

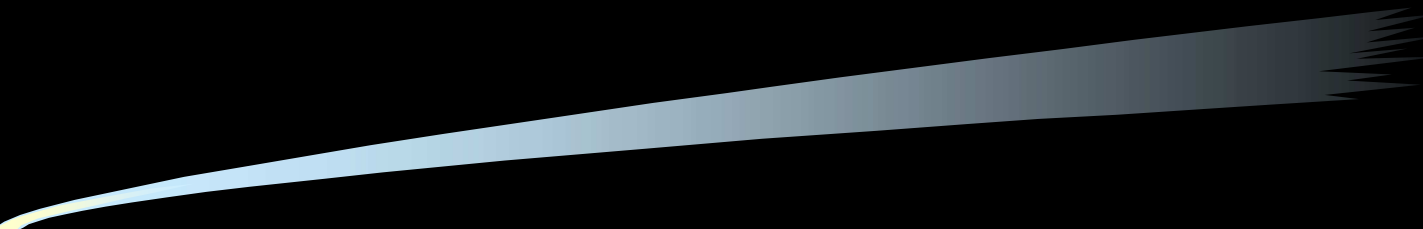
Employee Benefit Study for Children with Special Health Care Needs



Partners

- *Family Voices at the Federation for Children with Special Needs (Betsy Anderson, Nora Wells)*
- *Health and Disability Working Group at Boston University (Carol Tobias, Debby Allen)*
- *New England SERVE (Susan Epstein, Nancy Turnbull)*
- *MGH (Karen Kuhlthau, James Perrin; Chris Fluet, study coordinator)*

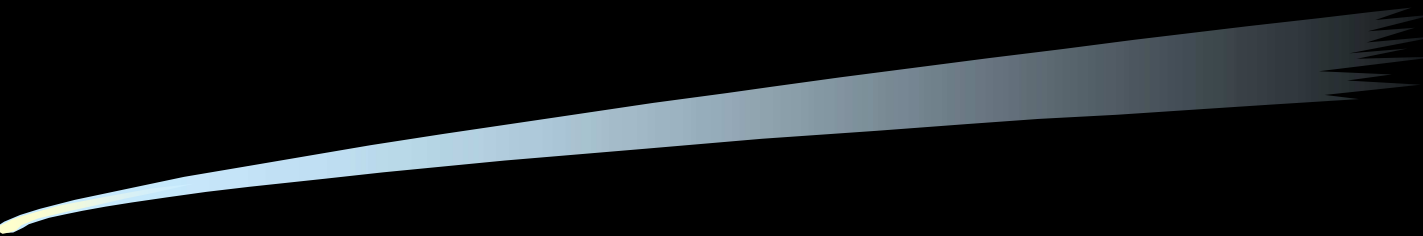
*A project of the
Center for Child and Adolescent Health Policy
MassGeneral Hospital for Children*



Healthy People 2010

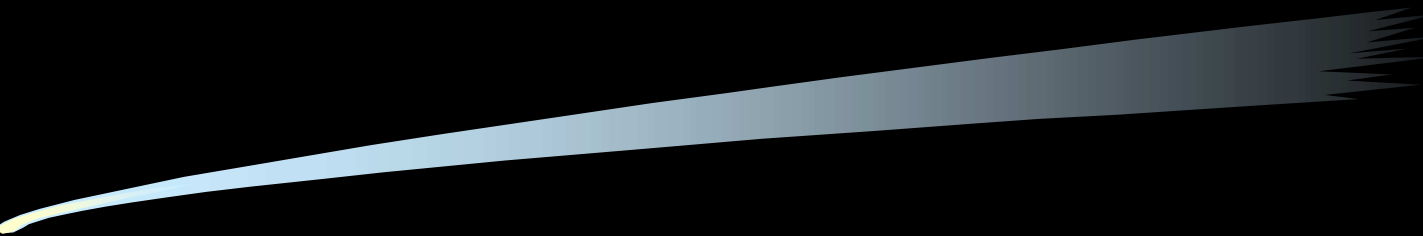
- *Objective 2:*

All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need



Project Goals

- To improve systems of care for children with special health care needs and their families
- To help families make active choices about employment and benefits
- To help employers develop and utilize benefits to increase workplace participation and performance

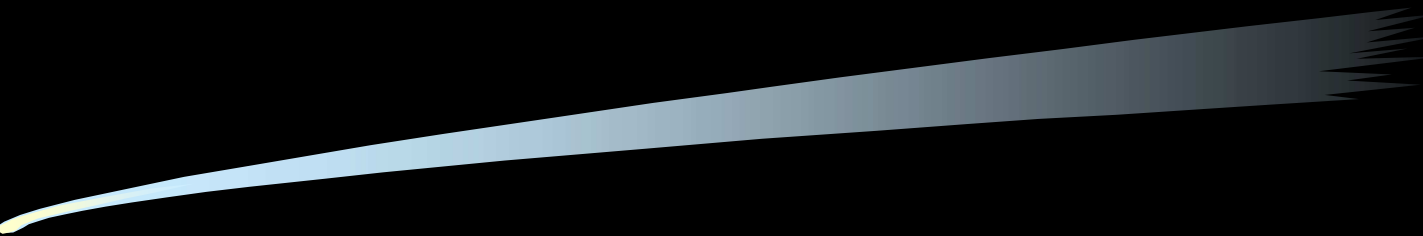


Main Questions

- how current benefit structures help families with children with special health care needs
- how employers/purchasers currently view the needs of families caring for CSHCN
- how employers/purchasers view opportunities for improvement.

Tales of Children with Special Health Care Needs

- Sam, 10yo with Attention-Deficit Hyperactivity Disorder; needs special after-school program; aggressive behavior with peers sometimes gets him in trouble
- Takitha, 3yo with spina bifida; had 3 surgical procedures in first year of life; now happy, in daycare; plans for another orthopedic operation in six weeks



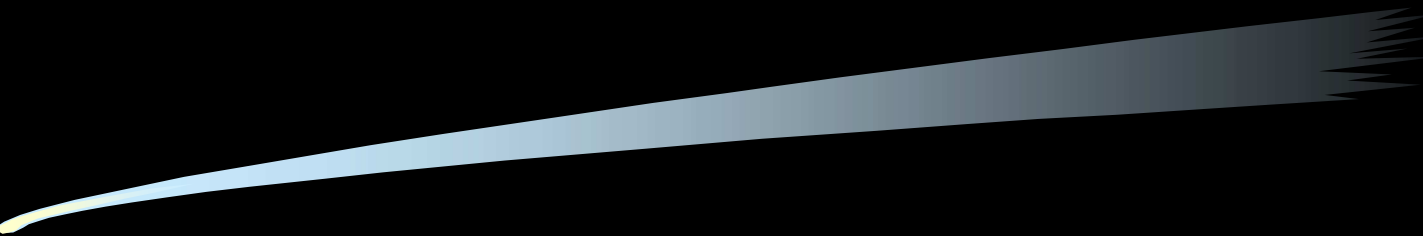
Further Tales

- Justin, 9yo with moderate to severe asthma; did well over the summer, but late fall and early winter are his hard times. In hospital twice last year. Uses inhaler; nurse at school once a week.
- Sandra, 14yo with depression; some illegal drug use. Never hospitalized, but has had school absences last few weeks.

Phase I: Key informant interviews

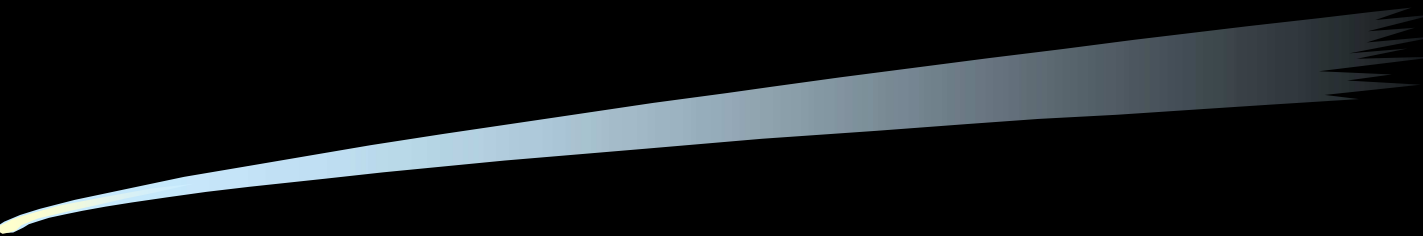
*Phase II: Employer and related
interviews, four US markets*

Phase III: Dissemination activities



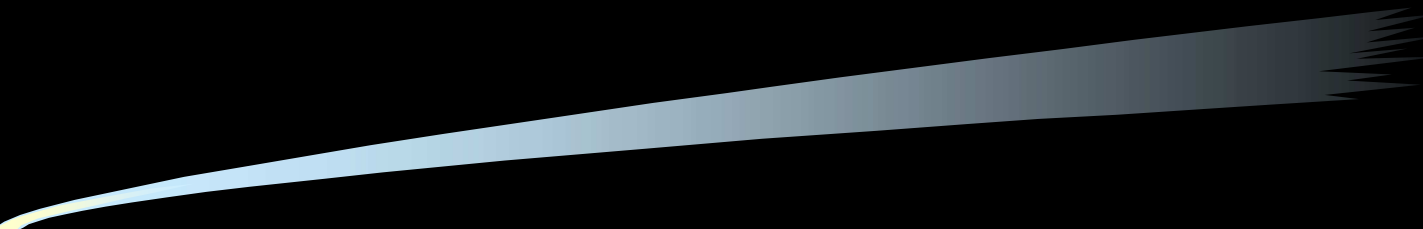
Phase I: Informants

- Benefits managers
- Benefit consultants
- Business group representatives
- Purchasers
- Work/life professionals
- Academics



Phase I: Findings

- *Limited understanding of benefits managers of CSHCN*
- *Tendency to focus on children with very severe conditions and costly needs*
- *Variations among industries in benefit interest, based mainly on type of employee (skilled, technical vs. other)*
- *Limited organization of employees to seek improved benefits*

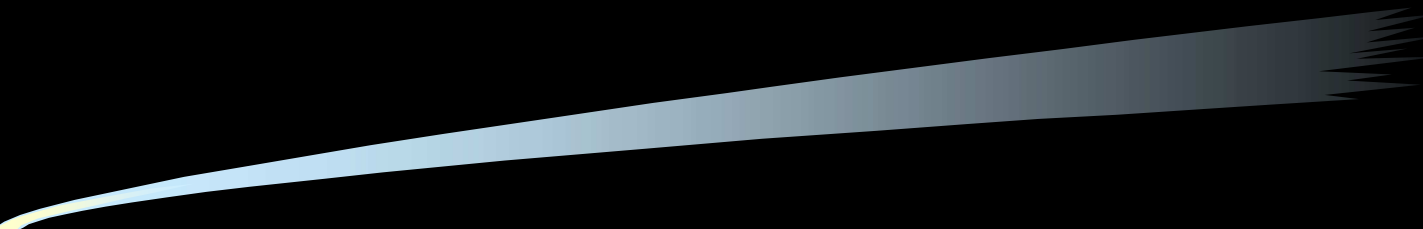


Phase II: City Market Interviews

- Best practices in four diverse communities:
 - Boston
 - Cleveland
 - Miami
 - Seattle
- Industry, family, and union representatives

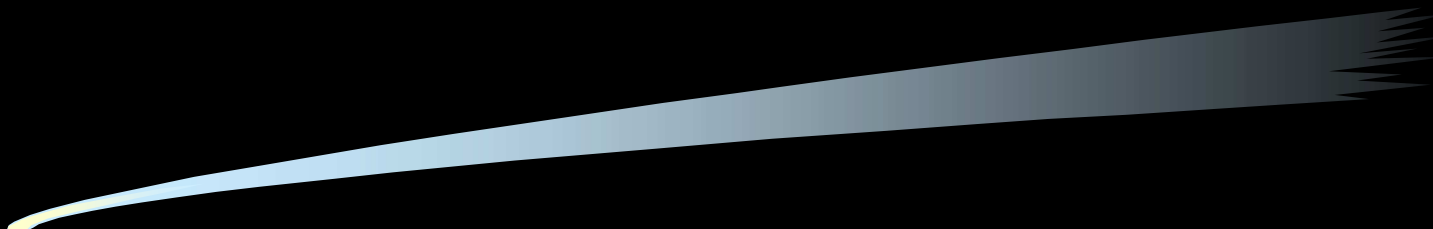
Building Connections between Families and Employers

- Learn more about employers' world, to better inform families and providers
- Understand barriers employers face in providing benefits
- Work with employers to understand the impact of children with special health care needs on workforce productivity

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Partnership Council

- A national collaborative effort with the Bureau to aid work with the purchaser community to improve services and quality of life of households with children with special health care needs



Products

- Policy paper
- Materials for purchaser
- Materials for families