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# Taking It On: Disclosure, Stigmatization, and Self-Esteem

Presented at:

Building on Family Strengths: State of the  
Science Conference, Research and  
Training Center on Family Support and  
Children's Mental Health.

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# Part One: Self-Esteem of Children with ADHD

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Presented by

- Judith Kendall, Principal Investigator
- Parents and Children Together Study
- School of Nursing
- Oregon Health & Science University

# Part Two: Disclosure, Stigmatization, & the Workplace

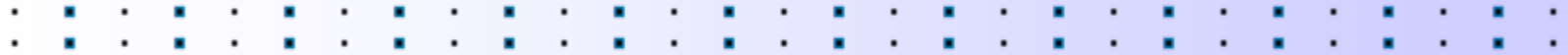
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Work-Life Integration Project--  
Research and Training Center  
on Family Support & Children's  
Mental Health; Portland State  
University.

- ✋ Julie M. Rosenzweig & Eileen M. Brennan, Co-principal Investigators,
- ✋ Anna Malsch, Project Manager,
- ✋ Lisa Stewart, Graduate Research Assistant, and
- ✋ John Conley, Project Intern.

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- ✎ Keep you updated on the progress of the work we're presenting today (and related news). We do this through monthly *rtcUpdates*.
- ✎ Evaluate our work and show our funders that what we do has an impact. We do this using very brief internet surveys.
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# Getting To Know You

 What interested you in this topic?

# Over a Decade of Work-Life Integration Research on Families of Children with Mental Health Disabilities

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- Support for Working Caregivers Project (1996-1999)
  - Secondary analysis of data from *North Carolina Caregivers Survey* (N = 243)
  - 5 focus groups with parents (N = 41)
  - In-depth interviews with parents (N = 60)
- Models of Inclusion in Child Care (1999-2004)
  - Interviews with staff and center directors at 9 inclusive centers (N = 49)
  - Interviews with parents at 9 inclusive centers (N = 25)
  - Interviews with state child care administrators (N = 24)
- Common Ground? Families & Employers (2000-2004)
  - *Parent Employment Experiences Survey* (N = 349)
  - *Workplace Support for Parents of Children with Mental Health Disorders Survey*; Mailed surveys (N = 31), interviews with supervisors (N = 27)

# Current Research Project

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## *Work-Life Integration for Families with Children and Adolescents Who Have Emotional or Behavioral Disorders (2004-2009)*

- ☞ **Phase I:** Caregiver Workforce Participation Study, N = 2,585;  
Secondary analysis of data from the national evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program (Brennan & Brannan, 2005).
- ☞ **Phase II:** **Focus groups: Parents and Human Resource (HR) Professionals;**  
**Parents: 5 groups, N = 28**, HR: 3 groups, N = 17
- ☞ **Phase III:** Work-Life Flexibility and Dependent Care Survey, N = 551;  
In partnership with WorldatWork
- ☞ **Phase IV:** Design and offer training to HR professionals
- ☞ **Phase V:** Resource development for families and businesses

# Work-Life Integration Project Goals and Objectives

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## Overall Goal

- To improve the extent to which families with dependent care needs have access to and awareness of employment-based supports that promote work-life integration — participation in the workplace, while permitting them to take part in family and community life and roles.

## Objectives

- To identify HR policies and practices that support employees with dependent care responsibilities, particularly children with special needs.
- To provide information and resources to HR professionals about best practices that support employees caring for children with mental health disabilities.

# Work-Life Integration Defined

- Work-family fit is pivotal to work-life integration. Fit is the degree to which an employed parent realizes the various components of an adaptive strategy for dealing with the boundary between work and family (Barnett, 1998).
- Acknowledges that the amount of time spent in either domain will vary over one's life span (Rapoport, Bailyn, Fletcher, & Pruitt, 2002).
- Affected by disclosure, stigmatization, and flexibility arrangements experienced by the parents (Brennan et al., 2005).
- Influenced by the availability of community resources and demands for both families and workplaces (Voydanoff, 2002).

# Workplace Culture and Support Can Promote Integration

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- ✎ **Workplace culture** defined as shared assumptions, beliefs, and values regarding the extent to which an organization supports and values the integration of employees' work and family lives (Thompson, Beauvais, & Lyness, 1999).
- ✎ ***Workplace support*** incorporates flexibility in work arrangements, supervisor support, supportive workplace culture, positive coworker relations, respect in the workplace, and equal opportunity for workers of all backgrounds (Bond, Galinsky, & Swanberg, 1998).
- ✎ Unfortunately some workplaces are less supportive and may actually stigmatize persons with mental health difficulties and their families.

# Stigmatization and Mental Illness

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- President's New Freedom Commission on Mental Health (2003) calls for national campaign for reducing stigma of seeking care. Noting that:
  - Stigma is particularly pronounced among older adults, ethnic and racial minorities, and residents of rural areas.
  - Research shows that the most effective way to reduce stigma is through personal contact with someone with a mental illness.

# Stigma Defined

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- ✎ “Stigma results when people find others different from their definitions of self and conceptualize that being different, they are also inferior” (Fernandez & Arcia, 2004).
- ✎ Involves labeling, stereotyping, separation, status loss, and discrimination (Green, Davis, Karshmer, Marsh, & Straight, 2005; Link & Phelan, 2001).

# Effects of Primary Stigma

## *Stigmatization*

- A cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illnesses.
- Stigmatization leads others to avoid living, socializing, or working with, renting to, or employing people with mental disorders - especially severe disorders, such as schizophrenia. It leads to low self-esteem, isolation, and hopelessness.
- It deters the public from seeking and wanting to pay for care.
- Responding to stigmatization, people with mental health problems internalize public attitudes and become so embarrassed or ashamed that they often conceal symptoms and fail to seek treatment.

President's New Commission on Mental Health (2003)

# Stigmatization: What Persons with Mental Illness Can Experience in the Workplace

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- ☞ **Direct stigmatization:** being the recipient of stigmatizing attitudes and behaviors
- ☞ **Indirect stigmatization:** observing stigmatization directed towards others
- ☞ **Perceived stigmatization:** person construes or anticipates stigmatization without observable evidence

(Rusinova, Nicolellis, & Rapp, 2006)

# Courtesy Stigma

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- ✎ Courtesy stigma (Goffman, 1963): the prejudice & discrimination extended to people associated with the person having the stigmatizing 'mark' (Norvilitis, Scime, & Lee, 2002; Corrigan, Miller & Watson, 2006).
- ✎ Also called "stigma by association," "associative stigma," "stigma of affiliation" & "family stigma".
- ✎ Four domains of courtesy stigma: 1) interpersonal interaction, 2) structural discrimination, 3) public images of mental illness, and 4) access to social roles (Angermeyer, Schulze, & Dietrich, 2003).

# Parent's Lived Experience of Stigma by Association

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*The experience of courtesy stigma can be real or perceived.*

- ✎ Enacted stigma: overt acts of discrimination and rejection (Gray, 2002).
- ✎ Felt stigma: feelings of shame, blame, self-blame, embarrassment (Gray, 2002).
- ✎ Subjective burden: psychological distress related to caring for the family member (Hinshaw, 2005).
- ✎ Objective burden: financial costs, logistical negotiations surrounding care responsibilities (Hinshaw, 2005).

# Stigma and Parenting Children & Adolescents with Mental Health Disorders

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- ✎ Parents of children and adolescents with serious emotional or behavioral disorders experience stigmatization associated with their children's behaviors related to the mental health disorder.
- ✎ Stigmatization experienced by parents of children and adolescents with serious emotional or behavioral disorders is based on the social-cultural assignment of responsibility for children's private and public behavior to successful or deficit parenting.
  - Mothers compared to fathers are held more responsible for the behavior and mental health of children.
  - Stigmatization experience by vary by cultural identity.
- ✎ Success of parenting is culturally evaluated by the youth's matriculation into adulthood roles and responsibilities, as signified by the diminishment of the active parenting.

(Gray, 2002; Fernandez & Arcia, 2004; Harden, 2005).

# Courtesy Stigmatization Management Strategies

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- Management strategies used by parents related to associated stigma focus largely on controlling the dissemination of information regarding their child's mental health disorder (Gray, 2002).
  - Concealment and secrecy.
  - Passing: "normal appearing round of family life" (Birenbaum, 1970).
  - Limiting exposure to stigmatizing reactions of others, including limiting public outings, selective disclosure, & restricting socializing to others who would understand (Gray, 2002).
  - Levels of disclosure across domains, roles, & relationships.

# Disclosure

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- ✎ Persons with mental illness and their family members face a decision about whether or not to tell others about their mental health difficulties.
- ✎ In a recent online survey of parents of children with emotional or behavioral disorders, a great majority (83%) told their supervisors and (86%) informed their co-workers about their children's situation (Rosenzweig & Huffstutter, 2004).
- ✎ Family members may experience personal and social benefits from disclosing (Ellison, Russinova, MacDonald-Wilson, & Lyass, 2003), but it may also trigger stigmatization.

# Research Questions

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1. How do parents experience **stigmatization** in the workplace?
2. Why do parents **disclose** or **conceal** their children's mental health challenges?
3. What are the **workplace factors** that encourage or inhibit parental disclosure of their children's mental health status?
4. What are the stigmatization management **strategies** used by parents in the workplace?
5. What effect does parental disclosure of children's mental health status in the workplace have on their **experience of stigmatization**?
6. What effect does parental disclosure have on their **experience of workplace support**?

# Methods: Sampling

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- ✎ Purposive sampling (Patton, 1990) of employed parents of children with emotional or behavioral disorders.
- ✎ Goal to reach employed family members from a variety of employment contexts and varied experiences.
- ✎ Recruitment of parents through children's mental health conferences, parent support and advocacy networks and RTC website and parent support networks.
- ✎ Study information provided with invitation to contact research team with questions or to sign up.

# Methods: Procedures

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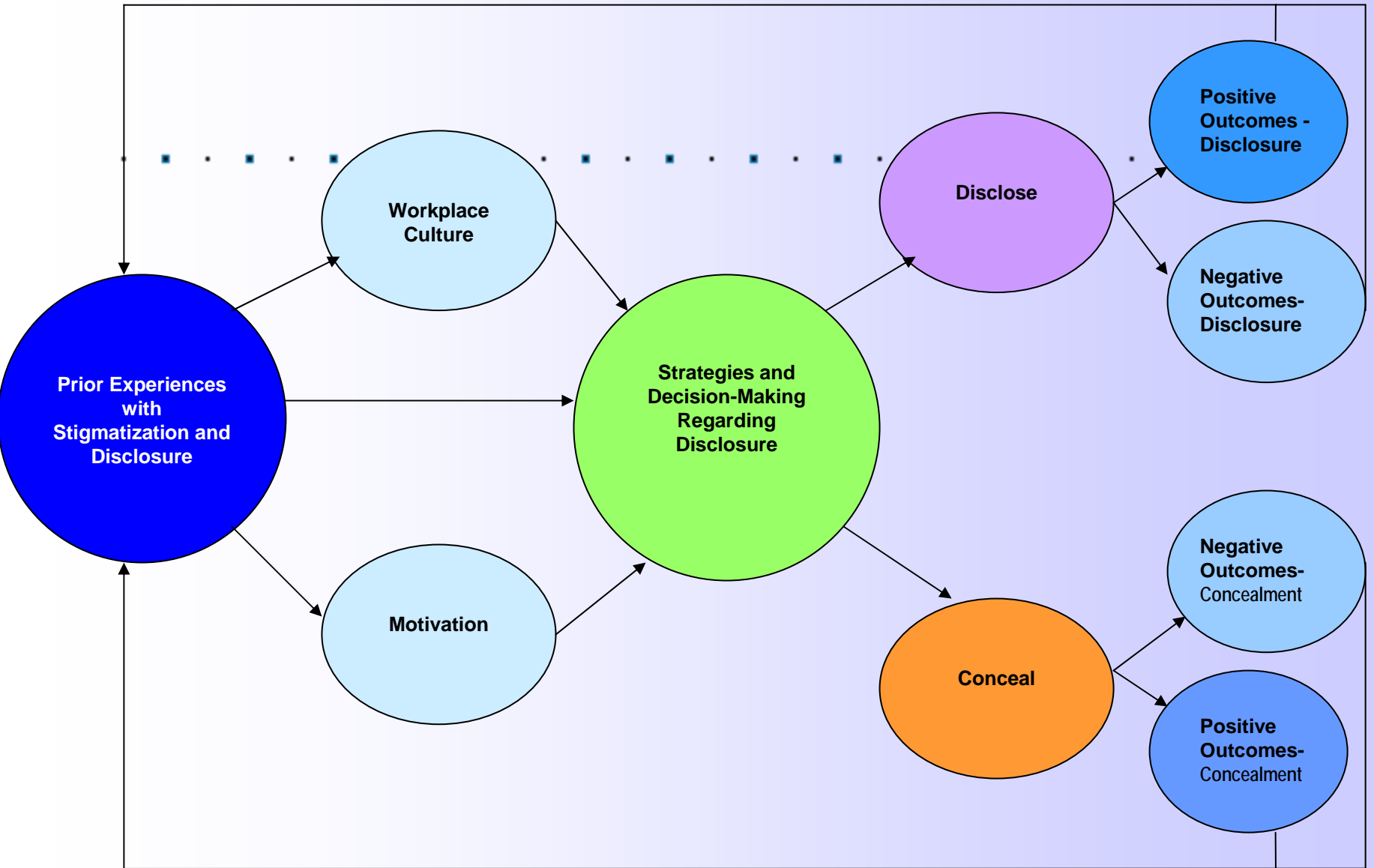
- ✎ Focus group discussion topics derived through prior research and literature reviews.
- ✎ Prior to start of group, informed consent collected and demographic questionnaire administered; permission to tape session obtained.
- ✎ Protocol began with more general questions to familiarize participants with the topic, then proceeded to more specific questions (Kreuger, 1997).
- ✎ Moderators supported discussion and probed to clarify information or deepen the conversation (Kreuger, 1998).

# Methods: Analysis

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- Audiotaped, transcribed, entered in to analysis software (NUD\*IST).
- Systematic coding process using grounded theory approaches (Charmaz, 2006).
- Open coding by four researchers working independently.
- Preliminary coding and agreement established through meetings of research team to discuss and compare interpretations.
- Secondary/axial coding focused on establishing substantive themes and relationships among them (Strauss & Corbin, 1998).





The relationship between stigmatization and parental disclosure of a child's mental health status in the workplace.

# Direct Stigmatization

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Parents spoke of their experiences of *direct stigmatization* as:

- ✎ Being blamed for being a bad parent,
- ✎ Co-worker resentment of reasonable accommodation,
- ✎ Lack of understanding about child's illness and exceptional caregiving,
- ✎ Discrediting of professional competence, and
- ✎ Equity issues.
  - *When my problems first started with my boys, my boss was good about letting me off, but he always made me feel like they were looking down on me" [Later, he] would say, 'Here she is, having trouble with these kids again'... I finally quit the job."*

# Indirect Stigmatization

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## *Indirect Stigmatization*

- ✎ Differential treatment of others because of their child's mental health status.
- ✎ One parent spoke of her experiences watching how her workplace responds to her co-worker's needs for flexibility for her exceptional caregiving needs:
  - “[I have a co-worker] *who misses more time than I do, so I think I kind of watch to see if she's going to get into trouble.... The phone rings and I am holding my breath. If it is for her, I am like, whew!*”

# Perceived Stigmatization

*Perceived stigmatization* occurs when parents perceive stigma even if it hasn't happened to them at the workplace. Parents who experienced this type of stigma in our study described it as:

- ✎ Feeling blamed for being a bad parent,
- ✎ Feeling that co-workers resent their requests for reasonable accommodations,
- ✎ Feeling that others lack understanding regarding child's illness and exceptional caregiving
- ✎ Discrediting of professional competence.

For example, one parent recalls her experience as:

- *"But still [co-workers] don't look at mental illness like a broken leg. That's hard, because I think that sometimes people do think ... you are just trying to get out of work."*

# Internalized Stigmatization

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*Internalized stigmatization* was expressed by parents through feelings of inadequacy related to:

- ✎ Their professional capacity
- ✎ Believing that they are being a bad parent (self-blame).

In the words of one parent who spoke of her experiences with this kind of stigmatization:

- *"I turn that on to myself, but I just can hear people thinking it and saying it. What is wrong with you as the parent, and then if you can't handle your child, can you do your job?"*

# Workplace Culture

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- ✎ Workplace culture played a significant role in parents' experiences of positive or negative consequences of disclosure.
- ✎ Parents described that their decision to disclose and their experiences of disclosure depended on the *level of family friendliness* of their workplace.

# Workplace Culture

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One parent spoke of her experiences as very family-friendly:

- *"I work at an oncology office. So people are dealing with death and dying and major issues on a daily basis, and many cancer patients suffer from depression or other mental health issues. I think that this gives a great compassion and understanding on the part of the people that I work with."*

Another parent described her workplace culture as extremely un-family-friendly:

- *"I feel like I'm the only one [who needs flexibility to care for child with exceptional care needs] though I know that it isn't true. I don't feel like there is a support network within my organization."*

# What Motivates Parents' Choice to Disclose or Conceal?

Parents spoke of their motivations for *disclosure* arising from need to:

- ✎ To work through crisis
- ✎ To gain formal supports
- ✎ In anticipation of crisis
- ✎ To avoid co-worker resentment
- ✎ When to disclose

Parents spoke of their decision to *conceal* their child's status:

- ✎ To maintain a "normal" working life

# Strategies & Decision Making Regarding Disclosure

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☞ Parents talked about their disclosure strategies:

- Full disclosure
- Telling enough, and not asking too much.
- Self-censoring
- Bending the truth

☞ and decisions:

- Whom they should tell about their child
- How much should they say about their child and family
- How they should time their disclosures.

# Strategy: Full Disclosure

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- ✋ Some family members decided to let everyone at their workplace know about their children's challenges. One mother's strategy was to bring her son who was affected by ADHD to the company picnic.
  - *"I found that right after I started working for the mill, which is the most challenging job already, we had a family gathering. I thought, you know, I am going to bring my son. The power of sight is an amazing thing...[My boss] came over to me and he put his hand on my shoulder, and he was like, "... anytime you need to take time off, we understand...He is a very active young man, isn't he?" Yes, he is, so [my boss] understood."*

# Strategy: Telling Enough and Not Asking Too Much

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- ✎ A mother spoke of her concerns about telling enough to get the accommodation of taking personal phone calls, but not "*pushing the envelope*:"
  - *"I find myself struggling. I am walking a pretty fine line here. What is going to happen? Am I pushing the envelope too far? At what point do they say 'You've gotten too many personal phone calls?' How do I ask HR 'How many school phone calls can I get in a day before I am going to be written up for not being able to do my job?'"*

# Strategy: Self-Censoring

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- ☞ Parents **self-censored** their communication and limited the amount of information disclosed in the workplace for “self-preservation:”
  - *“I don’t want to tell anybody, but I think I let my direct supervisor...know basic information and wait for her to ask me more questions. I could rattle off two days worth of information about what I have been going through with my son in the last 24 hours. I try to limit what I tell people in the workplace mostly for self preservation.”*

# Strategy: Bending the Truth

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✋ In organizations which did not have a workplace culture that accepted family differences, some parents felt they needed to **bend the truth** in their communications. For example, a parent and her partner had just returned from a family vacation. When co-workers asked how it had been:

- *“Well let me see. [I could have said ‘My son] threatened to kill himself... [My partner] had to hold him in a safety hold for about three hours’... People don’t want to hear that. Instead you say ‘Oh it was quite lovely, thank you. I don’t think the kids had quite as much fun as we had hoped they would.’”*

# The Decision to Disclose: Whom to Tell

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- ☞ Parents reported that they had to decide **whom to tell** about their child's needs and their own need for accommodations:
  - *"I know that the teacher I work for [is understanding] and I have shared with her my challenges with my child. She is aware of it, so I think that is helpful.."*
  - *"I tend not to be that forthcoming with other than immediate colleagues. I've got some very good friends who know, but with my supervisor...I don't know what I would tell her.."*
  - *"Because my son is at my day care [where I work] I have to share with the employees what is going on with him. If I don't then they think he is an out-of-control kid..."*

# The Decision to Disclose: How Much to Tell

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- ✎ Given an accepting work environment, some parents chose to share deeply.
  - *"Because of what everyone does where I work [a family support organization] it is more open to sharing, because we deal with those kind of things on an ongoing everyday basis... What I deal with at home, I deal with at work, so it is just kind of intertwined."*
- ✎ Other parents only told the bare minimum:
  - *"I just would explain I was having difficulty, and I didn't really say anything [about the mental health problem], because we didn't have a diagnosis. I would just say, well, he did this at school today and I have to go."*

# The Decision to Disclose: When to Tell

-  Some parents told employers immediately:
  - *“Before I became employed in this last job, I just let them know right upfront that I was on a one-to-one basis with the police, one-to-one basis with the emergency room, one-to-one basis with almost anybody who would be emergency personnel, the principal also.”*
-  Other parents talked about concealing their situations from new employers, and only communicating their family’s needs after they were valued as employees.
  - *“If I went to a new job, I wouldn’t even tell them, which is probably not fair...[After] you demonstrate that you are a very productive worker...[they are likely] to give you that flexibility.”*

# Positive Outcomes of Disclosure

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-  Employed parents who chose to disclose their children's mental health status and their families' needs benefited by:
  - Being given formal supports;
  - Obtaining flexible work arrangements;
  - Receiving emotional and instrumental (practical) support from supervisors, co-workers, and others ;
  - Finding similar others in the workplace;
  - Getting useful advice; and,
  - Having greater professional credibility on the job.

# Negative Outcomes of Disclosure

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- On the other hand, parents also reported the following negative aspects of disclosing their situation at the workplace:
  - Triggering stigmatization with its associated emotional costs;
  - Getting unhelpful, unsolicited advice;
  - Raising equity concerns;
  - Bearing the brunt of co-workers' resentment;
  - Setting off scrutiny regarding job performance; and
  - Becoming fearful of job loss.

# The Decision to Conceal

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- ✎ Some parents reported that they made the decision to conceal their families' situations.
  - *"I don't think there are many places out there that if I said, 'My kid is PDB and I am probably going to have to leave frequently,' that are going to give me a job."*
- ✎ Others talked about formal policies that made disclosure less likely:
  - *"I've watched processes change where now we try to insure confidentiality, that I am not asked as I am being hired or being interviewed, 'Do you have children? Are there any challenges that you may face?'...Because no one asks me, the burden is on me to tell or not to tell."*

# Positive Outcomes of Concealment

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- ☞ Parents spoke of some positive outcomes of concealment:
  - A more “normal” working life;
  - Escaping the realities that they have to face at home, by not mentioning them at work;
  - Avoiding stigmatization; and,
  - Gaining employment.

# Negative Outcomes of Concealment

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- Those parents who chose to conceal their situation also experienced difficulties:
  - Not having special workplace accommodations;
  - Feeling isolated and alone.

# Implications of Our Findings for Employers

- Prior disclosure can help employees set up arrangements to handle family challenges before they cause work crises.
- Disclosing that a child has a mental health problem can cost an employee dearly if the workplace culture is not supportive and targets that worker for stigmatization.
- Workforces need training regarding diversity in their organizations, to combat stigmatization of both adults and children affected by mental health problems and of their families.
- Creating a “family friendly” place of employment includes establishing an environment in which all caregivers are welcome to disclose their family needs and ask for the accommodations they require to be effective employees.

# Implications of Our Findings for Families

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- ✎ When looking for employment, accommodation for your family's needs may be most easily found in a family-friendly organization, which has a supportive workplace culture.
- ✎ Disclosure of your child's mental health problems should be carefully considered.
  - Why should you disclose and to whom?
  - What information should you share?
  - What assurance of confidentiality should you request? (Rosenzweig & Huffstutter, 2004).
- ✎ Family organizations need to work to "teach tolerance" in the workplace and combat stigmatization there.

# Implications of the Findings for Service Providers

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- Service providers should ask families of children with mental health issues about their workplace situations and the types of challenges that they may face there:
  - Working through stigmatization caused by disclosure and/or isolation caused by concealment, and
  - Assisting with plans for disclosure which will help gain the workplace supports that parents need to be effective employees.
- Service providers need to combat stigmatization of persons with mental health problems and of their families through their professional organizations, and by joining with others who want to end this societal problem.

# Question

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- How do we take on stigmatization in the workplace, school, and community?
  - As family members,
  - Co-workers,
  - Employers,
  - Community members?



Portland, OR



Center for Mental Health Services,  
Substance Abuse and Mental Health  
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of Health and Human Services



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