



Portland, Oregon



Research and Training Center  
on Family Support and  
Children's Mental Health

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# Pathways Across the Work-Life Boundary: How Parents with Children with Mental Health Challenges Avoid Stigmatization and Reach Flexibility

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# Work-Life Integration Project Research Team

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- ✎ Julie M. Rosenzweig & Eileen M. Brennan, Co-principal Investigators,
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# Work-Life Integration Project

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**Overall Goal:** *To improve awareness and access for families with dependent care needs to 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 & practices that support employees with dependent care responsibilities, particularly children with special needs.
- ✎ To provide information & resources to HR professionals about best practices that support employees caring for children with mental health disabilities.

# Work Life Integration for Families with Children who have Emotional or Behavioral Disorders (2004-2009)

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- ☞ Phase I: Caregiver Workforce Participation Study
- ☞ Phase II: Focus groups: Parents and HR Professionals
- ☞ Phase III: Work-Life Flexibility and Dependent Care Survey
- ☞ Phase IV: Design and offer training to HR professionals
- ☞ Phase V: Resource development for families and businesses

# Children with Special Needs

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- 21.8% of families in the U.S. have a child with special health care needs (U.S. Department of Health and Human Services [HHS], 2008).
- 24% of those families with children who have health conditions report that it interferes with their daily activities (U.S. Department of Health and Human Services [HHS], 2008).
- 9.2% of families in the U.S are raising a child with a disability (Wang, 2005).

## Concept: Work-Life Integration

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☞ Refers to the degree to which people are able to find a functional and satisfactory level of assimilation in their work and personal lives.
- ☞ Is affected by disclosure, stigmatization, and flexibility arrangements experienced by the parents (Brennan et al., 2005).
- ☞ Impacted by the availability of community resources and demands for both families *and* workplaces (Voydanoff, 2007).

# Exceptional Caregiving Responsibilities

## Caring for a Child with Typical Development

- ☞ Constant care that diminishes
- ☞ Extraordinary input of time and energy
- ☞ Easier as time goes by
- ☞ Few interruptions are emergency-driven
- ☞ Child grows increasingly independent
- ☞ Requires some lifestyle adjustments
- ☞ Challenges and successes are easily shared

## Caring for a Child with Special Needs/Disabilities

- ☞ Constant care that often escalates
- ☞ Extraordinary input of time and energy
- ☞ Often harder as time goes by
- ☞ Many interruptions are emergency-driven
- ☞ Child may grow increasingly dependent
- ☞ Requires numerous lifestyle adjustments
- ☞ Challenges are rarely shared; successes are fewer

# Exceptional Caregiving Responsibilities and Employment

- Approximately 33% of families caring for a child with special needs reported reducing their work hours or quitting their jobs in order to tend to their children's special needs (Child and Adolescent Health Initiative, 2004; Powers, 2003).
- In a survey of 349 caregivers of children with mental health disorders, 48% reported having quit work at some point to care for their child and 27% reported being terminated because of child-related work disruptions (Rosenzweig & Huffstutter, 2004).

# Support for Employed Caregivers is Often Lacking

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- Community supports commonly available to parents of typically developing children such as child care and after-school programs are not always options for parents of children with mental health .
- Therefore, parents are often forced to accommodate their child's needs mainly through employment adjustments.
- However, supports in the workplace often assume that the needs will be relatively short-term (Lewis, Kagan, & Heaton, 2000).

# Caregiver Strain

- ☞ Parents with exceptional care responsibilities report significantly more work-to-family and family-to-work conflict, less satisfaction with marriage, family, life and work as well as higher amounts of stress (Stewart, 2009).

# Concept: Flexibility

- Flexibility is a cross-domain concept: workplace flexibility, family flexibility, and childcare flexibility are necessary to maximize work-life integration (Emlen, 1999).
- Employee-driven workplace flexibility permits family members to have a degree of autonomy to control work location, timing, and/or process (Kossek, Lautsch, & Eaton, 2005).
- Workplace flexibility can be either formal or informal (Eaton, 2003).

# Concept: Disclosure

- Disclosure of child's mental health status at work comes with risks and benefits.
- Benefits include greater support, such as social support or formal supports such as flexibility, and in some cases protection from job loss.
- Risks include negative reaction from supervisors or coworkers and the potential of job insecurity or job loss.  
(Rosenzweig & Huffstutter, 2004).

# Concept: Courtesy Stigmatization

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- ✎ Mental health courtesy stigmatization refers to, “a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illness” (President’s New Freedom Commission on Mental Health, 2003).
- ✎ Parents of children with mental health disabilities experience stigmatization associated with their children’s behaviors related to the mental health disorder (“courtesy stigma”; “stigma by association”; “family stigma”).

# Research Questions

- 1. What are the disclosure strategies used by parents to obtain flexibility and support in the workplace?
- 2. What are HR professionals' management strategies in response to employees' requests for flexibility?

## 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).



## Participants: Employed Caregivers

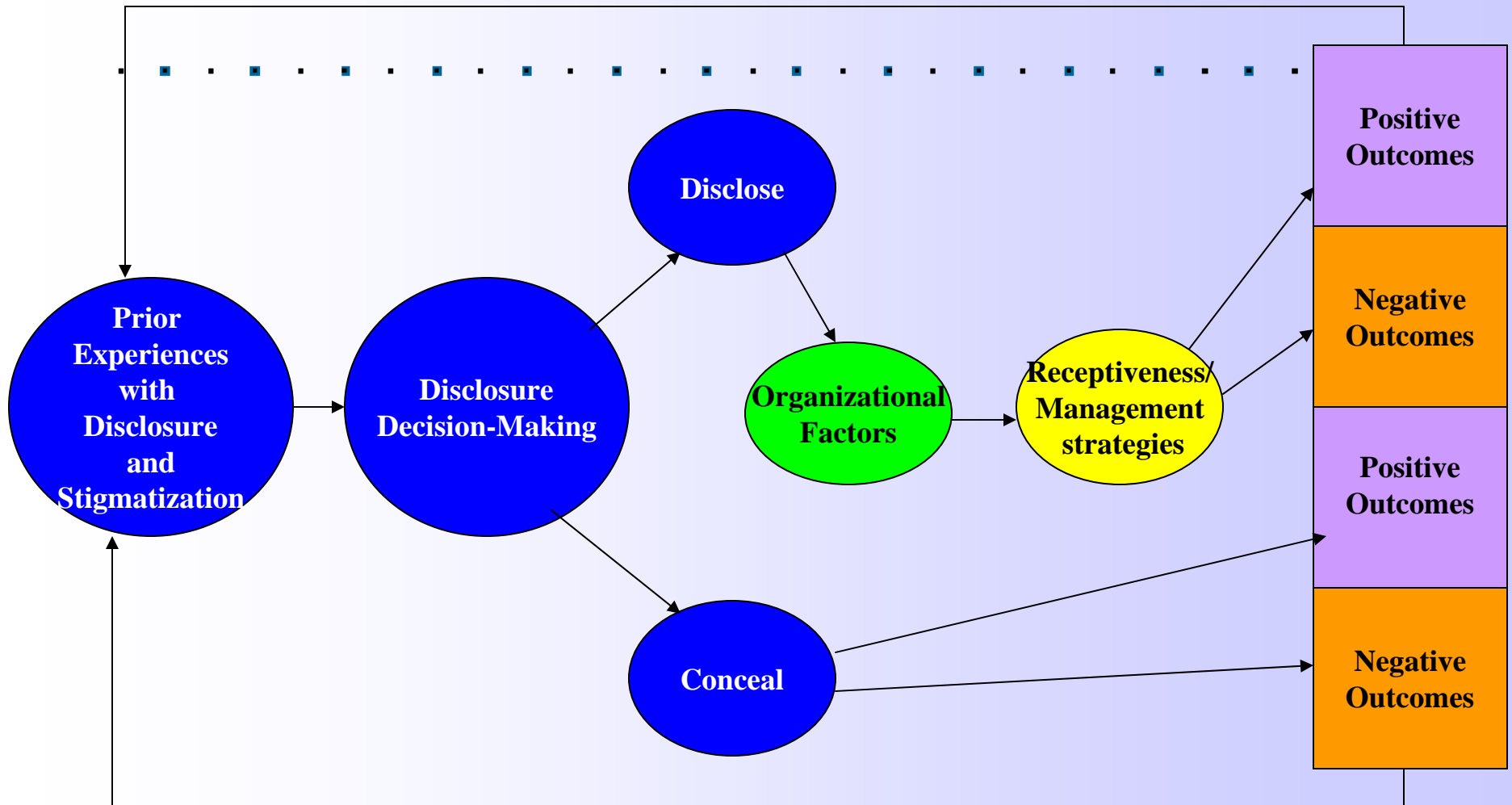
- 5 groups of female caregivers ( $N = 28$ ).
- Mean age = 41.5 ( $SD = 9.1$ ).
- Median family income between \$30,000 and \$39,000; 57% had high school diploma as highest educational level.
- 59 dependents, 43 (75%) w/EBD.
- 54% shared parenting duties w/partner.
- 54% White, 15% African-American, 7% Hispanic.
- Hours per week spent in care = 5-83; in work = 7-60.
- 68% had benefits, mostly flexibility (79%), sick leave (75%), vacation (71%), medical leave (64%), and health insurance (61%).

# Participants: HR Professionals

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- 3 groups of HR professionals ( $N = 17$ )
  - Female (87.5%)
  - Middle aged ( $M = 45.2$  yrs,  $SD = 8.4$ )
  - European American (88.2%)
  - Experienced in HR profession ( $M = 15.6$  yrs,  $SD = 9.1$ )
  - Held certifications in HR field (58.8%)
  - Supervisors (82.4%)

# Building the Conceptual Model



# Employed Caregivers: Prior Experiences with Disclosure and Stigmatization

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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  
(Russinova, Nicolellis, & Rapp, 2006)
- ✎ **Internalized stigmatization**: directing stigmatizing attitudes towards oneself  
(Brennan et al., 2007)

## Direct Stigmatization

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*"I also get a lot of people who don't understand a lot, or who say, 'Oh, it is just one day, what is the big deal?' Or who say, 'I had ADHD. That is just baloney. Everybody is overmedicated. Nobody needs Zoloft' ..."*

## Indirect Stigmatization

“My supervisor has not indicated to me—but I’ve observed her interactions with other employees who have had situations, either immediate family, children, or parent, or spouse, those kinds of situations, and her expectation is that that does not impact on your work. You don’t bring that—work and family are two different things.”

# Perceived Stigmatization

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*"I think that I am judged, that what is wrong with you. Why do you have a son that acts this way? Can't you handle your child? Why are you getting these phone calls at work? Maybe because I am judgmental, 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?"*

# Internalized Stigmatization

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*“I believed that anybody who knew what was going on with my child was right, that my kid was just bad. Eventually that worked in to I must be a bad mom too.”*

# Employed Caregivers: Decisions to Disclose



## Conceal

- To gain employment
- To avoid stigmatization
- To maintain “normal” working life
- To escape the realities that they have to face at home



## Disclose

- To work through crisis
- To gain formal supports
- In anticipation of crisis



## Other considerations when disclosing

- How much? When? To whom?

# Disclosure Strategies

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- ✎ **Full disclosure**: Telling the employer about the child's mental health condition and the challenges the worker faces due to the child's interaction with a variety of systems.
- ✎ **Limited disclosure**: Letting the employer have just enough information to be able to justify workplace adjustments.
- ✎ **Bending-the-truth**: Speaking with the employer and coworkers about the child's and family's experiences in a way that only partially conforms to the facts.
- ✎ **Self-censoring**: Not disclosing the challenges faced by the family due to child's mental health difficulties.

## Full Disclosure

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*“I just let them know right upfront that I was on a one-to-one basis with the police, a one-to-one with the emergency room, a one-to-one basis with almost anybody who would be emergency personnel, the principal also...with that I was just really upfront with this job that I have now. I said my child gets into trouble.”*

## Limited Disclosure

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*"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."*

## Bending-the-truth

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*“Eventually I did have to let him know...I was leaving and saying I was sick and going home, but going to the school. It was kind of hard, because I didn't want them in my business like that.”*

## Self-censoring

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*“You sit there all day, because most employers don’t want to hear it. They do the sighing and then they get angry. I just got to the point that I wouldn’t even tell them. ‘I’m going home for the day.’ That is how I would leave it, because if I tried to be honest and tell my situation, they weren’t very understanding.”*

# Organizational Factors

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- Workplace culture
  - Business case
  - Position requirements
  - Policy considerations
  - Legal considerations
  - Organizational justice

# Workplace Culture

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*“We really try to educate our employees, too, to make sure they are that they are leaving [...] their worries in the worry basket at the front door when they walk into the office, not taking a dozen personal phone calls at the office that are going to interfere with their productivity during the day, and taking just those emergency calls when there is an issue at school.”*

*“Our organization is family driven, so it caters to the needs of the family as well as yours. I don't have that problem where it is like a 9 to 5 and so forth. It is very flexible. As a matter of fact, if we have problems we all talk about what we go through with our children and so forth and exchange information and so forth. We are very supportive with each other on that.”*

## Business Case

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*"I think the really smart companies right now realize that we are moving into a workforce crisis. The companies that are behind the times, who I think have either just been oblivious or have, by rote, mistreated and created a revolving door for their workforce are going to put themselves at risk of losing their business because they lose their workforce."*

*"You earn a lot of loyalty from your people, as an employer, when you do work through these difficult times with them. You have had their babies with them, and you have been through their cancer treatments, and that, I think, goes a long way in building loyalty in your employees."*

# Position Requirements

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*“Unfortunately what I see with my clients is that first the higher up you are, the greater the flexibility you have. If you are a top performer in sales, you can do whatever you want. [...] Unfortunately, as a receptionist, you are the person they want to see every day. When you are not there and they walk in at 8:00, where is she? It is not fair, but that is the way it is.”*

# Policy Considerations

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*“We also start with the policy as our first point of reference, but it is only that. You have to obviously be cognizant of being fair and being equitable, and draw on precedent from prior experiences that may relate. At the same time [...] it would be impossible to come up with a guideline that would work in all scenarios, because it is as individual as the people and the situation involved.”*

# Legal Considerations

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*“It is such a litigious environment. I’m dealing with one situation right now, it is not related to this, but you really have to watch your P’s and Q’s, because just the slightest thing can set someone off. [...] You have to be absolutely careful every step of the way. Otherwise you are opening yourself up to an enormous potential lawsuit.”*

# Organizational Justice

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*“If you allow one employee to do a certain flexibility on issues and then you say no to another, then that brings up a whole other situation of equity that you might have to speak to or you might be breaking your work rules and whatnot. There are just a ton of factors, like everything else in human resources. It is not black and white.”*

# HR Professionals' Receptiveness and Management Strategies

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- ✎ Managing flexibility in a climate of accountability
- ✎ Trusting the employee seeking workplace supports
- ✎ Negotiating the boundaries of communication
- ✎ Balancing the dual roles of HR personnel

# Managing Flexibility in a Climate of Accountability



*" If there was a situation where a sales associate would need flexibility, it would really have to be dealt with on an individual basis... because the showrooms are driven very hard to make money. As for...administrative positions...we can be very flexible in allowing parents to flex their schedule."*

# Managing Flexibility in a Climate of Accountability

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*" We have very narrow margins that we run under. We would attempt to help...we would refer to whatever community resources that I could come up with for this person, but as far as employment, that would be a rough thing for our organization."*

# Trusting the Employee Seeking Workplace Supports

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*“If I have an employee who has been a good employee and trustworthy...then I can make a lot of accommodations.”*

*“Hopefully [employee], I know you are not going to take advantage of me. This is going to work for both of us, and I hope you stay with me as we grow.”*

# Negotiating the Boundaries of Communication

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*" [We] may be motivated by fear that in a situation that is highly personal like this, you have conflicts with confidentiality issues and you have [to worry] how much as I as an employer should know, and how much do I dare ask, and how much do I need to rely on the employee."*

*" Most HR people would agree that it is very difficult to get into that, because you want to be careful that you are following the law, but you don't want to get into a situation where you are overstepping whatever boundaries."*

# Negotiating the Boundaries of Communication



*" When the other employees don't know and don't understand the circumstance, then the rumor mill gets cranked up, and then the peer pressure and the backbiting and whining and moaning goes on... You can't walk in and say...her son is a schizophrenic and he is nervous and slashing himself ."*

*" ...Mental health is a scary issue to people because there is still a lot of mystery surrounding it."*

## Dual Roles of HR Personnel

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" I think the more compassionate your culture is, the less people are going to get mad at you if you do something that is probably not right. They will cut you a little more slack and are less likely to sue you later. "

" A lot of it is the attitude of the organization. If you are willing to work with them, you can pretty much figure out a way to stay legal and get around issues. "

# Implications for Employed Caregivers

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- ✎ Prior disclosure can help employees set up arrangements to handle family challenges before they cause work crises.
- ✎ The timing and amount of disclosure depends on employees' past experiences with stigma and their current needs regarding their child.
- ✎ 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.



# Future Directions

- **Dissertation (Stewart, 2009):** Different types of particularly demanding dependant care are conceptualized within a single construct called **exceptional care**.
  - Secondary analysis of the National Study of the Changing Workforce (NSCW, 2002)
  - Found that exceptional care responsibilities are significantly different from typical family care responsibilities in terms of work-life supports, barriers and outcomes
  - Multiple group SEM models predicting work-life conflict, stress and satisfaction with life and work indicate employed parents with exceptional care responsibilities experience significantly different levels of support than do parents with typical family care responsibilities (Stewart, 2009).

# Future Directions



- ✎ Develop training for HR professionals aimed at increasing awareness and skill regarding the needs of employees with exceptional care responsibilities.
- ✎ Create resources for family members and HR organizations to help both groups in articulating their needs and achieving the support they need to optimize their flexible solutions and achieve a positive work-life fit.