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Supporting Working Parents of Children and Youth with Mental Health Challenges

National Federation of Families for Children’s Mental Health
Our Team

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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

<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>

(ROUNDTREE AND LYNCH, 2006)
What are the exceptional caregiving responsibilities families experience when a child or youth has mental health difficulties?
Job Insecurity and Job Loss

Rosenzweig & Huffstutter, 2004

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).

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. (US Equal Employment Opportunity Commission, 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.
• 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.
“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.
Making Decisions

• 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

### Possible Outcomes of the Disclosure Decisions

<table>
<thead>
<tr>
<th>Disclosure</th>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Access formal supports</td>
<td>• Courtesy stigmatization</td>
</tr>
<tr>
<td></td>
<td>• Flexible work arrangements</td>
<td>• Equity concerns</td>
</tr>
<tr>
<td></td>
<td>• Increase informal supports</td>
<td>• Performance scrutiny</td>
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<tr>
<td></td>
<td>• Educate others</td>
<td>• Co-worker resentment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Job insecurity/loss</td>
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</tbody>
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<table>
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<th>Concealment</th>
<th>Positive</th>
<th>Negative</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>• Avoid courtesy stigmatization</td>
<td>• Diminished access to formal supports</td>
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</tr>
<tr>
<td></td>
<td>• Avoid co-worker resentment</td>
<td>• Isolation</td>
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<tr>
<td></td>
<td>• Escape worries from home</td>
<td></td>
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<tr>
<td></td>
<td>• Maintain a “normal appearing” work life</td>
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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!

Portland, Oregon
Home of Pathways RTC

Project Contact Information:
www.pathwaysrtc.pdx.edu/proj-trainingcollaborative.shtml
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