

## Executive Summary and Action Plan

### Sloan Work and Family Research Network Panel Meeting at Boston College

#### *Work-Family Issues for Employed Parents of Children with Disabilities*

#### Background and Agenda

On May 6, 2008, the Alfred P. Sloan Work and Family Research Network sponsored a one-day think tank at Boston College on the unique challenges of parents who care for children with disabilities. For the past five years, the Sloan Work and Family Research Network—the premier online destination for work and family information—has convened panel meetings to promote discussion about important work-family issues from diverse disciplinary perspectives. The purpose of this meeting was to assess the current knowledge base about this particular work-family issue and formulate an agenda for future initiatives. Nearly 14% of children and youth ages 0-17 in the U.S., or more than 10 million children, have special health care needs (National Survey of Children with Special Health Care Needs, 2005/2006). “Although considerable attention has been paid to the work-family issues of working parents, needs of parents with children who have physical, emotional, and learning disabilities have not received significant attention. The number of families affected, the stress on family relationships, and the impediments to workforce participation are considerable” according to the Sloan Network’s Director, Judi Casey. The following Executive Summary and Action Plan provide an overview of the meeting and highlights areas of consensus that resonated among the attendees.

Co-organizers of the panel meeting Judi Casey and Stephen Sweet, together with an advisory committee<sup>1</sup>, identified leading scholars, workplace innovators, and policy analysts engaged in addressing the needs of working families with children with disabilities.<sup>2</sup> To prepare for the meeting, participants selected 35 “must read” publications that provided an overview of the topic from varying perspectives, the impact that various types of disabilities have on work and family functioning, and examples of successful work-based interventions. This material was made available prior to the meeting to inform the presentations and group discussions.

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## **An Overview of Disability and the Work-Family Connection: Concepts, Definitions and Demographics**

The meeting began with a discussion about the prevalence of various types of disabilities among children in working families including physical, sensory, emotional, behavioral, developmental, and learning disabilities. Estimates of the number of families that have children with disabilities vary depending on the type or severity of the disability being assessed and the methods used to identify these families. Some studies using cross-sectional data (working families at one point in time) underestimate incidence rates, while other studies of employees fail to include parents who left the workforce to care for their children with special needs. With these considerations in mind, the panel concluded:

- ***Estimates suggest as many as one in ten American families care for children with disabilities, although the numbers do vary by source.***
- ***Having a child with a disability is not recognized by employers or the general public as a common situation, and as such, remains a “hidden” problem.***
- ***Poverty rates among families caring for children with disabilities are higher (21%) than families who do not have children with disabilities (12%)” (Census 2000).***
- ***The risks of caring for a child with a disability are most strongly associated with gender and with social class.***

## **Challenges and Experiences of Working Families with Children with Disabilities: Insights from Academic Research**

Attendees discussed how caring for a child with a disability impacts work and family lives. Regardless of the type of disability, families face enormous challenges in securing quality care for their children while accessing the supports needed to manage their jobs and personal lives. Parents of children with special needs, in particular families having children with emotional or behavioral disorders, often experience dual stigmatization as they may be viewed as both inadequate parents and inadequate employees on the basis only of having a child with a disability (Rosenzweig & Brennan, 2008). The cumulative stress of caregiving and lack of peer and community support may interfere with their work performance and overall health. The impact on families can vary depending on the type of disability, family situation, and employment circumstances. The discussion of existing scientific literature and current research conducted by the panelists indicated that:

- ***Families who care for children with disabilities need flexibility in the workplace to accommodate the time to take their children to health care appointments, attend school meetings, and handle child care concerns.***
- ***The strain of caring for a child with a disability, within an employment situation that does not accommodate family needs, can introduce many forms of negative spillover from work to family and from family to work.***

- **Nearly 24% of families with children with special health care needs respond by reducing work hours by one or both parents or having one parent exit from the paid labor force (National Survey of Children with Special Health Care Needs, 2005/2006).**
- **Having a child with an unstable medical condition increases the odds that a mother will reduce her hours of employment by two and a half times (Leiter et al., 2004). For many mothers, caregiving for their child essentially becomes their occupation.**
- **Family supports—especially from schools, employers, and other community resources—can facilitate retention in the labor force and improve overall coping.**

### **Best Practice Workplaces for Employees with Children with Disabilities: The Business Case and Business Drivers**

The Center for Child and Adolescent Health Care Policy estimates that in any given company in the U.S. approximately 8.6% of employees will be caring for a child under the age of 18 who has special health care needs. Leading workplace practitioners described innovative programs where companies and unions have provided information and supports for families with children with disabilities. Their experiences indicated that:

- **Parents with children with special needs and their employers can benefit from the identification of existing resources that may alleviate strain (employee support networks, case management services, community-based supports and inclusive child care).**
- **Employers could potentially benefit by assessing the impact of child care needs (including the care needs of children with disabilities) on recruitment, retention, and productivity.**
- **When securing child care is problematic for employees, responsive resources and interventions provided by employers (e.g., coordination of back-up child care) may be viewed as a return on investment.**
- **Employer efforts to leverage their influence in order to improve the responsiveness of community-based supports (such as schools and health care) can help all working parents.**
- **Establishing a return on investment specific to the retention of employees with children with disabilities is not necessary if their concerns are included in a wider work-life agenda.**

### **The Public Policy Case: What Laws, Policies, and Services Exist to Help Working Families with Children with Disabilities?**

Policy analysts who attended the panel meeting identified ways that families with children with disabilities are served—and sometimes ignored—by existing social policies. For example, the Family Medical and Leave Act provides for 12 weeks of unpaid leave per year, which is often

insufficient for families responding to the needs of children with significant care needs and for whom care outside of the family may be difficult to obtain. With these observations in mind, panelists concluded:

- ***Responding to the needs of working families necessitates access to health care, educational resources, and income supports that consider the duration and level of care needed by children with disabilities.***
- ***As existing supports are commonly provided to minor children with disabilities, there needs to be ways to extend or establish supports to children and parents when their children “turn 22.”***

### **Where Do We Need to Be? How Do We Get There?**

To wrap up the discussion, panelists were asked how to move forward in order to be more responsive to the needs of working families with children with disabilities. A summary of the primary recommendations follows:

#### **Recommendation 1 – Advance the knowledge base**

While the attendees were able to identify numerous ways in which disability affects employment and how working affects the capacity to provide care to children with disabilities, the picture remains incomplete. The panel suggested supporting new data collection on the links between disability and work-family issues, as well as including select questions (to be informed by expert consultation) concerning disability into specific ongoing work-family surveys. In addition, the attendees recommended that surveys of families having children with disabilities include questions about parental employment. There was consensus that current instruments do not effectively assess the situation.

Panelists also concluded that there is an absence of work-family research examining families (at home and at work) having children with disabilities over time, impact on siblings, as well as studies that focus on broader ecological connections (e.g., communities) and the ways families are involved with other institutional arrangements (e.g., schools, health care centers). In particular, few studies have examined the work-family and child care issues for families having children with disabilities. Attention to hourly workers, union/labor work environments, gender differences, and strategies from other countries were also suggested as areas for further investigation.

#### **Recommendation 2 – Increase the visibility of the issue**

The prevalence of the situation and the accompanying stressors suggest that there is a pressing need to make visible the hidden problem of working parents caring for children with disabilities and to shift what is currently a private trouble into a public issue. Workplaces need to embrace a culture of flexibility to accommodate the needs of their employees who face extraordinary care responsibilities, or they run the risk of losing capable workers. Across diverse perspectives, there were numerous stories of families trying, with varying degrees of success, to manage their work responsibilities while providing care for their children. These narratives were coupled with statistics indicating that many families are in similar circumstances. While there are numerous ways to bring the challenges of work, parenting, and disability to the forefront of a public agenda, attendees recommended a media campaign or public relations effort to engage both

the intellect and the heart around these concerns. Efforts to encourage legislators to advance public policy to support these families were also recommended.

## References

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## CONTACTS AND FURTHER INFORMATION

For more information about issues facing working parents with children with disabilities or to learn more about the Sloan Work and Family Research Network, please go to <http://www.bc.edu/wfnetwork>. The Network has posted an Encyclopedia Entry on [Disabilities and Work-Family Challenges: Parents Having Children with Special Health Care Needs](#) by Brennan, Rosenzweig, and Malsch (2008) and created a Topic Page on [Parents Caring for Children with Disabilities](#) which contains statistics, overviews, readings, links, and audio clips.

Founded in 1997, the Sloan Network offers multi-disciplinary, credible teaching resources, evidence-based information on cutting-edge workforce issues and unbiased policy data about work and family topics for academics, workplace practitioners and state public policy makers. In addition to special needs, the Sloan Network provides information on various work and family issues; including child and afterschool care, multi-generational workforce, flexible work arrangements, low wage workers, family leave, breastfeeding, domestic violence, military families and overwork. For more information about the Sloan Network, please go to <http://www.bc.edu/wfnetwork>.

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