Juggling and Struggling: A Preliminary Study of Work-Life “Balance” among Mothers Raising Adolescents with Developmental Disabilities

A presentation based on the work of Susan L. Parish, PhD, MSW

Prepared by Adrienne Rooks
UNC School of Social Work
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Introduction

- The current qualitative study examined how mothers of adolescents with developmental disabilities balance work and family responsibilities.
Background

- Extensive literature exists on the balancing act working mothers face
- Working mothers have to juggle work, caregiving, and household chores
- Very little research exists on working mothers of children with developmental disabilities
  - Some research has examined foregone work of such mothers

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Adolescents With Developmental Disabilities

- Children with developmental disabilities often need continued care throughout adolescence and adulthood
  - Their care needs do not abate as they age, unlike their typically-developing peers

- Traditional support services (e.g., child care, after school programs) end at the onset of adolescence
Purpose

- To understand how mothers of adolescents with developmental disabilities balance work and household responsibilities
Existing Research

- Extensive research on psychological consequences for mothers of children with disabilities exists (e.g., Neely-Barnes & Marcenko, 2004; Noojin & Wallender, 1997; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001)

- Somewhat less research on financial impact of raising children with disabilities (e.g. Parish et al., 2004; Shattuck & Parish, 2008)

- Some research exists that shows the high costs of childhood disability in the U.S. (e.g., General Accounting Office, 1999; Kuglthau, Hill, Yucel, & Perrin, 2005; Newacheck & Kim, 2005)
  - Research shows that high costs continue into adolescents and increased costs are linked to maternal employment (Parish et al., 2004)

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Work-life research

- Examines the relationship between work and home life and how intimate partners negotiate care and housework responsibilities
- Role conflict and role enhancement theoretical perspectives inform this body of research
- Leading researchers suggest a life course perspective is also critical
Role Conflict Theory

- Employment and caregiving roles are inherently conflicting because they compete for time, energy and engagement (Barnett & Gareis, 2006)

- Based on this theory, mothers of children with disabilities likely experience heightened levels of incongruity due to the increased care needs of their children

- Some mothers reduce their work hours to accommodate their children with disabilities (e.g., Shearn & Todd, 2000; Parish et al., 2004)
Role Enhancement Theory

- Caregiver, homemaker, and worker roles are not incongruent (Barnett & Gareis, 2006)
- Having multiple roles provide many benefits
  - Positive mental and physical health
  - Better relationship outcomes
- In families with children with disabilities, work may cause parents to exhibit less stress as caregivers
  - Work may be a respite from difficult caregiving
  - Financial benefits of working can be significant, because of the elevated costs of caring for children with disabilities

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Life Course Perspective

- Takes into account families’ life cycle and the developmental trajectory of parents and children (Sweet & Moen, 2006)
  - Families’ care needs change over time as family life changes

- Parental milestones should be considered when studying families’ of children with disabilities (Seltzer, Greenberg, Floyd, Petee, & Hong, 2001)
Maternal employment decreases associated with more and younger children (Waldfogel, 1997)

Higher pay (associated with education level) associated with higher rates of maternal employment (Blau & Robins, 1991)

Strategies to accommodate their dual roles
- Reduce work hours
- Quit paid work altogether
- Seek less responsible positions (Moen, 1992)
- These strategies greatly reduce income
Employment of Mothers of Children With Disabilities

- Limited research exists on the impact of children with disabilities on maternal employment.
- Research has shown reduced employment among:
  - Mothers of children with disabilities (e.g., Heck & Makuc, 2000; Kuglthau & Perrinm 2001; Parish et al., 2004)
  - Parents of children with severe, but not moderate disabilities (Lukemeyer, Meyers, & Smeeding, 2000; Wolfe & Hill, 1995)
Study Method

- Conducted 2 focus group with mothers of adolescents with developmental disabilities
  - held in one suburban North Carolina county
Procedure

- Demographic data collected via written questionnaires
- Interview guide included open-ended questions about maternal employment, social support, leave time, and child care for the child with disabilities
- Focus groups were audiotape recorded and transcribed
Sample

- Recruited by local disability service organization to all mothers of children aged 13-18 yrs with developmental disabilities

- Eligibility
  - Biological or adoptive mother of a child with developmental disabilities
  - Live with their child with disabilities

- 8 Participants

- Incentive
  - Mothers received $25 honorarium to thank them for participating in the study

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## Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
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<tbody>
<tr>
<td><strong>Age</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>50-59</td>
<td>4 (50.0)</td>
</tr>
<tr>
<td>60-69</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td><strong>Race: White</strong></td>
<td>8 (100.0)</td>
</tr>
<tr>
<td><strong>Married</strong></td>
<td>5 (62.5)</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
</tr>
<tr>
<td>Employed full-time (40)</td>
<td>4 (50.0)</td>
</tr>
<tr>
<td>Employed part-time (&lt;40)</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Not employed</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td><strong>Maternal education</strong></td>
<td></td>
</tr>
<tr>
<td>HS or less</td>
<td>3 (37.5)</td>
</tr>
<tr>
<td>&gt; HS</td>
<td>5 (62.5)</td>
</tr>
</tbody>
</table>

<sup>a</sup>One mother declined to report her age
## Participant Characteristics Cont.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
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<tbody>
<tr>
<td><strong>Household income</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;200% of FPL&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>≥ 200% of FPL</td>
<td>6 (75.0)</td>
</tr>
<tr>
<td><strong>Age of child w/ disabilities</strong></td>
<td></td>
</tr>
<tr>
<td>13-14</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>15-16</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>17-19</td>
<td>5 (62.5)</td>
</tr>
<tr>
<td><strong>Child’s diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Autism spectrum disorders</td>
<td>3 (37.5)</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Mental Retardation</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Multiple impairments</td>
<td>2 (25.0)</td>
</tr>
</tbody>
</table>

<sup>b</sup>Federal poverty level, 19,350 for a family of 4 living in the 48 contiguous states (U.S. DHHS, 2005)
Analysis

- Developed coding framework using role-conflict and role-enhancement theories
- Independently coded transcripts, generating new codes as needed
- Codes eventually divided into 4 organizing categories
  - Service Issues
  - Work-related issues
  - Care-related issues
  - Maternal responsibility

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Findings: Service Issues

Themes:
- Gratitude for services
- Insufficiency of existing services
- Belief that service agencies are unresponsive to families’ needs
- Need for advocacy skills to secure services
- Lack of available services for adolescents
Support Services: Use and Deficiencies

- Support services were useful to them/their families
- Service deficiencies were most acute when school was closed (e.g., summer, holidays)
  - Greater challenge finding childcare for children with severe physical or behavioral impairments
  - Securing services and child care was a source of ongoing stress
Local Disability Organizations/School Supports

- Supports from local disability service organizations
  - Essential to managing family life
  - Helpful services: respite care, summer programs, after-school care (available for younger children), and training services through Medicaid

- Supports from schools
  - Children enrolled in different schools across various school districts
  - 1 mother felt school services were satisfactory
  - All others believed the school programs were inadequate
    - Examples: Inappropriate curriculum, late or missing transition planning, and failure to provide individualized plans

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Inadequacies of Available Services

- Inadequacies related to the spectrum of services available, including
  - Local disability services providers
  - Schools
  - Vocational rehabilitation

- Common concerns
  - Difficulties encountered in securing care or services for their child
  - Absence of child care or services when school was closed
  - Drastic decline of services for adolescents
Frustration With Service Providers

- Failure of service providers to recognize lifelong, ongoing needs of their children
  - Services modeled after typically developing children
  - Ignored the extended care needs of children with disabilities

- Mothers felt the government had a responsibility to provide funding and support for families

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Other Service Related Issues

- Ongoing struggle to ensure their child continued to receive services
- High turnover rates among care providers
  - Increased mother’s caregiving responsibilities
  - Heightened mothers’ anxiety about their child’s continuity of care

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Lack of Coordination of Care or Support Services

- Mothers wanted improved communication among the different service providers.
- Mothers had to serve as conduits between service organizations.
- Mothers wanted a centralized system:
  - To quickly react to the mothers’ needs.
  - Show greater resilience to unexpected events (e.g., illness or weather emergencies)

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Service Issues: Challenges of Adolescence

- Decline in services included:
  - Aging out of Saturday programs
  - Long waiting lists for “teen nights”
  - Aging out of after-school programs
    - Some mothers were unable to maintain employment once their child aged out of after-school programs
Findings: Work Issues

Themes:
- Work roles directly conflicted with mothers’ caregiving responsibilities
- Women saw work as emotionally crucial as well as financially important
- Women decreased their work hours or responsibilities as a result of their caregiving responsibilities
Work Issues: Conflict of Roles

- Mothers reported stress from balancing work and managing their family responsibilities
  - Had to juggle their own schedules and the schedules of various care providers
  - Inability to secure caregivers was the most commonly reported reason why they decreased or ended their employment

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Balancing roles influenced the nature of work the women sought and the level of responsibility.

Limited availability of care before school became an issue when children reached adolescence.

Case workers lacked understanding of the level of care needed by the children.

Strategies used by mothers to balance work and home responsibilities:
- Fit work schedule around their child’s care needs
- When able, took advantage of flexible work schedules
- Hired private caregivers for the few who could afford to
- Shared caregiving responsibilities with their spouse or ex-spouse
Work Issues: Importance of Work

- Healthcare providers encouraged working because of the emotional and psychological benefits.
- Women reported benefits including:
  - Satisfaction derived from work
  - Having supportive coworkers
  - Financial and emotional benefits
  - Improved self-esteem
- Some mothers reported seeing work as a buffer to the eventual end of caregiving roles.

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Work Issues: FMLA

- Family and Medical Leave Act (FMLA)
  - Most of the mothers had some awareness of FMLA
  - None of the mothers had used FMLA
  - All of the mothers felt they would not qualify solely on the basis of having a child with disabilities
  - Most felt taking leave would risk their jobs
Findings: Care Issues

Themes:

- Importance of extended-family’s support to the mother’s well-being
- Organizing and securing childcare was an ongoing stress
Care Issues

- Women who articulated the fewest problems between work and caregiving relied on extended family help
  - Majority of participants had no family in the area
- Nondisabled children were often important source of support
Findings: Maternal Responsibility

- All the participants carried the burden of handling the needs of their adolescent
  - Even women with partners living at home, the mother still endured the majority of the childcare responsibility

- Many women reported feelings of isolation, depression, and being overwhelmed
  - These experiences were directly linked to the stress of balancing work and family responsibilities
Present Study Findings Consistent With Past Research

- Mothers decreased their work hours to accommodate their children’s care and supervision needs (e.g., Heck & Makuc, 2000; Kuglthau & Perrin, 2001; Shearn & Todd, 2000)

- Inadequacies of existing services and the continuing role mothers assume in obtaining services (e.g., Freedman & Boyer, 2000; Read, 2000)

- Caregiving responsibility falls primarily to the mother (e.g., Cohen & Petrescu-Prahova, 2004; Heller, Hseih & Rowtiz, 1997, Read, 2000, Traustadottir, 1991)
Present study suggests that:

- Maternal role as primary caregiver continues into adolescents

- The desire to form an ordinary family forces parents toward traditional gender roles (Traustadottir, 1995)

- Parental stress associated with raising young children with disabilities carries into adolescence (e.g., Noojin & Wallander, 1997; Read, 2000)
Study Limitations

- Small sample size – not representative of all mothers of adolescents with developmental disabilities
- All mothers were receiving some supports from a service organization, so their experiences likely differ from women receiving none
- Sample included only white women, so not representative mothers of color
  - Previous research has identified important cultural differences among women of different races

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Suggestions for Further Research

- How role conflict and role enhancement effect maternal employment patterns and stress related to balancing work and family responsibilities
  - Including a culturally diverse sample
- Factors that reconcile the mother’s perceived role conflicts and promote her sense of role enhancement
- The kinds of supports and policy changes that would help low-income mothers of adolescents with disabilities obtain employment
- How are women of color faring?
## Support for Previous Theory

<table>
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<tr>
<th>Theory</th>
<th>Evidence</th>
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<tbody>
<tr>
<td><strong>Life Course Perspective</strong></td>
<td>New challenges of adolescence (decrease in services and added stressors associated with balancing work and caregiving role) for the mothers’ lend credence to the importance of situating work-life research in a life course perspective (Seltzer &amp; Heller, 1997)</td>
</tr>
<tr>
<td><strong>Role Conflict Theory</strong></td>
<td>Juggling work and family responsibility causes competing objectives in the mother’s life (e.g., Williams, 2000)</td>
</tr>
<tr>
<td><strong>Role Enhancement Theory</strong></td>
<td>Mothers experiences and reported feelings support the idea that multiple roles are beneficial for individual well-being (e.g., Barnett &amp; Gareis, 2005)</td>
</tr>
</tbody>
</table>
Policy and Practice Suggests for Support Services

- Increase services to assist with adolescent children’s care needs during school closures, in particular
- Make services seamless between providers, including schools and other service providers
- Improve mother’s access to care for their children with developmental disabilities
Additional Policy and Practice Suggestions

- Increase services for families of adolescents with developmental disabilities
  - Expand current service model to include the experiences of adolescents with developmental disabilities

- Redistribute caregiving responsibilities more equitably with male partners (Cohen & Petrescu-Prahova, 2004)
  - However, mothers in this study did not ask for or expect their partners to increase their caregiving responsibilities
References


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Resources Cont.


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