Supporting Working Parents of Children and Youth with Mental Health Challenges

National Federation of Families for Children’s Mental Health

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Work-Life Integration

- Refers to the degree to which people are able to find a functional and satisfactory level of accommodation in their work and personal lives (Rapoport, Bailyn, Fletcher, & Pruitt, 2002).

- Affected by the availability of community resources and the level of demands in both families and workplaces (Voydanoff, 2005).

- Workshop today is based on 20 years of work-life integration research by a team at the Portland RTC, and years of experience in family organizations.
Workshop Objectives

Participants will learn to:

1. Explain the differences between exceptional caregiving and typical care responsibilities.
2. Identify major federal policies addressing the work-life concerns of family members raising children and youth with mental health challenges.
3. Recognize formal and informal workplace supports.
4. Develop a plan to disclose the information that is necessary to obtain needed workplace supports.
5. Describe and use communication strategies for negotiating with employers.
Mental Health and Parenting

• 11% of children under 18 have mental health disorders severe enough to cause significant difficulty (Surgeon General, 2001).

• 20% of U.S. households care for children with special needs (Child & Adolescent Health Initiative, 2004).

• Nearly 20% of children experience symptoms of a mental health disorder over the course of a year; 5% are considered to have serious emotional disorders (U.S. Department of Health & Human Services, 1999).

• In the U.S., approximately 9% of employees care for children or youth with disabilities (Perrin et al., 2007).
Work-Life Challenges

• Working caregivers of children/youth with disabilities experience **exceptional care responsibilities** and deal with atypical:
  – Physical
  – Psychological
  – Emotional
  – Familial
  – Time
  – Financial demands

• Often care responsibilities continue into young adulthood (Brennan, Rosenzweig, & Malsch, 2008).
### Exceptional Caregiving Responsibilities (Roundtree and Lynch, 2006)

<table>
<thead>
<tr>
<th>Caring for a child/youth with typical development</th>
<th>Caring for a child/youth with special needs/disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant care that diminishes</td>
<td>Constant care that often escalates</td>
</tr>
<tr>
<td>Ordinary input of time and energy</td>
<td>Extraordinary input of time and energy</td>
</tr>
<tr>
<td>Easier as time goes by</td>
<td>Often harder as time goes by</td>
</tr>
<tr>
<td>Few interruptions are emergency-driven</td>
<td>Many interruptions are emergency-driven</td>
</tr>
<tr>
<td>Child/youth grows increasingly independent</td>
<td>Child/youth may grow increasingly dependent</td>
</tr>
<tr>
<td>Requires some lifestyle adjustments</td>
<td>Requires numerous lifestyle adjustments</td>
</tr>
<tr>
<td>Challenges and successes are easily shared</td>
<td>Challenges are rarely shared; successes are fewer</td>
</tr>
</tbody>
</table>
What are the exceptional caregiving responsibilities families experience when a child or youth has mental health difficulties?
Job Insecurity and Job Loss

- Currently Unemployed: 18%
- Cannot Find Employment: 11%
- Lost Employment: 27%
- Quit Employment: 48%

Rosenzweig & Huffstutter, 2004
Part Two: Federal Policies
Key Policies and Legal Issues

• Family and Medical Leave Act (FMLA).

• Americans with Disabilities Act (ADA), Association Provision.

• Individuals with Disabilities Education Act (IDEA).

• Family Responsibilities Discrimination.
Family Medical Leave Act (FMLA)

• Provides entitlement of up to 12 weeks of job-protected, unpaid leave during any 12-month period.

• Applies to all public sector employers but only those private sector employers with 50 or more employees.

• Eligibility requires the employee has worked continuously for 12 months for the same employer and has worked 1200 hours during the previous 12 months.
FMLA Basics

• Family circumstances require that the employee be absent from work due to
  – Newborn child/newly adopted child or foster youth
  – Her/his own serious health condition
  – Spouse, parent, or child/youth with serious health condition.

• Can be taken in full, part, or intermittently

• Employers can require that employees use paid leave as part of the entitlement.
State FMLA Policies

• Some states have provided more protections:
  – Oregon FMLA has policies protecting workers in small businesses.
  – California provides paid FMLA for workers who participate in the state’s disability insurance program (55% of pay for up to 6 weeks, maximum of $850 per week).
The Association Provision of ADA (2005)—prohibits discrimination in the workplace aimed at persons who care for children/youth or adults with disabilities.

Employers cannot refuse to hire, to promote, or fire employees because of their association with persons, or relationship to persons with disabilities.
• Must provide flexible work arrangements if they are available to other workers. (USEEOC, 2007).

• Although employers must provide reasonable accommodations for workers with disabilities, ADA does not require employers to provide for the particular needs of a parent of a child with a disability. (Pittman vs. Mosley, 2002).
• Schools are obligated to teach children/youth with disabilities in as inclusive a setting as possible.

• They may only be removed from this setting if their disability inhibits their learning.
IDEA Basics

• Children/youth identified as having a disability are entitled to specialized services in school (including counseling and IEP, ITP)

• Parents have the right to be involved in the development and review of IEPs.

• Some employers provide flexibility in schedules for parents to participate in education meetings.
Family Responsibilities Discrimination (FRD)

• Newly emerging area of employment law (Williams & Calvert, 2006).

• Brought against employers by employees who believe they have been discriminated against because of their caregiving responsibilities.

• Example: demoting a mother who returns to work after caring for a young person with a chronic illness, based on the assumption of her commitment to her caregiver role.

• Center for WorkLife Law provides resources.
Part Three: Workplace Strategies / Supports
“I loved my job. They were good about it for a long time. Then, leaving for appointments and meetings started to be a problem. I tried to explain, but I think they were just tired of the excuses.”

-Parent of a child with behavioral health issues
Reality

• Getting into a routine between changes and crises may be challenging.
• There are ongoing expectations of parents and caretakers, such as:
  – Being a parent and “caretaker” of the home and each individual family member;
  – Attending to needs within the context of family, culture, and community; and
  – Working to provide food, shelter, and other basics.
The Outcome

• Families often have problems at work resulting from excessive absences due to school problems or appointments.

• Some employers are sensitive to problems.

• Others do not understand the demands or issues families deal with.
To Get Support

• It is important to:
  – Help employers understand unique family needs and how these may impact them on the job.
  – Keep them updated on what is happening so they do not think absences are examples of poor work ethics.
Top 5 Strategies Used by Parents

1. Find a family-friendly workplace
2. Learn about rights and relevant benefits
3. Structure work to maximize flexibility
4. Make a disclosure plan
5. Negotiate reciprocity
Workplace Strategy and Support Basics

Information Gathering & Research

Making Decisions

Developing an Option Plan
• Information and research will allow:
  – Planning and preparation;
  – Realistic expectations;
  – An understanding of promising or best practices;
  – New and emerging trends in employee support; and
  – An understanding of company specific policies and provisions relative to employees.
Information and Research

• Developing a strategic path for information gathering might include:
  – Company policy manual and website
  – Similar companies in the area of like size and service policies and website;
  – Web search for awards and recognition to companies who offer exemplary support to employees;
  – Research and data on approaches to employee’s with a special needs family member support.
• Decisions regarding the following are often precursors to developing a plan:
  – What would a model work environment look like?
  – What are the desired work factors that would produce a supportive work environment?
  – Is disclosure necessary to get the support required for success?
NOTE about Accommodations

• Accommodations in the workplace, while not required by law, can and do occur as supports offered by the workplace to facilitate employee success and tenure.

• While they cannot be demanded, they can still be negotiation points with employers by family members with a child or youth who has mental health challenges.
Developing an Option Plan

Map current or anticipated work issues:

- Absences
- Fatigue
- Crises
- Burnout
- Disclosure
Developing an Option Plan

Outline options regarding:

- Requesting accommodations
- Flexibility
- Potential policy change
- Change in workload, structure, or location
Possible Accommodations

• Work Environment & Support
  – Telecommuting
  – Car rental/leasing allowed
  – Calls related to child/family needs allowed at work
Possible Accommodations

• Schedules
  – Flexible start and end times
  – Schedules consider school holidays and vacations
  – Job sharing
  – After typical hours work allowed
  – Hour banks
Part Four: Developing Disclosure Plans
Workplace Factors

- Type of job/position the employee holds
- Workplace culture
- Availability and accessibility of formal support
- Perceptions of informal support
- Concerns about privacy and confidentiality
• **Courtesy stigmatization** is based on assignment of responsibility for children’s private and public behavior to successful or deficient parenting.

  – Mothers compared to fathers are held more responsible for the behavior and mental health of children.

  – Stigmatization experiences vary by cultural identity.

• Success of parenting is culturally evaluated by the youth’s successful attainment of adult roles and responsibilities, as signified by the diminishment of the active parenting.

  (Gray, 2002; Fernandez & Arcia, 2004; Harden, 2005).
• Management strategies used by parents:
  – Concealment and secrecy
  – Limiting exposure to stigmatizing reactions of others, including limiting public outings, selective disclosure, and restricting socializing to others who would understand (Gray, 2002).
  – Levels of disclosure differ from across domains, roles, and relationships (home, school, work, child care, and community activities).
Dimensions of Disclosure – Timing

- Never
- During the interview process
- When the job is secured
- When a positive performance pattern is established.
- When a response to a non-crisis family matter is needed
- When a crisis occurs
Dimensions of Disclosure – Target Audience

- No one
- Employer
- Immediate supervisor
- Higher level manager
- One or more co-workers
- HR personnel
- Employee assistance staff
- Can request confidentiality under HIPPA
Dimensions of Disclosure – Type

- Disability
- Chronic illness
- Mental health disorder
- Specific diagnosis
- Description of specific behaviors
- Type of treatment needed
- Impact on self and family
# Disclosure Outcomes

<table>
<thead>
<tr>
<th>Disclosure</th>
<th>Positive</th>
<th>Negative</th>
</tr>
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</table>
|            | • Access formal supports  
  • Flexible work arrangements  
  • Increase informal supports  
  • Educate others | • Courtesy stigmatization  
  • Equity concerns  
  • Performance scrutiny  
  • Co-worker resentment  
  • Job insecurity/loss |

| Concealment | • Avoid courtesy stigmatization  
  • Avoid equity concerns  
  • Avoid performance scrutiny  
  • Avoid co-worker resentment  
  • Escape worries from home  
  • Maintain a “normal appearing” work life | • Diminished access to formal supports  
  • Diminished flexible work arrangements  
  • Diminished informal support  
  • Isolation |
Part Five: Communication Strategies for Workplace Negotiations
Successful Communication

• Includes the capacity to:
  – Listen;
  – Read and use body language;
  – Speak clearly;
  – Ask open-ended questions;
  – Summarize for clarity;
  – Manage and use emotions; and
  – Follow through and follow up.
Effective communication is necessary to:

- Present needs, ideas, and plans
- Negotiate optimum outcomes
Presentation

• When presenting ideas, needs, requests:
  – Use plans to guide and provide direction, information, and reference
  – Prepare when possible
  – Know negotiable components
  – Remain calm
  – Repeat when necessary
  – Share knowledge
  – Take informational fact sheets
Negotiate Reciprocity

• Reciprocity is a relational process
  – A mutual exchange between employee and immediate supervisor/coworker resulting in benefits to all stakeholders.

• Based in respect and trust
  – Requires negotiation and accountability for commitments made.

• Used to:
  – Create a friendly environment for acceptance and change
Strategies Used by Parents

• Be proactive
  – Make an informed decision on disclosure prior to needing it.
  – Have an option plan before it is an emergency.
  – Alert supervisor/co-worker whenever possible.
  – Learn about availability of flexibility (flex) options at your workplace, both formal and informal.
Strategies Used by Parents

• Offer win-win solutions
  – Brainstorm and make specific suggestions about mutually beneficial exchanges.
  – Identify unique skill set developed through exceptional caregiving responsibilities experience.
  – Recognize employer contributions to your current work skills and ethics.
  – Leverage skills in exchange negotiation.
Strategies Used by Parents

• Demonstrate Organizational Commitment
  – Highlight your community presence when appropriate.
  – Build on your work history.
  – Follow through on the agreement made with supervisor/co-workers.
  – Communicate appreciation to supervisors/co-workers on a regular and ongoing basis.
Use Your Resources

• Get someone to accompany you:
  – Professional, Support Provider, etc.

• Create a folder to share at work (if comfortable)
  – With current disorder and movement information and keep it up to date

• Build a sense of presence with your employer
  – Invite them to mental health awareness activities
Application – Susan

Role play in groups of 3-5

– Susan

– Supervisor

– Peer Support Specialist

1. What information does Susan need to disclose and to whom?
2. What resources does Susan need?
3. What points come up in negotiation?
Thank you!

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www.pathwaysrtc.pdx.edu/proj-trainingcollaborative.shtml
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