Who’s Here?

- Parent of a child with special health care needs (CSHCN)?
- Co-worker or supervisor of employee caring for CSHCN?
- Child’s age?
  - Birth – 3
  - 3 – 6
  - 7 – 12
  - 13 – 18
  - Older than 18

Why Focus on the Workplace?

- 60% of children with special health care needs are covered by health insurance through a parent’s workplace
- 33% of parents report inadequate health insurance coverage for their child
- 24% of families report cutting down on work hours or stopping work altogether to care for their child


Research and Policy Regarding Private Sector Benefits for CSHCN

- Massachusetts General Hospital, Center for Child and Adolescent Health Policy, Employees Benefits Study for Children with Special Health Care Needs (2001-2006)
- Work of Brannan, Brennan, Friedman, Kuhlthau, Leiter, Litchfield, Porterfield, Rosenzweig, and Warfield
MGH Employee Benefits Study For Children with Special Health Care Needs

Goal: To better understand how care for children with special health care needs can be improved through employer-sponsored benefit systems

Research Partners:
- Massachusetts General Hospital/Harvard Medical School
- Boston University School of Public Health
- Family Voices
- New England SERVE

Supported by a Cooperative Agreement from the U.S. DHHS, Maternal and Child Health Bureau (1U93MC00183)

Early Lesson

• Most significant opportunities relate to addressing work-family challenges and needs through company Work-Life and EAP benefits

We Also Learned

• Many benefits and programs that can help already exist and some can be provided at low or no cost
• Employers are often unaware how existing programs and benefits can be applied to this population; incentive = maximize their investment
• Employees often don’t know about employer-sponsored benefits and services that can be helpful and/or how to access them
• Public programs, such as Title V, generally do not consider how employer-provided benefits and public benefits can interface to better serve families

Employees’ Views of Work-Family Needs

• In focus groups, parents indicated that they were reticent about disclosing family circumstances to their employer, even when disclosure would support their case for a flexible work arrangement or use of leave time. Parents feared reprisal—loss of their job, a promotion, or career opportunities or being perceived as a “problem” employee.
• Some were reluctant to appeal a claim or make their health insurance coverage needs known, for these same reasons.

To learn more about the project:

• www.massgeneral.org/ebs

POLL: The most pressing issue for me and my family right now relating to my child’s special need is:

• Adequate health insurance coverage
• Financial pressures
• Finding appropriate health care providers and therapists
• Finding appropriate child care providers (including before/after school, summer time, sick care, business travel care)
• Education and school issues
• Family impacts: marriage, siblings, extended family, holidays, family activities, time together
• Knowing how to best nurture my child’s development
• Legal: guardianship, conservatorship, long-term financial planning
• Effects on my work life, maintaining work-family balance
• My own health: physical, emotional, psychological, spiritual
• Other
Does your employer know that you have a child with special needs?

- You may be comfortable openly discussing your child’s and family’s needs with your employer. Or you may prefer not to share information about your family life in your workplace.

- Letting your employer know about your child’s medical needs could in some cases give the employer an opportunity to respond sensitively and helpfully—while allowing you as an employee to avail yourself of the relevant benefits.

Is this something you want your employer to know?

- One advantage to discussing your child’s specific needs with your employer (Office of Work/Life, Benefits Services Group, local HR Office) is that they may be able to consider those needs when creating or negotiating new programs or enhancing existing programs.

- Below are some examples of special populations/issues that were made known in the workplace at Harvard and, in turn, programs/resources were developed:
  - Elder care
  - Alcohol/substance abuse
  - LGBT
  - Cross-cultural issues
  - Low wage earners
  - Child care
  - Adoption
  - Breastfeeding

Opportunities for Employees

- Have you thought about how Harvard can help you?

- Do you know where to go for information about your benefits and work-life programs (what they are and how to use them)?

- Do you know how to find information about your child’s condition or disability?

Flexible Work Arrangements

http://harvie.harvard.edu/working/flexwork/

- How many already do flex time?

  - Questions/Assistance:
    - work_life@harvard.edu / 617-495-4100
    - huctw.info@huctw.org / 617-661-8289

  - If a requested flexible schedule arrangement cannot be reached between an employee and supervisor, the request will be examined further in consultation with the human resources department and HUCTW. If an agreement cannot be reached, the employee will be given a reason for the decision.
Harvard Employee Assistance Program

• Resource and Referral:
  – Will conduct specialized searches for available child care and other resources for children with disabilities
    – Residential/treatment day and boarding schools, special needs advocates, educational consultants, and local chapters of resources like The Autism Society, CHADD, etc.
    – Can assist in identifying educational testing and assessments that may help to identify special education needs
  – Support in acute situations such as dealing with the news of a diagnosis, or free consultation related to your child’s legal rights
  – Budget and debt counseling

Child Care Resources

• Parents in a Pinch (PIAP)
  – Have providers who are qualified to care for children with various disabilities
  – The earlier the request is made, the better the chance that they can accommodate the special request
  – They send a child care provider to your home when your usual arrangements change
    – You pay provider $15/hour
    – Minimum of 4 hours
    – Download form from HARVie

• Just in Time Care
  – Provides up to $350/year in backup care subsidy for child or elder care and paid to the provider of your choice
    – Minimum of 4 hours
    – Under $70,000 FTE salary eligibility requirement
    – Register before you need it
    – Call the EAP at 877-327-4278

Child Care Scholarships

http://harvie.harvard.edu/workandlife/children/scholarship.shtml

• Several funds, now totaling nearly $3 million
  – Based on financial need
  – Determined once per year for each employee group
  – Look for an announcement email in the early summer
• ‘Portable’ awards
  – Can be used anywhere—in your home, in a center, for summer camp
  – Grant sizes range
  – Intended to defray costs, not cover them entirely
  – Increasing applicant numbers may result in lower awards
• They are considered taxable income
  – Flexible spending accounts can be a smart move

Health Insurance

In general, if you have a child with a physical disability or a medical condition, you should pay particular attention to the following when choosing a health insurance plan:

• Primary Care Physician (PCP), Networks, Referrals
• Co-pays, coinsurance, out-of-pocket maximums
• Durable medical equipment
• Lifetime maximums (Currently none on Harvard University sponsored plans)

Benefits

http://harvie.harvard.edu/benefits

Flexible Spending Accounts (FSA)

Medical Dental Care
  – For expenses not reimbursed by insurance
  – Deductibles, co-payments, eye glasses, etc.

Dependent care
  – Only care that is necessary so that employee and spouse, if married, can work or go to school
  – Must provide Social Security number or Taxpayer ID number of provider/center
    • Unused money is forfeited
Harvard University Co-Pay Reimbursement Program

Harvard University has a cap on co-payments and reimburses above the cap, for eligible employees under certain income limits, once you meet a threshold.

1 - Office visits (in-network) and 2 - Prescription drugs

• No enrollment, University paid
• File claims for reimbursement by 3/31 of following year
• Administered by CROSBY Benefit Systems

Life and Disability Benefits

• Short Term Disability - employer paid
• Long Term Disability - employee paid
• Life Insurance
  • Basic - employer paid
  • Supplemental - employee paid
• Long Term Care Insurance - employee paid

Benefits on HARVIE

Benefits Services Group

– Call 617-496-4001 to speak with a Benefits Representative or request materials 8:30-4:00
– Email: benefits@harvard.edu
– Visit Holyoke Center room 664, 6th floor 8:30-5:00
– For more information visit: harvie.harvard.edu

University Disability Coordinator

Marie Trottier
University Disability Coordinator
Holyoke Center 635, 1350 Massachusetts Avenue, Cambridge
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Marie's responsibility is not only to ensure access to all qualified persons with disabilities, but also to serve as a resource for information and problem-solving on disability issues, and to raise awareness in the Harvard community. Although any member of the Harvard community is welcome to contact the University Disability Coordinator, staff members are asked to consult the Office of Work / Life Resources as initial sources of information.

Resources

This presentation is meant to be an introduction that can help you care for your child –
We would like to remind it was not meant to be fully comprehensive. We would like to stress that if you have any specific questions related to your child's situation, you should feel free to contact any one of us with any comments/questions/suggestions!

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