td>Stress</td>
<td>16</td>
<td>19</td>
<td>-</td>
</tr>
<tr>
<td>Social support</td>
<td>8</td>
<td>-</td>
<td>9</td>
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</tbody>
</table>
Question #2

What factors explain variation in parental well-being and adaptation to the challenges of lifelong caregiving?

Hypotheses:

- effective coping strategies
- occupying multiple roles
- social support
Hypothesis # 1

*** Effective coping strategies
Stress and Coping Theoretical Framework (Pearlin)

- Problem-focused coping aims to alter/manage the problem
- Emotion-focused coping aims to reduce/manage emotional distress
- Stressful situations
  - high levels of caregiving demands
  - severe behavior problems
Buffering of Depressive Symptoms by Problem-Focused Coping


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Amplification of Depressive Symptoms by Emotion-Focused Coping

![Graph showing the relationship between caregiving demands and CES-D scores with low and high use of EFC.](Image)
Hypothesis # 2

*** Positive or negative effects of occupying multiple social roles
Multiple Role Effects

- Other roles
  - employee
  - caregiver
  - volunteer
  - spouse
  - parent/grandparent
  - friend
  - relative
  - neighbor

- Role overload hypothesis
  - multiple roles are overwhelming

- Role enhancement hypothesis
  - multiple roles promote social integration, social support, and self-esteem

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Psychological Well-Being Across Number of Roles


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Hypothesis # 3

*** Positive effects of social support
Potential Sources of Social Support

- Having a large social support network
- Being a member of a support group
- Having close friends with a child with MR/DD
Social Support Effects - DD

- Size of social support network
  * smaller network predicts depression
- Being a member of a support group
  * is not related to depression or burden
- Having close friends with a child with MR/DD
  * predicts burden - if mother is pessimistic
Negative Social Support

What Can Older Maternal Caregivers Do To Maintain Well-Being?

- Use problem-focused coping and avoid emotion-focused coping
- Maintain multiple roles
- Cultivate a large and diverse social support network
Unanswered Questions

- Are the results unique to parenting a child with MR/DD, or are they common across disability groups?

- Are the results biased by volunteer samples?
Study #2
Comparison with Aging Parents of Adults with Schizophrenia
(with Jan S. Greenberg, PhD)

Funding:

National Institute on Aging – R01 AG08768

National Institute of Mental Health – R03 MH46564 and R01 MH55928 to Jan Greenberg
Comparison with Aging Parents of Adults with Schizophrenia

Central Questions:

Does the diagnosis of the care recipient (MR vs. MI) alter the impact of lifelong caregiving?

What factors explain diagnostic-group differences in maternal well-being in later life?
MR vs. MI Contrast

- Similarities
  - Feelings of grief and loss
  - Limitations in independent functioning
  - Need for ongoing care
  - Common history of deinstitutionalization
  - Worries about the future
MR vs. MI Contrast

- Differences
  - Parental age at time of child’s diagnosis
  - Stability vs. unpredictability of the behavior of the adult with disabilities
  - Social stigma
Study Design

- Sample Criteria (both studies):
  - mothers age 55 and over
  - son or daughter with disability lives at home

- Frequency of Data Collection
  - DD Study: 8 waves of data collection every 18 months (1988 - 2000)
  - MI Study: 2 waves of data collection every 36 months (1990 - 1993)
Sample Characteristics

- Average age of mothers: 66 years (55-85)
- 2/3 married
- Income
  - median: $25,000 to $30,000
- Average age of adults
  - with MR: 33 years
  - with MI: 35 years
- Gender
  - MR: 54% sons
  - MI: 70% sons
Depressive Symptoms

![Graph showing depressive symptoms comparison between MR and MI groups]
Conclusion

Parenting an adult child with mental illness is much more stressful than parenting an adult child with MR/DD.
Possible Sources of Bias in Family Caregiving Research

- Non-probability samples – all volunteers
- Volunteers may have more favorable well-being and adaptation
- Volunteers tend to be middle class and well-educated
- Under-representation of persons of color
- Well-connected with the service system
Why is this a Problem?

- Unknown limitations on generalizability of research results
- Underestimation or overestimation of service needs
Study #3: Secondary Data Analysis

Life Course Impacts of Nonnormative Parenting
(with Jan Greenberg, PhD & Frank Floyd, PhD)

Funding:

National Institute on Aging

R03 AG15549 (1998-1999) and R01 AG20558 (2002-2007)
to Marsha Seltzer

P01 AG21079 (2002-2007) to Robert Hauser, PhD
Life Course Impacts of Nonnormative Parenting

Central Questions:

What is the effect of self-selection bias (volunteer samples) on what we have learned about the effects of lifelong caregiving?

How do the effects of lifelong caregiving unfold from early adulthood to midlife to old age?
The Wisconsin Longitudinal Study

- Survey of 10,317 high school seniors in 1957 (born in 1939)

- Times of data collection
  - 1957 (age 18)
  - 1975 (age 36)
  - 1992 (age 53)
  - 2003 (age 64)

- Survey of a randomly selected sibling (n=5363)
WLS Structure

- Mother
- Father
- Respondent (1957 grad)
- Spouse or Widow(er)
- Other Child
- Random Child
- Random Sibling
- Other Child
New Use of the WLS

- Some WLS parents have had a child with a disability (DD or MI).
- An unselected sample
- Advantages of WLS: prospective methods, assessment prior to parenthood, and continuing to mid-life.
Sample (1992 data)

- 165 parents of a child with DD
- 53 parents of a child with severe MH problems
- 218 comparison parents
Research Questions

1. Do the three groups differ in family background?
2. Do parents of children with disabilities diverge from the comparison group in patterns of life course attainment?
3. Do parents of children with disabilities diverge from the comparison group in well-being?
Comparison of Groups in 1957

- Similar in family background
  - Parental education, occupation, income
  - Family size
  - Population of town in residence

- Similar in IQ score

- Different in family religion \( (p=0.096) \)
  - Found women who later had a child with a disability were more likely than men in these groups to be from Catholic families; no difference in comparison group
  - Religion controlled in subsequent analyses
Similarities in Life Course Attainment

- No differences among the three groups in post-secondary educational attainment
- No differences among the three groups in family income
- No differences among the three groups in marital status
Figure 1. Number of Weeks Employed in Previous Year (1975)

F (type of case) = 3.42, p<.05
Figure 2. Percent of Respondents Employed (1992)
Figure 3. Years in Present Job (1992)

F (type of case x gender) = 4.85, p < .01
Figure 4. Family Matters Reduce Time for Job (1992)

F (type of case) = 4.81, p < .01
Figure 5. Expect to Work in Ten Years (1992)

F (type of case) = 5.25, p < 0.01
Differences in Occupational Attainment

- Parents of children with MH problems:
  - elevations in maternal employment
  - less stability in father’s employment
  - greater expectation that they will be employed in 10 years.

- Parents of children with DD:
  - Reduced maternal employment
  - More family-work role strain
Figure 6. Target Child Lives at Home (1992)
Figure 7. Number of Visits with Friends in Past 4 Weeks (1975)

- Father: DD*
- Mother: MH
- Father: COMP
- Mother: COMP

F (type of case) = 3.68, p < .05
Figure 8. Number of Visits with Friends in Past 4 Weeks (1992)
Figure 9. Number of Physical Symptoms (1992)

- DD
- MH*
- COMP

F (type of case) = 3.81, p < .05
Figure 10. Depressive Symptoms (1992)

F type of case = 3.45, p < .05
Figure 11. Alcohol Symptoms (1992)

% With Any Symptoms

DD
Mother 20
Father 30
Mother 15
Father 25
Mother 10
Father 10

MH
Mother 30
Father 50
Mother 20
Father 25
Mother 15
Father 15

COMP
Mother 20
Father 15
Mother 10
Father 10
Mother 5
Father 5

F (type of case) = 4.18, p < .05
Summary

- Support for prior pattern of findings
- New insights
  - Similar at age 18
  - Divergence thereafter – but linked in time with the diagnosis of the child
Next Steps

- New round of WLS data collection in 2003-2006
  - Full sample screening for DD or MI
  - Data collection from original respondents, siblings, spouses, widows/widowers
  - Questions about caregiving
  - New comparison group – death of a child
Next Steps

- New round of WLS data collection in 2003-2006
  - Larger sample and more definite ascertainment (thus far):
    - DD: 239 (vs. 165 in 1992)
    - MI: 219 (vs. 53 in 1992)
    - DOC: 1060 (vs. 714 in 1992)
Public Health Risks of Parenting a Child with a Disability

- Elevations and health problems, depression and alcohol use (MH)

- Alterations in lifestyle – by mothers (DD)
Take Away Points

- Importance of both focused studies and population-level data
- Multiple comparison groups
- Longitudinal research/life span perspective
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“Stray Cats”