

**Employee Benefits Study
For Children
With Special Health Care Needs**



Partners

- Family Voices at the Federation for Children with Special Needs (*Betsy Anderson, Nora Wells*)
- Boston University School of Public Health (*Debby Allen, Carol Tobias*)
- New England SERVE (*Susan Epstein, Nancy Turnbull*)
- MassGeneral Hospital for Children (*Jim Perrin, Karen Kuhlthau, Chris Fluet*)

*A project of the
Center for Child and Adolescent Health Policy
MassGeneral Hospital for Children*



Overarching Goal

To better understand how systems of care for children with special health care needs and their families can be improved through

employer-sponsored benefit systems

Work-Life and EAP Benefits:

- Flexible Work Arrangements
- Flexible Use of Leave Time
- Information and Referral
- Legal Services
- Wellness Programs

Health Care Providers:

- Medical
- Dental

Families Caring for CSHCN

Community Resources:

- Child Care
- Respite Care
- Parent to Parent Groups
- Recreation Activities

Health Insurance:

- Public Programs, e.g. SCHIP, Medicaid
- Private, Employer-Sponsored Insurance

Services Through School:

- Specialized Therapies (PT, OT, Speech, Behavior)
- Learning Accommodations



Why focus on the workplace?

- **60%** of children with special health care needs are covered by health insurance through a parent's workplace
- **34%** of parents reported inadequate health insurance coverage for their child
- **28%** of parents reported that they or other family members have cut down on work hours to care for their child
- **13%** of parents reported that they or other family members have stopped working because of their child's health condition *

[findings from 2001 National CSHCN Survey]



Why focus on the workplace?

The cost to replace an employee averages
30 to 150 percent of his/her annual
salary, depending on skill level. *

[American Management Association]



Main Questions

- How do current employer-sponsored benefit structures help families with children with special health care needs?
- How do employers currently view the needs of families caring for CSHCN?
- How do employers view opportunities for improvement?



Methodology

Qualitative study

Data sources:

- Key informant interviews
- Structured interviews with employers and unions
- Parent focus groups

Sample:

- 10 key informants, 41 employers, 4 unions
- 5 parent focus groups
- Four U.S. markets: Boston, Cleveland, Miami, Seattle



Early Lesson:

Most significant opportunities relate to
addressing work-family challenges and needs

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Work-life and EAP benefits



What We Learned

- Programs and structures to improve lives of employees with CSHCN *already exist*
- Increase understanding and impact of CSHCN on employees and workplace
- Expand employer awareness of application of current benefits to employees with CSHCN
- Expand employee awareness of benefit programs and access to them
- Expand Title V awareness of employer-provided benefits and how to interface



Historical context of work-life and EAP

Response to “special” populations/issues:

Child care

Elder care

Sexual orientation

International workers

The younger worker

Breastfeeding

Alcohol and substance abuse

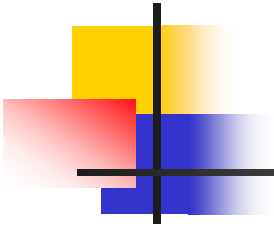
Workers of color

Cross-cultural issues

The older worker

The low wage earner

Adoption



So, “Why NOT focus on the workplace?”



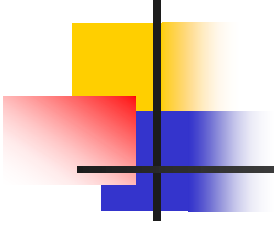
Current Work – Dissemination and Trials

- Employers and benefit vendors:
 - Ernst & Young and their vendor, LifeCare
 - Progressive Insurance
 - Raytheon and their vendor, United Behavioral Health
 - Ceridian
- Labor Project for Working Families
- Alliance of Work-Life Progress (AWLP)



“Raising the Bar”

- Potential to address CSHCN in workforce surveys:
- Families and Work Institute National Study of the Changing Workforce: survey of employees – every five years
 - “Working Mothers” Magazine Best Companies List – annual survey



Thank You!