



Challenges and Supports for Employed Parents of Children and Youth with Special Needs

Eileen M. Brennan, Julie M. Rosenzweig, Pauline Jivanjee, and Lisa M. Stewart

Presentation at the Work and Family Researchers Network Conference, June 20, 2014

Problem Statement and Motivation. Over the past two decades, heightened international attention has been given to employed parents who are raising children and youth with disabilities (Heymann, 2006; Rosenzweig & Brennan, 2008, Lewis, Kagan, & Heaton, 2000). Estimates of U. S. households raising children with special needs range from 9-21% (U.S. Department of Health and Human Services, 2008; Wang, 2005). These parents are engaged in exceptional care responsibilities which include spending time arranging for health care appointments, meeting with special education personnel, providing special supports for young people transitioning to adulthood, and providing home health care supports (Roundtree & Lynch, 2006; Earle & Heymann, 2012). Workforce engagement is lessened for many of these parents, who may cut back on employment because of heavy care responsibilities, or lose their jobs due to competing family demands (Brennan & Brennan, 2005; Powers, 2003). Our presentation will provide a systematic review of the current literature on employed parents providing exceptional care and answer the questions, “What challenges are faced by employed parents of children and young people with disabilities?” and “What supports are necessary so that they can meet the special needs of their families and the responsibilities of their jobs?”

Approach. We will first present key concepts from the disability field needing recognition by work-family scholars: special needs/disabilities; exceptional caregiving versus typical care, community integration, stigma, and disability disclosure. Next, we adapt the socio-ecological systems model (Voydanoff, 2007; Pocock, Williams, & Skinner, 2012), and examine the literature documenting the specialized demands and resources, including supports, experienced by employees giving exceptional care in the domains of work, family, and community. Finally, we examine policy issues associated with access to supports for working caregivers of children with special needs.

Results. The review resulted in recognition that family care demands differ by the developmental stage of the young person being cared for in terms of parent time, emotional investment, and economic requirements. We also found that family care demands and resources are affected by the type of special needs children have. Some parents face their children’s chronic illnesses or disabilities with predictable paths, while others struggle to deal with special needs that result in intermittent crises. Both developmental stage and type of special needs had a further impact on the strain experienced by the individual caregiver, the subsequent stress on family relations, and the difficulty employed exceptional caregivers experienced as they attempted to achieve work-family fit. Our review also uncovered community resources that provided effective assistance to working exceptional caregivers such as inclusive child care, school-based services, respite care services, and peer support provided by other parents who are experienced navigating service systems. The literature synthesis also revealed helpful workplace supports: flexible work arrangements, workplace affinity groups, generous family leave policies, and inclusive workplaces. Finally, our review synthesized policies at the governmental and organizational level that took targeted vs. universal approaches to providing supports for these employed exceptional caregivers and their families.

Conclusions. Although advances have been made in scholarship examining the situation of employed parents raising children with special needs, and in research on workplace and family supports that have been set in place, there is still much work to be done. Another wave of research is needed to further document the effects of community resources such as formal programs, and informal peer support on the workforce engagement and work-family fit of these employed caregivers.

Cross-national Workplace Flexibility and Family Leave Entitlements for Parents of Children with Special Health Care Needs

	Universal entitlements					Targeted entitlements		
	Workplace flexibility	Maternity leave	Paternity leave	Parental leave	Total post-natal leave (months)	Leave for children with special health care needs	Total leave for children with special health care needs (months)	
Canada	X	√√	X	√√	F E	12 (12)	√ [+]	12 (9)
Québec	X	√√√	√√√	√√√	F	18 (18)		
United Kingdom	√	√√	√√	√	F/I/E		√ [+]	---
United States	X	X	X	X		0	X [+]	4 (0)
California		√√				7 (4)	√√ [+]	
New Jersey							√√ [+]	4 (2)
Rhode Island							√ [+]	4 (2)
Vermont	√							4 (1)

Notes. Workplace flexibility, Maternity, paternity, parental leave and leave for sick children columns: X – no statutory entitlement; √ statutory entitlements but unpaid; √√ statutory entitlement, paid at a low flat rate or earnings related at less than fifty percent of earnings or not universal or for less than full period of the leave; √√√ statutory entitlement, paid to all parents at more than 50 percent of earnings (in most cases up to a maximum ceiling). √√√√ statutory entitlement, option for higher payments under a special plan.

Parental leave column: F = family entitlement, I = individual entitlement, F/I = some period of family entitlement and some period of individual entitlement, E = indicates extension to entitlement if child has a disability or chronic condition.

Total postnatal leave column: Unbracketed numbers indicate total length of leave in months to nearest month; bracketed numbers indicate length of leave, which receives some payment. [+] Indicates any extensions to time limits if child has a disability or chronic health condition.

Leave for sick children column: [+] indicates entitlements covering a wider range of family members.

Total leave for sick children: Unbracketed numbers indicate total length of leave in months to nearest month; bracketed numbers indicate length of leave, which receives some payment. --- Indicates no established time limits.

Country footnotes (fn):

Canada: Most employees have access to flexible work arrangements under employer contracts. Parents of children with disabilities or chronic conditions may access two types of entitlements if their child is critically ill (up to 35 weeks paid leave) or faces imminent death (8 weeks paid, 26 weeks total). Nine jurisdictions allow 2 to 10 days of additional unpaid family leave.

United Kingdom: Time off to care for dependents must be emergencies, amount of time must be ‘reasonable’ though the exact amount of time off is not defined in the legislation.

United States: Parents may take up to 12 weeks of unpaid leave for childbirth and care of an ill child as part of the Family Medical Leave Act. Only three states have paid family leave. San Francisco and Vermont have ‘right to request’ flexibility legislation.

Funders

This document was developed with funding from the National Institute on Disability and Rehabilitation Research, United States department of Education, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (NIDRR grant H133B090019). The content of this document does not necessarily reflect the views of the funding agencies.

