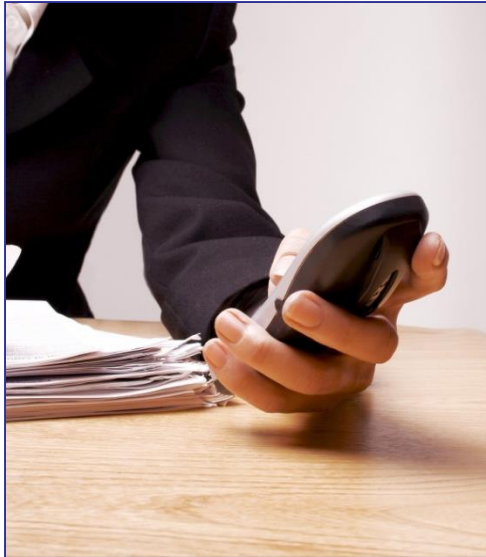




# Work and Family Researchers Network Conference

RESEARCH & TRAINING CENTER FOR PATHWAYS TO POSITIVE FUTURES



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

**Symposium:** Challenges and Supports for Parents of Children with Disabilities

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# Location & Context



School of  
**Social Work**



- Portland State University
- School of Social Work
- Regional Research Institute for Human Services
  - Research and Training Center on Family Support and Children’s Mental Health
  - Research & Training Center for Pathways to Positive Futures
- Funding sources



# Our Review Answers Two Questions:

1. What challenges are faced by employed parents of children and young people with special needs?
2. What supports are necessary so that they can meet the special needs of their families and the responsibilities of their jobs?



# Prevalence of Special Needs

- Measurement affected by the term used: disability, special health care needs, special needs.
- Global estimates of 93 million children with disabilities (WHO, 2011).
- American Community Survey estimates 62.2 million children/youth (8.4%) with disabilities in U. S. (Brault, 2012).
- 23% of U.S. households with children have at least one child with special health care needs (CAHMI, 2012).



# Exceptional Caregiving Responsibilities

- Exceptional caregiving responsibilities differ from typical caregiving responsibilities:
  - time spent arranging care
  - ongoing parental responsibilities-childhood into young adulthood or beyond
  - frequent, intense, and crisis-driven care needs
- Exceptional caregiving responsibilities include:
  - Health/mental health care
  - Special education arrangements
  - Inclusive child care
  - Health related crises

*(Brennan & Rosenzweig, 2008; Lewis, Kagan, & Heaton, 2000; Porterfield, 2002; Roundtree & Lynch, 2006; Stewart, 2013)*



# Community Integration

- *Community Integration*—family members are not just physically located in a community, but they take on key roles and participate in community activities (National Center for Dissemination of Disability Research, 2004).
  - Provides them with a psychological feeling of inclusion and belonging, access to full participation in education, recreation, housing, citizenship, and religion/spirituality (Salzer, 2006).
  - Full participation in workplaces and work roles, not constrained by caregiving responsibilities.
- *Stigmatization* and *courtesy stigmatization* (stigmatization by association): commonplace experiences for persons with disabilities and their families (Corrigan, Markowitz, Watson, Rowan & Kubiak, 2003).



# Challenges and Supports

- Reviewed using Voydanoff's (2009) framework that examines work and family *demands* and *resources* within the context of community characteristics.
- Placed in the framework of family development.





# Care demands-differ by type of SN

- Higher rates of unemployment for parents of children with sensory or orthopedic impairments, traumatic brain injuries, or autism or multiple disabilities compared with others receiving special education (Wei & Yu, 2012).
- Care experience differs by:
  - Severity
  - Unpredictability
  - Communicability of child's health condition (Major, 2003).
- Serious symptoms can heighten the experience of caregiver strain (Bussing et al., 2003), and lead to workforce disengagement (Brennan & Brannan, 2005).





# Care demands--transition to parenthood

- Typically a time when families respond to demands of a new child, and may expand work hours and search for stable employment (Kaufmann & Uhlenberg, 2000).
- Parent (usually the mother) of a child with a disability must learn about the child's condition, provide special in-home services, and coordinate care (Lewis et al., 2000; Scott, 2010).
- Often results in mothers not returning to work force after maternity leave (Hauge et al., 2013).



# Care demands—preschool child

- Find and maintain inclusive child care or early childhood arrangement in their community (Montes & Halterman, 2011; Warfield, 2005).
- Understand, advocate, and coordinate special services (Ward et al, 2009).
- Perform “articulation work” (Timmermans & Frieden, 2007).
- Often results in maternal disengagement from work, especially for single mothers with lower levels of education (Porterfield, 2002).



# Care demands—school aged child

- Children may receive special services during the school day, relieving some care coordination tasks; more parents return to work (Okumura et al., 2009).
- However, if needs are acute, parents may be called to school to provide immediate assistance (Rosenzweig et al, 2002).
- Out-of-school care may refuse to accept children with disabilities (Jinnah & Stoneman, 2008).
- Children with special needs may spend substantial time in self-care (Parish & Cloud, 2006).



# Care demands—youth & emerging adult

*Transition to adulthood is a time of tunnels and cliffs, when services are specialized and hit different age limits from system to system (Podmostko, 2007).*

- Parents may continue to share home and provide intensive support (Jivanjee, Kruzich, & Gordon, 2009).
- Help emerging adult with transition plan for self-care (Holmbeck et al., 2010), sometimes resulting in family conflict (Preto, 2005).
- Parents of young people with intellectual disabilities report this is the most difficult time—greater needs with fewer services (Parish, 2006).



# Supports

Supports and needed resources should be “defined by each family according to its needs, preferences, and values” (Friesen et al., 2008, p. 33).





# Family Support

- Family supports—*constellation of formal and informal services and tangible goods that are determined by families* (Federation of Families for Children’s Mental Health, 1992).
- Effectiveness increases when supports are family-centered; specific to a family’s needs, values, and preferences (Friesen et al., 2008; King et al., 2004).
- Supports include:
  - Peer advocates & supporters, system navigators
  - Respite services
  - Economic support



# Workplace Supports

- To obtain workplace supports, parents must decide on *disclosure* of their family's special needs.
  - Will often result in needed formal and informal work adaptations.
  - Can result in *stigmatization* (Rosenzweig et al., 2010).
- Flexible work arrangements are key to managing family demands (Jacob et al., 2008; Grzywacz et al., 2008).
- Human resource professionals can be instrumental in negotiations for supports (Sutton & Noe, 2005).



# Community Supports

- Inclusion of children/youth in education, child care, and out of school care (Carlson et al., 2012).
- Integrated treatment services (Hoagwood et al., 2010)
  - Systems of care
  - Wraparound programs (comprehensive, tailored).
  - Medical homes.
- Family centered services
  - Evidence-supported practices to assist families to learn about their children's special needs and develop the skills to manage them (Mendenhall & Mount, 2011).





# Policy Supports for Families Raising Children/Youth with Special Needs

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# Cross-national Comparison

- Liberal welfare model countries emphasize personal choice and responsibility (Bambra, 2005; Esping-Andersen, 1990).
- Canada, United Kingdom, and United States differ in workplace flexibility and leave supports available to parents of children affected by disabilities.



# Leave and Flexibility Entitlements

	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)
<b>Canada</b>	X	√√√	X	√√√ F E	12 (12)	√√ [+]	12 (9)
<b>Québec</b>	X	√√√√	√√√√	√√√√ F	18 (18)		
<b>U. K.</b>	√	√√	√√	√ F/I/E		√ [+]	---
<b>U. S.</b>	X	X	X	X	0	X [+]	4 (0)
<b>California</b>		√√			7 (4)	√√ [+]	
<b>New Jersey</b>						√√ [+]	4 (2)
<b>Rhode Island</b>						√ [+]	4 (2)
<b>Vermont</b>	√						4 (1)



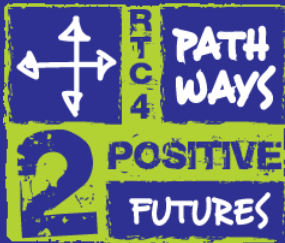
# Future Directions—What We Know

- Financial burden and caregiver strain associated with exceptional care responsibilities.
- Link between children's/youths' special needs and parental workforce disengagement.
- Strategies parents use to gather supports they need to stay employed while providing exceptional care.



# Future Directions—Needed Research

- Effects of policy shifts and supportive formal and informal services on caregiver strain and work engagement.
- Community based participatory research on challenges and supports for culturally-diverse and low-income families including children/youth with special needs.
- Work-life integration for emerging adults with special needs.
- Longitudinal studies tracking the employment trajectory of those providing exceptional care, identifying supports needed at turning points of their careers.



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