



Portland, Oregon

## “Come Pick Up Your Child!”: Integrating Work and Family Life for Parents of School- Aged Children with Mental Health Challenges

Presented at:

Building on Family Strengths: Research  
& Services in Support of Children and  
their Families

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# Work-life & Your Experience



- How many of you have experienced challenges in managing work and family responsibilities?
- What are your biggest challenges?
  - Child care
  - School
  - Appointments
  - Work disruptions
- Primary concern addressing the integration level of work and family life for parents who have children with emotional or behavioral disorders

# Today's Agenda



## Voices of family members

- Dr. Kendall's Research
- Work-Life Integration Project
  - Caregiver work participation study
- Putting it all together
  - Your thoughts

# Research Projects....



- **Study 1: R15 HD32664, NICHHD, Experiences of Doing Well in Families with ADHD Children, 1994-1997**
- **Study 2. NINR R01- NR05001. ADHD, Ethnicity, and Family Environment, 2000-2005**

# Source of the data....



- Approximately 200 interviews with family members during course of both studies
- Qualitative, Grounded Theory Design
  - Interested in their perception of their experiences
  - Interested in gaining understanding of family life living with a child with ADHD
  - Interested in their emotional and subjective experience
  - Interested in what families said they needed

# Voices of Family Members....



- Mothers
  - Chronic sorrow, exhaustion, loss, grief, guilt, fear,
- Fathers
  - Confusion, sorrow, loss, powerlessness
- Siblings
  - Victimization, loss, anger, resignation
- ADHD children
  - Sadness, defeat, anger
- ADHD adolescents
  - Cluelessness, resistance, externalization. anger, depression, defeat

# Burned Out....

- Yea - I'm burned out - **nothing that's normal works with these kids** - us parents are burned out on school, on homework, and we're tired of the criticism from everyone, and getting the negative phone calls from teachers about how poorly he's doing in school. I need to change my expectations of him - but it's hard to accept his limitations when I see such potential and talent and I keep waiting. It seems like it is just being in a constant state of grieving. Tell me, when is it that we should lower our expectations? When they're young - so we don't get burned out hitting our heads against the wall? Or later, when it seems everyone in the family has finally given up hope that this kid can do anything with his life?"

# Emotional Exhaustion....



- “Some days, a lot of days, I just can’t handle it. I don’t know the answers anymore. The books, the advice no longer works and I don’t know what does. I think back on all the counselors and all the doctors we saw and no one ever really did anything, except give meds. I’m exhausted - I am so exhausted. I can’t do it anymore. I have sacrificed my whole life to these 2 ADD men in my life - my son and my husband. My husband has never dealt with his ADD. Well, I’m not doing it anymore. I’m exhausted. I’m tired. My whole life has been sacrificed.”

# ADHD Rules the Family....



- “Knew early on my son, had something going on. I counted one night that we were up 23 times and that was like at a year and a half. He’s never slept well. He was on the go all the time. All the attention is focused on him. He was the textbook ADHD child with the epitome of hyperactivity and didn't sleep--on the go all the time--just wild. And so when, even if you have two ADHD children or one that has some slight ADHD tendencies, the one that is the most hyper rules how the family will function.”

# Assessment of Child's Self-Esteem...



- Mothers assumed that their ADHD children suffered from low self-esteem and felt that if they viewed themselves more positively they would get along better with others.
- Father's saw their ADHD children as having an inflated self-esteem, needing to be in control - needing to be the boss - and if they didn't get their way then they were miserable to be with.
- ADHD children seemed to need in relation to their social inadequacies was help gaining a sense of reciprocity and mutuality with others.

# The Meaning of ADHD as Disruption...



- “The noise, the fights, the talking just never stops, never is there any quiet, never is there a spare moment. Then I get upset and I feel guilty when I explode. I know I should do better. I wish I could be better role model. I just want one day a week when I don’t have to take care of him and be responsible for it all. The burden is always on me to organize, to structure”.

# Financial Costs....



- Higher than any other chronic illness of childhood
- Medications, doctors appts. diagnostic tests, reading specialists, tutors, out of district tuition, private schools, counseling, costs of litigations with schools in order to get services, loss of work, treatment for depression in parents and siblings, etc.
- Loss of work income

# Primary Concerns of Parents....



- Difficulty obtaining the right kind of services
- Primary care providers uninformed and unaware
- The view of ADHD as mental illness was a barrier in seeking support, especially in Hispanic families.
- Mothers felt distressed/fearful/at a loss. Left with little time or energy.
- Working parents had to make work-related adjustments in order to care for their ADHD child.
- Parents wanted more information, resources, and education about ADHD.

# Primary Concerns of Parents....



- Parents wanted relief from the financial burden associated with costs of ADHD.
- Low cultural competence and lack of Spanish proficiency of health professionals.
- African American and Hispanic families raised concerns about racism, discrimination, and referral bias

# Conclusions....



- Family members experience a high and intense level of emotional distress.
- Victimization was the primary experience of siblings.
- The day-to-day difficult life experience of family members stood in stark contrast to the ADHD child's "cluelessness" and apathy about his/her behaviors.

# Conclusions....



- The difficulties these families have may be more stressful than most health care providers, teachers, extended family members, neighbors, friends are aware of.
- Because of stigma and misunderstanding about the disorder, parents often believe they are to blame for their child's problems and delay getting the services they need.

# Conclusions....

- Health providers need to assess the mental health of all family members and recognize that
  - psychiatric conditions may be present in family members and aspect of the presenting clinical picture
  - Family members at risk for depression, anxiety and substance abuse disorders
- ADHD is particularly disruptive to family functioning

# Work-Life Integration Project



- Primary aims of the project
  - Increase the awareness and knowledge of the work-life integration experiences of employed parents of children with emotional or behavioral disorders among HR professionals, and the workplace
  - Increase the capacity of the workplace to support work-life integration of parents of children with emotional or behavioral disorders
  - Improve the extent to which parents of children with emotional or behavioral disorders have awareness of and access to employment-based supports that promote their participation in the workplace while permitting them to take part in family and community life.

# Work-Life Integration Project



- Project Components
  - Caregiver workforce participation study
  - Focus groups
    - Parents (3 groups)
    - Human Resource (HR) professionals (3 groups)
  - National HR survey
  - Pilot training
  - Resources for families and employers

# Key Concepts



- ***Work-life integration***
- ***Community Integration***
- ***Family Support***
- ***Workplace Support***

# Work-life Integration



- “The degree to which a person is able to successfully combine paid work with other aspects of personal life” (Lewis, Rapoport, & Gambles, 2002).
- Work-life integration depends on the availability of family and workplace supports in the community (Brennan & Brannan, 2005).

# Community Integration



- Community integration is more than merely residing in a community, but includes access to resources and social supports for family members
- Work-life integration happens within the context of the community
- Employment supports for parents who have children with emotional or behavioral challenges are necessary for full participation in community life

# Family Support



- Federation of Families for Children's Mental Health (1992) defines family support as a constellation of formal and informal services and tangible goods that are determined by families.
- Family support is intended to help families achieve balanced lives that are not overwhelmed by the needs or behaviors of the child or by demands of the service systems designed to help (Rosenzweig, Friesen, & Brennan, 1999)

# Workplace Support



- 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).
- Family supportive workplaces: enhance employees' capacity to support the growth and development of family members, promote employee participation in community based supports, family support services and work-life enhancement programs (Family Support America, 2005).

# Caregiver Work Participation Study



- ***Growing numbers of parents of children with emotional or behavioral problems are entering the workforce.***
- ***However, parents often must quit work, or are terminated due to their responsibilities to care for a child with mental health challenges.***  
***(Rosenzweig & Huffstutter, 2004)***

# Why do parents become unemployed?



- ***Factors affecting employment for all parents***
  - *Age of youngest child*
  - *Level of caregiver education*
  - *Availability of affordable child care*
- ***Factors affecting parents of children with mental health needs***
  - *Lack of suitable child care*
  - *Level of child functioning*
  - *MH treatment that disrupts the work day*
  - *School systems unable to cope with child's behavior*

# Research Hypotheses



- ***The more severe the child's symptoms, the more days of school the child will miss.***
- ***The greater the number of child absences, the greater the disruption in the caregiver's employment.***
- ***Some caregivers will have to stop working outside the home because of frequent disruptions.***

# Methods

- *We conducted a secondary data analysis of data from the Comprehensive Community Mental Health Services for Children and their Families Program (CCMHS).*
- *Analysis uses a sample of caregivers of children ages 5-17 who were receiving mental health services in a Systems of Care site.*

# Sample



- ***To be included the caregiver:***
  - ***Had to care for the child in their home***
  - ***Had to have answered all relevant questions.***
- ***And the child :***
  - ***Had to be 5-17 years of age and currently receiving services***
  - ***Had to attend some form of school at some point in the past 6 months.***

# Caregiver Characteristics



- **Caregiver education**
  - **22.2% Less than HS/GED**
  - **34.7% HS/ GED**
  - **43.1% More than HS/GED**
- **Median number of children: 2**
- **Caregiver works outside the home: 52.2%**

# Child Characteristics (N = 1,826)



- **Child is male: 68.6%**
- **Child age:**
  - **25.4% 5-9 years**
  - **53.2% 10-14 years**
  - **21.4% older than 14 years**
- **Child race:**
  - **18.5% African American (non Hispanic)**
  - **11.0% Hispanic**
  - **49.5% European American (non Hispanic)**
  - **21% other or missing**

# Child Functioning (N = 1,826)

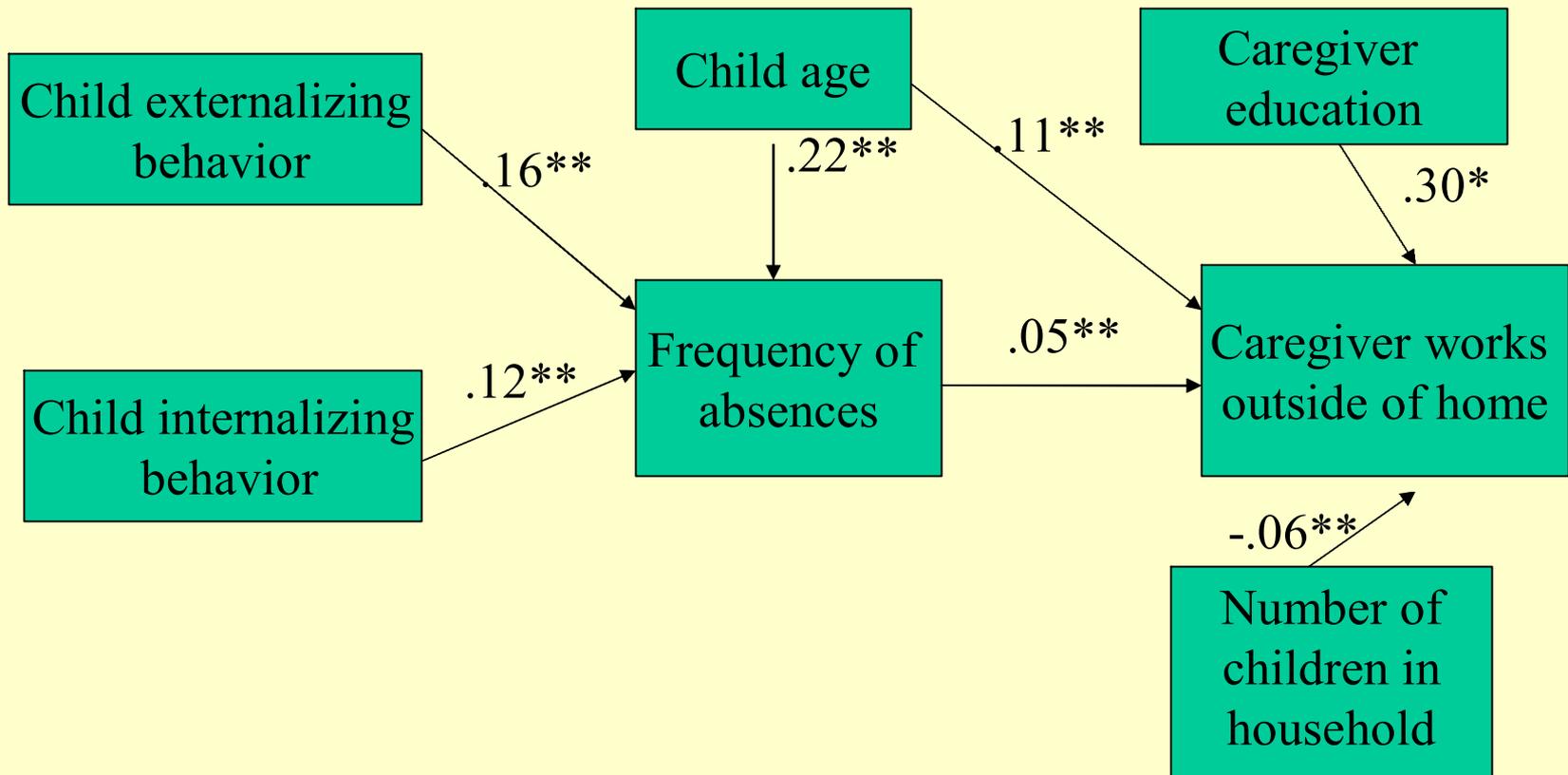


- **Internalizing symptoms:  $M = 62.9$ ;  $SD = 11.7$ .**
- **Externalizing symptoms:  $M = 67.5$ ;  $SD = 10.9$ .**
- **Days absent from school past 6 months:**
  - **48% Less than 1 day per month**
  - **17.1% About 1 day per month**
  - **12.6% About 1 day every 2 weeks**
  - **8.9% About 1 day per week**
  - **7.8% 2 or more days per week**
  - **5.5% 3 or more days per week**

# Analysis



- ***Used structural equation modeling to examine the relationship among:***
  - ***Child symptoms (internalizing and externalizing scores on CBCL; Achenbach, 1991)***
  - ***School absences (measured through parent reports of school attendance)***
  - ***Caregiver participation in workforce (parent report of being employed outside the home or not)***
- ***Control variables: age of youngest child, number of children in home, caregiver education level.***



Note: Overall model  $\chi^2 = 9.43$ ,  $df = 3$ ,  $p = .02$ ;  $R^2 = .11$ .

\*\*  $p < .0001$

\*  $p < .025$

# Conclusions



- ***Support for the hypothesis that a caregiver's ability to participate in the paid labor force was negatively affected by the demands of caring for a child with emotional or behavioral disorders.***
- ***Have not tested for other factors which also affect workforce participation.***

# Conclusions

- ***Schools and out-of-school care programs need to have additional supports for staff so that they can successfully nurture children with mental health challenges.***
- ***When caregivers wish to participate in the workforce and cannot, the family's economic situation is worsened, and may even put the family in jeopardy.***
- ***Labor force participation should become a standard caregiver and family outcome measure in mental health services research.***

# Building on Family Strengths



- ***Employed parents require a combination of support & flexibility from multiple systems including the community, the workplace and the family in order to successfully combine work and family.***
- ***Individual families have managed to integrate work and family responsibilities through specific strategies, such as seeking employment in family-friendly workplaces, restructuring employment, disclosure at work about the child's mental health status, and reciprocity negotiation (Rosenzweig & Huffstutter, 2004).***

# Your Thoughts....



- 1. From your experience, what is the connection between a child or youth in the family and with emotional or behavioral challenges and participating in day-to-day activities (work, school, family events, social activities)?***
- 2. What would be most helpful for you and your family (or the families you work with) in increasing opportunities to participate in these activities?***

# Contact Us

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Portland, Oregon

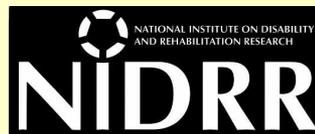


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