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# Improving Work-Life Integration for Families of Children and Youth with Mental Health Disorders

Julie M. Rosenzweig
*Portland State University*

Eileen M. Brennan
*Portland State University*

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# Improving Work-Life Integration for Families of Children & Youth with Mental Health Disorders

**Symposium:** Parents of Children with Special Needs in the Workplace: New Knowledge, New Strategies

**Presented By:** Julie M. Rosenzweig & Eileen M. Brennan
Portland State University

# Location & Context

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- Portland State University
- School of Social Work
- Regional Research Institute for Human Services
  - Research and Training Center on Family Support and Children's Mental Health
  - Research & Training Center for Pathways to Positive Futures
- Funding sources

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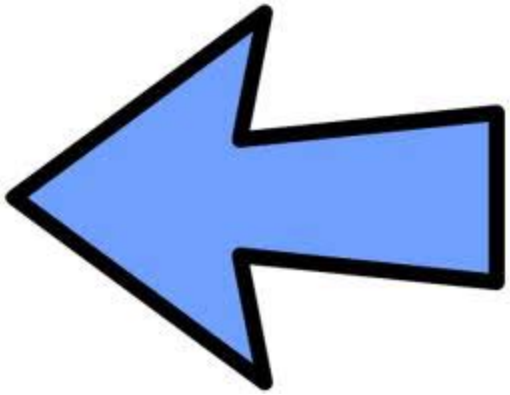
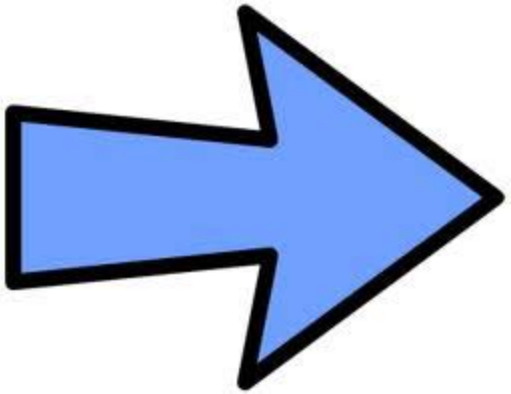


# Looking Back & Looking Ahead



# The Beginning



- From Jayhawks to Vikings
  - Women's development & work
- The work of Arthur C. Emlen
  - Founding Director, Regional Research Institute for Human Services, 1973-1989
  - Pre-eminent leader in Work, Family and Dependent Care Surveys
    - 60,000 employees, at 146 companies and agencies, in 25 cities and 13 states
  - *Solving the Childcare and Flexibility Puzzle: How Working Parents Make the Best Feasible Choices and What That Means for Public Policy*. Boca Raton: Universal Publishers, 2010.

# Over 15 Years 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)

# Over 15 Years of Work-Life Integration Research on Families of Children with Mental Health Disabilities

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

- Caregiver Workforce Participation Study, N = 2,585;
- Focus groups: Parents and HR Professionals
- Work-Life Flexibility and Dependent Care Survey, N = 551;
- Design and offer training to HR professionals
- Resource development for families and businesses

**Pathways Transition Training Collaborative** (2009-2014)

- Improving Youth Transitions Course, N = 45
- Webinars on Transition Competencies, Medication, Family Involvement, Employment
- Online Training Modules

# Children & Youth with Mental Health Disorders: Definition & Prevalence Considerations



- Definitional challenges
- Prevalence prediction challenges
- Service utilization challenges
- Work-life integration challenges

# Narrative in Graphic Format

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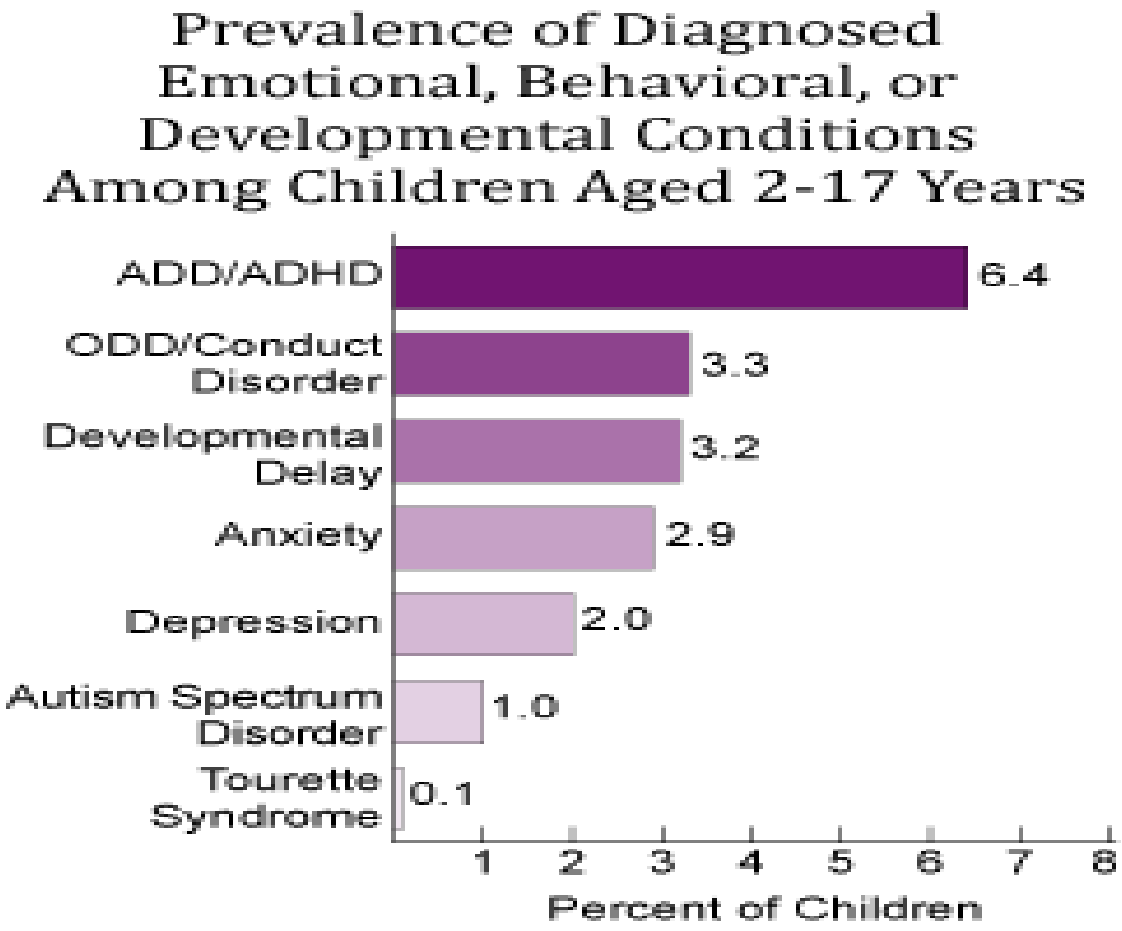
## *The Mental and Emotional Well-Being Children: A Portrait of States and the Nation 2007*

Published by Health Resources & Services Administration's Maternal and Child Health Bureau (MCHB) in July 2010, The Chartbook is based on data from the 2007 National Survey of Children's Health

Children with special health care needs (CSHN) are defined as children "*who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally*" (McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B., 1998).

# Prevalence Estimates
## Based on CSHN Definition






In total, 11.3 percent of children aged 2-17 years were reported to have at least one of these seven conditions at the time of the survey.

# Male/Female, Age, Conditions, Family Income Level

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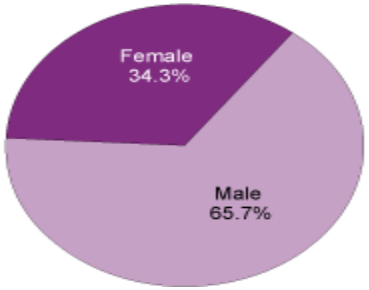
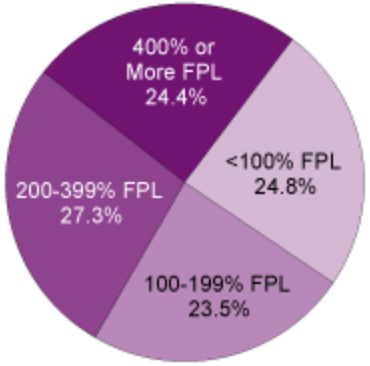
Children Aged 2-17 Years with Emotional, Behavioral, or Developmental Conditions, by Sex

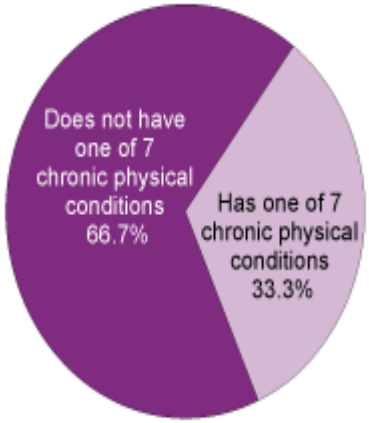



Children Aged 2-17 Years with Emotional, Behavioral, or Developmental Conditions, by Poverty Status*



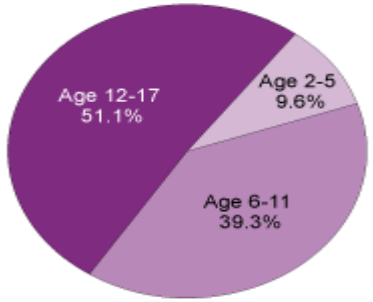

*Federal poverty level was $20,650 for a family of four in 2007. Percentages may not add to 100 due to rounding.

Prevalence of Chronic Physical Conditions* Among Children with Emotional, Behavioral, or Developmental Conditions

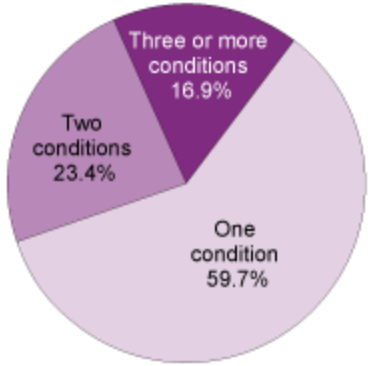



*Of the 7 conditions asked about in the survey: asthma; diabetes; bone, joint, or muscle problems; hearing problems; vision problems; epilepsy or seizure disorder; and brain injury or concussion

Children Aged 2-17 Years with Emotional, Behavioral, or Developmental Conditions, by Age



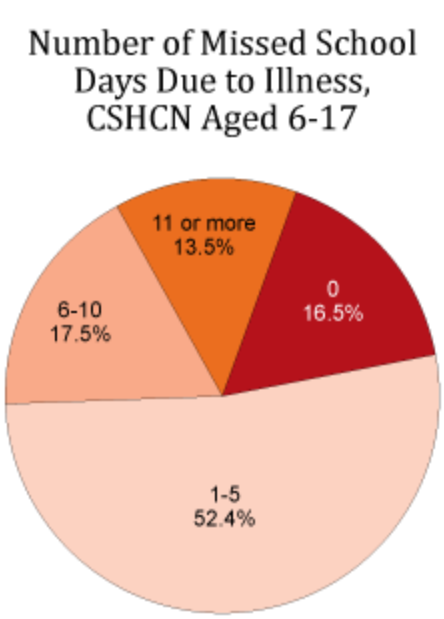

Number of Emotional, Behavioral, or Developmental Conditions among Children with at Least One Condition*

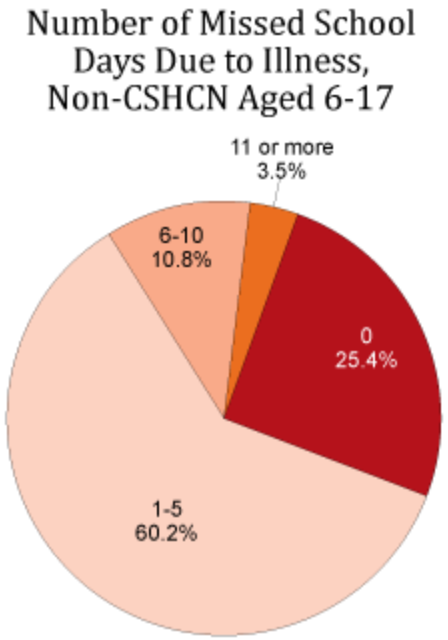



*Including only the seven conditions asked about in the survey.

# Number of School Days Missed





# Parent's Stress

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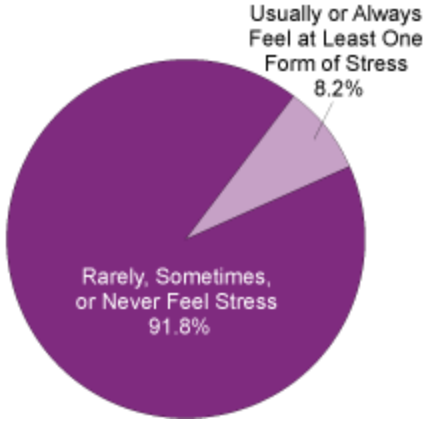
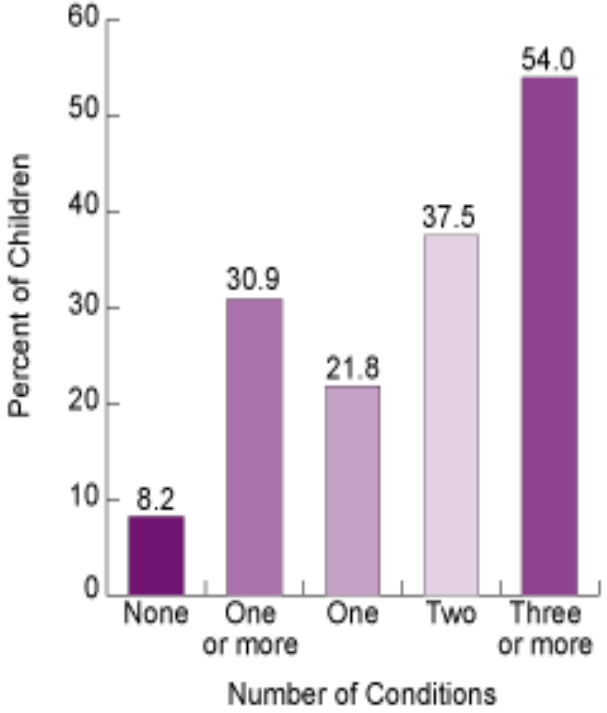
Percent of Children with Emotional, Behavioral, or Developmental Conditions Whose Parents Report Stress


Percent of Children without Emotional, Behavioral, or Developmental Conditions Whose Parents Report Stress




Children Whose Parents Usually or Always Feel Stress, by Number of Emotional, Behavioral, or Developmental Conditions



# Parent's Health

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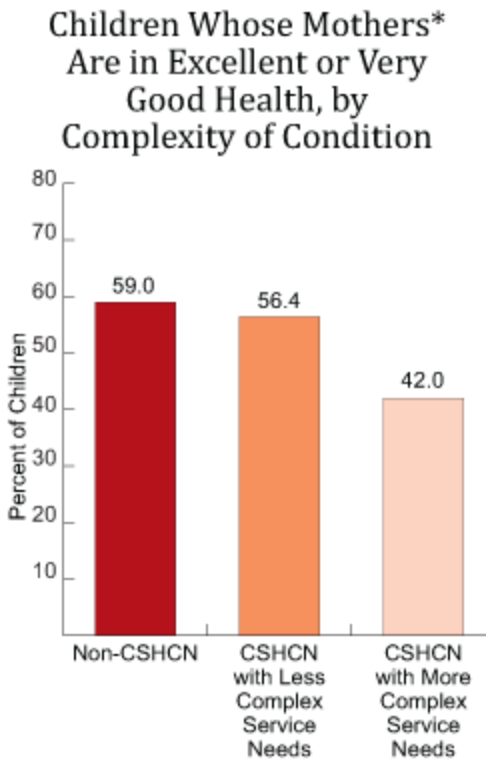


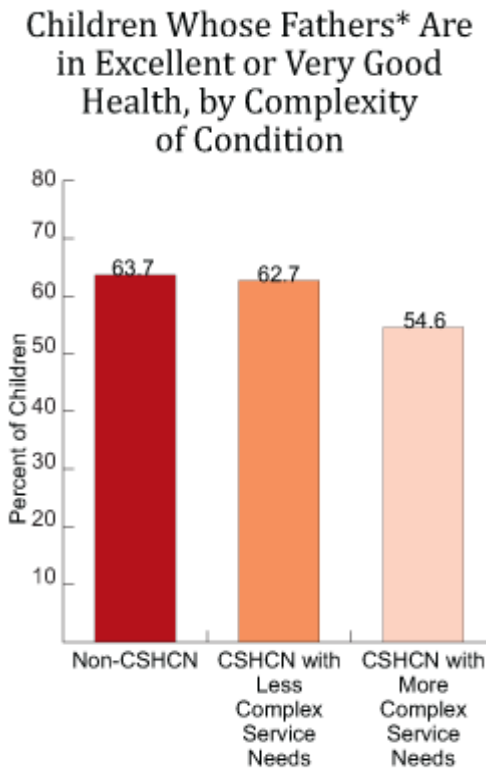

# Parent's Employment

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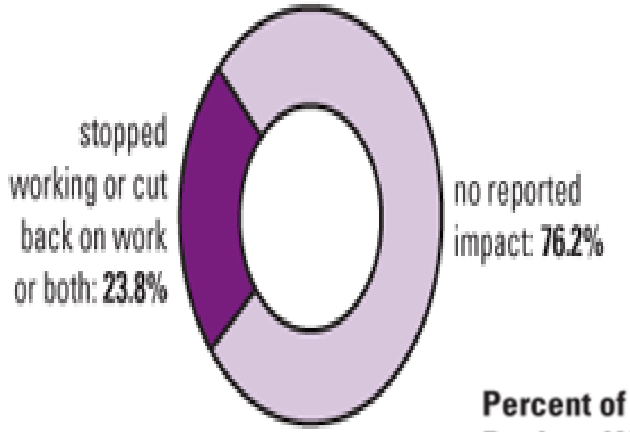
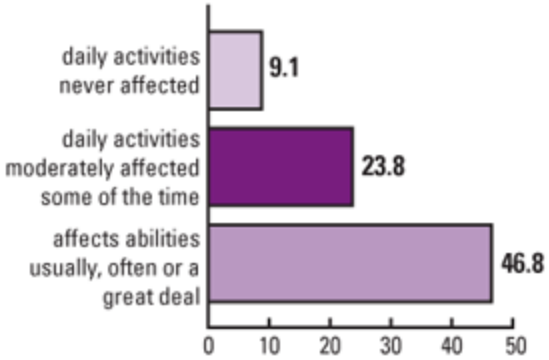
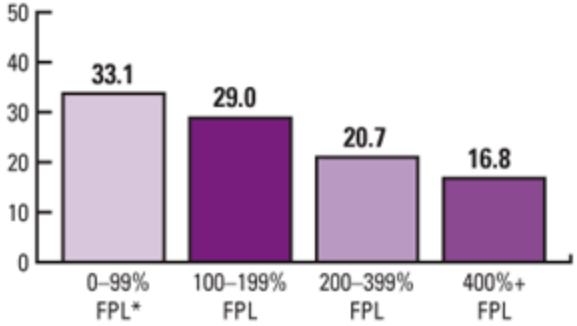
## Impact of Child's Condition on Parent's Employment




## Percent of CSHCN Whose Parents Cut Back on Work or Stopped Working to Care for the Child: Impact of Child's Condition on Child's Functional Ability



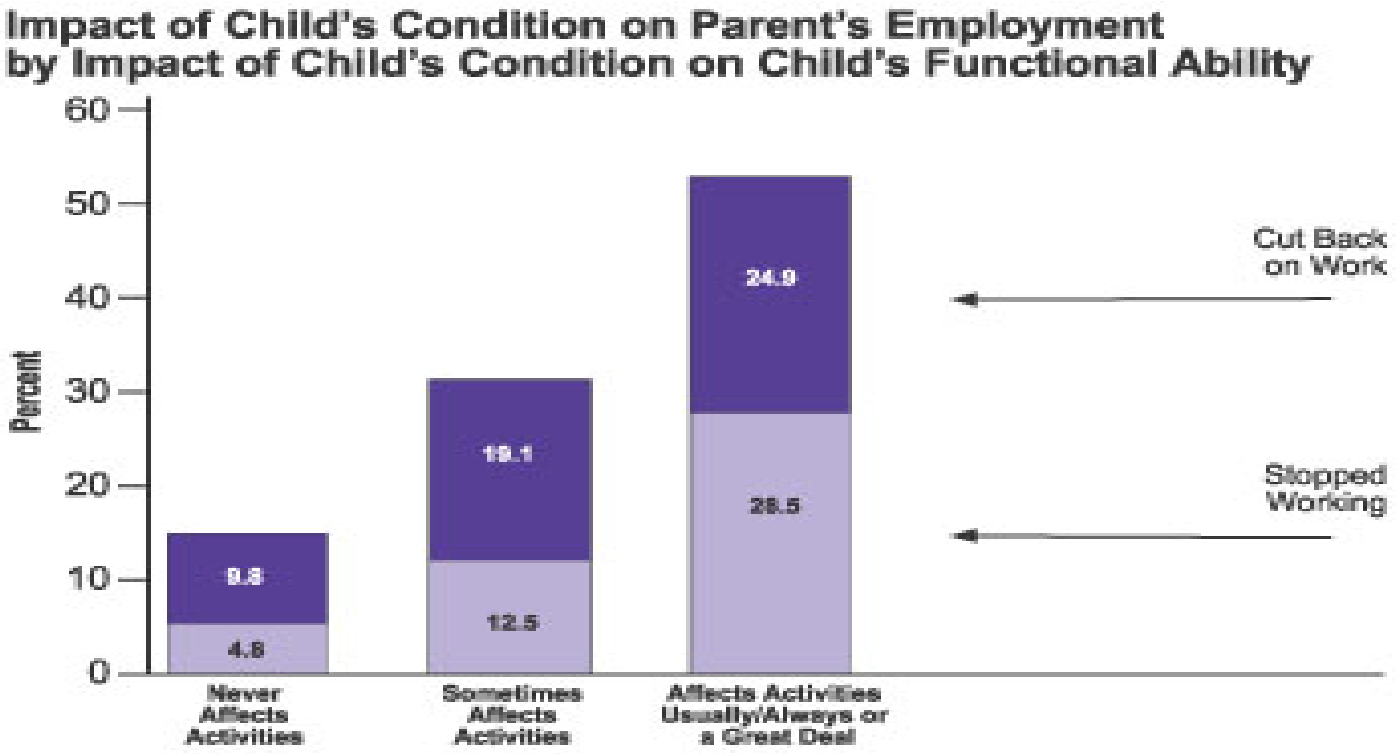

## Percent of CSHCN Whose Parents Cut Back on Work or Stopped Working to Care for the Child: Family Income




*Federal Poverty Level. In 2005, the DHHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

# Parent's Employment and Child's Functionality






A change in employment status is also more apt to occur in families that have a child who is more affected by his or her condition. The parents of over half of children who are affected usually, always, or a great deal by their conditions either cut back on work hours or stopped working entirely. Among children who are never affected in their abilities, only 15 percent have parents who decreased work hours to care for their children.

# Adolescents: DSM-IV Disorders

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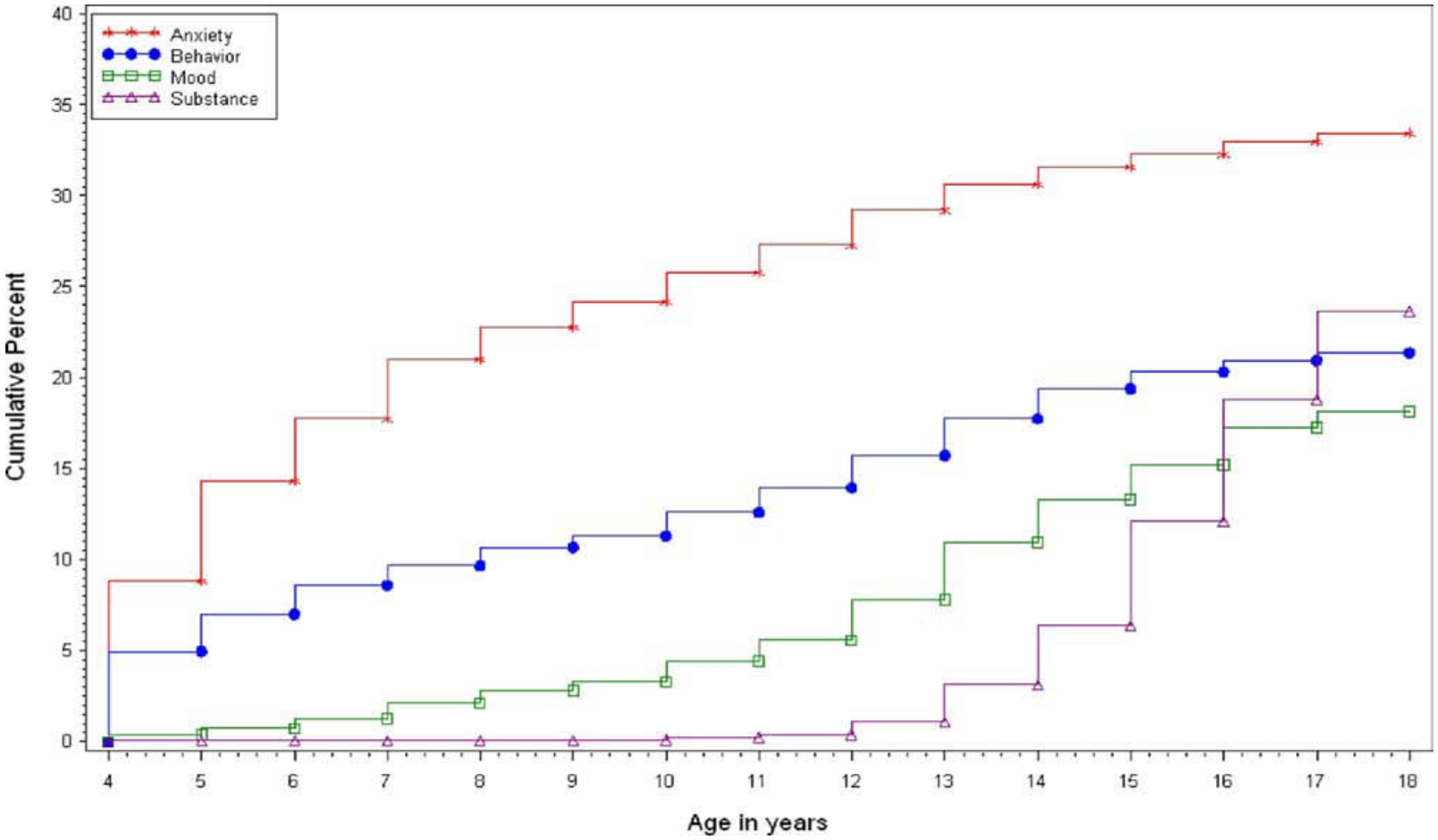


FIGURE 1. Cumulative lifetime prevalence of major classes of *DSM-IV* disorders among adolescents (N = 10,123). (Merikangas, et al., 2010)

# Transition-age Youth (18-26)

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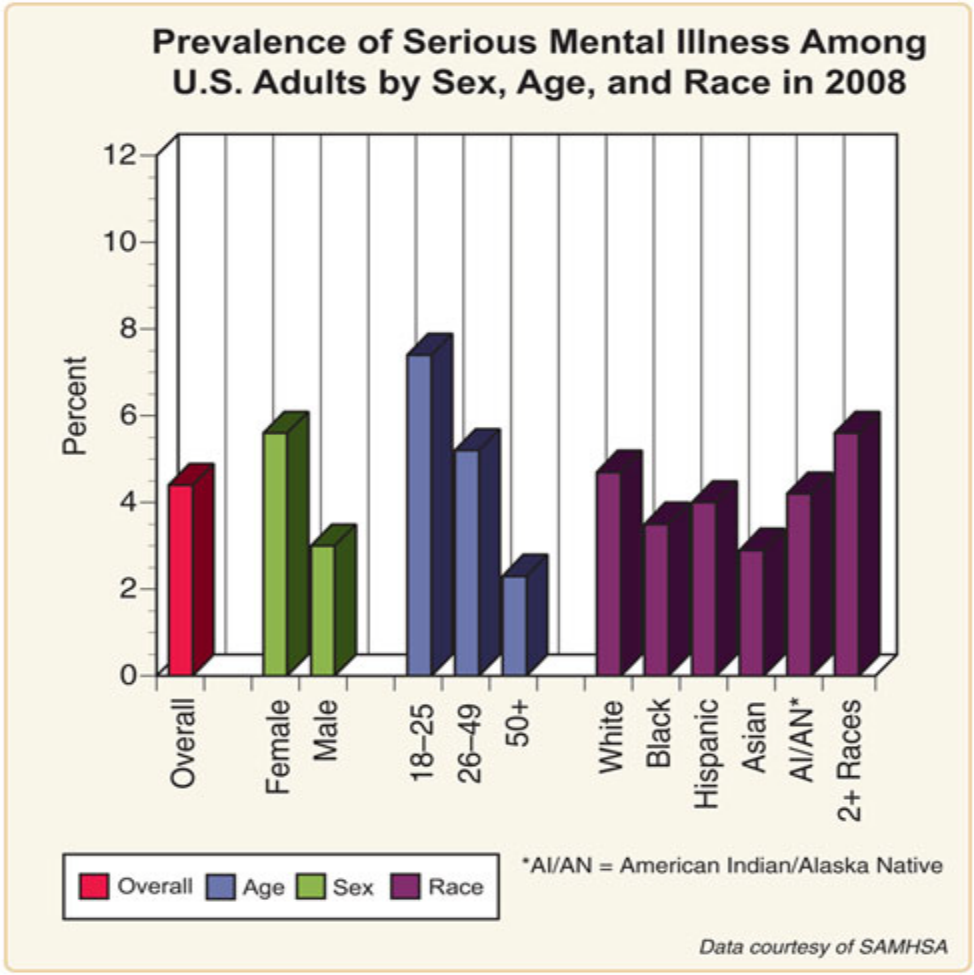

# Service Utilization

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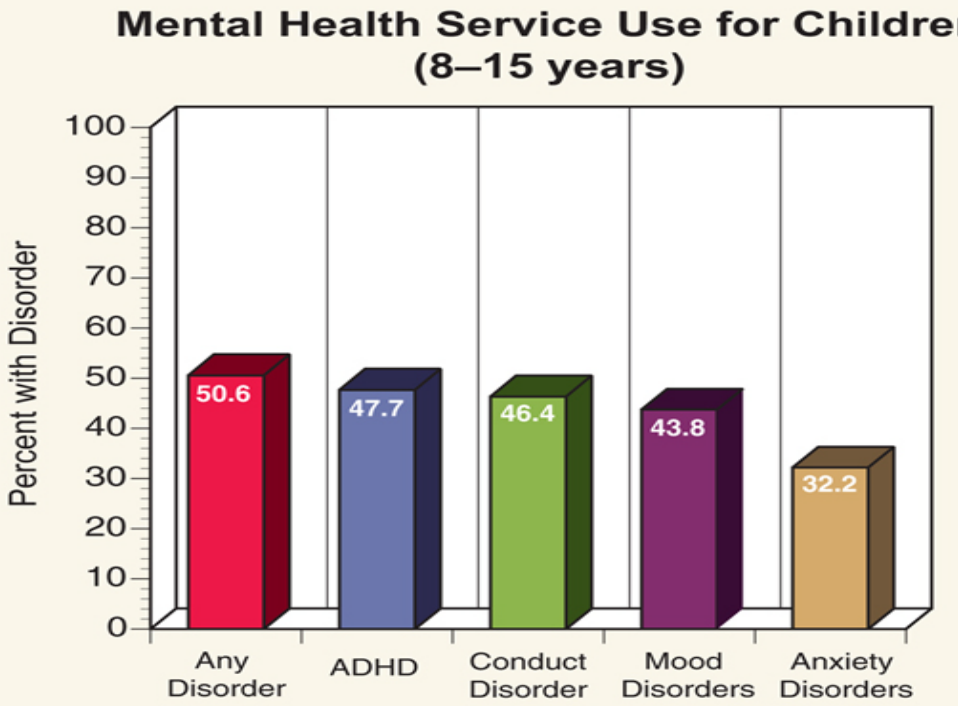


**Demographics Associated with Mental Health (MH) Service Use:**

- Females are 50 percent less likely than males to use MH services.
- 12–15 year olds are 90 percent more likely than 8–11 year olds to use MH services.
- No differences were found between races for mood, anxiety, or conduct disorders. Mexican Americans and other Hispanic youth had significantly lower 12-month rates of ADHD compared to non-Hispanic white youth.

*Data courtesy of CDC*

# Matrix of Primary Studies

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- **Studies include:**
  - Secondary analysis of dependent care and mental health evaluation data sets.
  - Focus group studies of family members and human resource professionals.
  - Written and face to face surveys of family members, workplace supervisors, and mental health and child care service providers.
  - Online surveys of human resource professionals.

# The Conceptual Model

# Work-Life Integration Defined

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- 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).

# Primary Concepts

- Exceptional Caregiving Responsibilities
- Courtesy Stigmatization
- Disclosure Decisions & Strategies
- Family Support
- Inclusive Organizational Culture
- Community Integration

# Exceptional Caregiving Responsibilities



- Exceptional caregiving responsibilities differ from typical caregiving responsibilities:
  - time spent arranging care
  - ongoing parental responsibilities-childhood into young adulthood or beyond
  - frequent, intense, and crisis-driven care needs
- Exceptional caregiving responsibilities include:
  - Health/mental health care
  - Special education arrangements
  - Inclusive child care
  - Health related crises

*(Brennan & Rosenzweig, 2008; Lewis, Kagan, & Heaton, 2000; Porterfield, 2002; Roundtree & Lynch, 2006)*

# Courtesy Stigmatization

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- **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 by vary by cultural identity
  -
- Parents of children and adolescents with serious emotional or behavioral disorders experience **courtesy stigmatization** associated with their children's behaviors related to the mental health disorder.

- 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).

# Stigmatization Management Strategies



- Management strategies used by parents related to associated stigma focus largely on controlling the spread 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, 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).

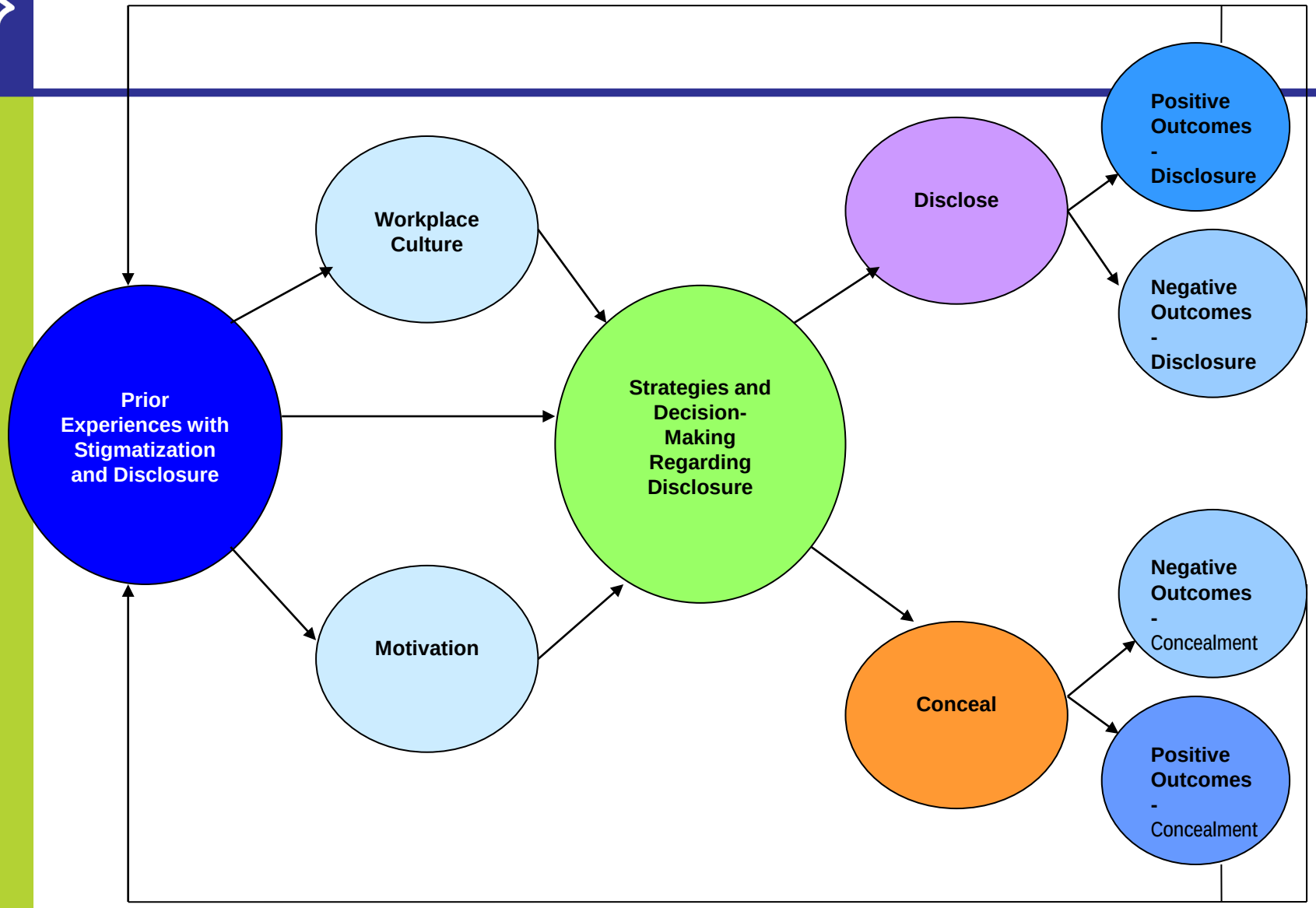
# Disclosure Strategies



- Employed parents carefully weigh the risks and benefits of disclosing their children's mental health status at work (Rosenzweig & Huffstutter, 2004).

- Benefits: Improved access to formal benefits and flexibility, informal support from supervisors and coworkers, reduced stress (Ellison, Russinova, MacDonald-Wilson, & Lyass, 2003; Rosenzweig & Huffstutter, 2004).

- Risks: Increased courtesy stigmatization, coworker resentment, job insecurity (Rosenzweig, Brennan, Malsch, Stewart, & Conley, 2007).




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

# Culture of Inclusion



- "…an organizational environment that allows people with multiple backgrounds, mindsets and ways of thinking to work effectively together and to perform to their highest potential in order to achieve organizational objectives based on sound principles." (Pless & Maak, 2004)

- Differs from diversity: **Inclusion** is about creating a culture in which diversity is understood, respected, encouraged, valued and leveraged, in ways that ensure that talented people thrive, and our clients and our reputation both benefit. KPMG,

# Family Support



- Family supports—constellation of formal and informal services and tangible goods that are determined by families (Federation of Families for Children's Mental Health, 1992).
- Natural supports can be found from friends, neighbors, and community members—but these usual sources often are exhausted due to child's behavior.
- Formal and informal supports are available through peers and mental health professionals in
  - family support organizations
  - mental health agencies.
- Services need to be family-designed, and family-driven to have "whatever it takes" to assist the family to function well. (Friesen, 1996).
- Family support can lessen caregiver strain, thereby promoting workforce participation (Brennan & Brannan, 2005).

# Community Integration

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- Community Integration—family members are not just physically located in a community, but they take on key roles and participate in community activities. (National Center for Dissemination of Disability Research, 2004).
- Encompasses *physical spaces* in which families are located, *relationships*, and *resources* which impact a family's ability to participate fully in community life.
- Provides them with a psychological feeling of inclusion and belonging.
- Full participation in workplaces and work roles, not constrained by caregiving responsibilities.

# Framework: Proximal & Distal Predictors

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## Proximal Predictors

**Parent Characteristics**
Age, Gender, Ethnicity, Education, Partnered Status, Caregiving Status: Exceptional vs. Typical

**Child Characteristics**
Age, Gender, Ethnicity, Education Level, Mental Health & Functioning, Physical Health

## Distal Predictors

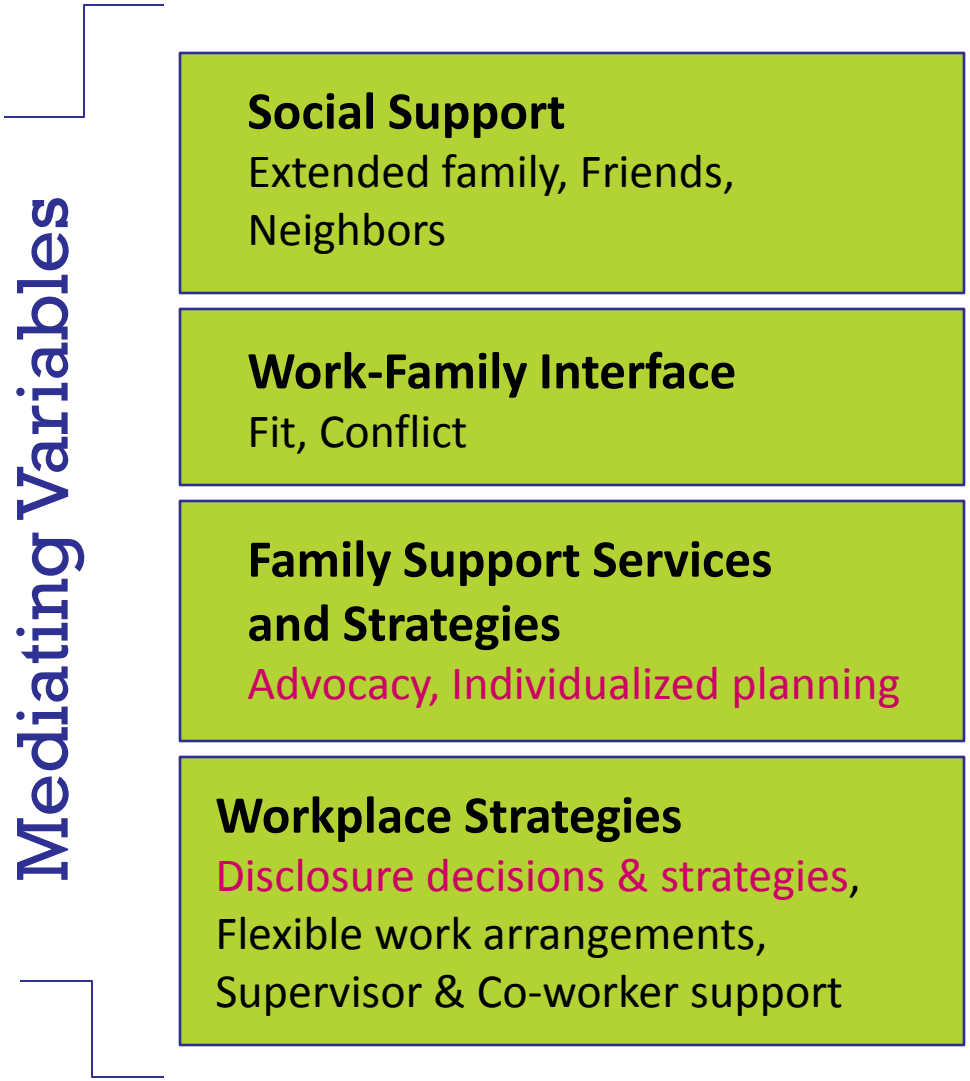
**Community Environment**
Family Support Resources, Need Specific Services (e.g., childcare, educational, mental health, transportation)

**Workplace Environment**
Relationships, Working Conditions, Resources, Culture of Inclusion, Stigmatization, Policies/Flexibility

**Family Environment**
Inclusive Child Care, Flexibility, Income, Other household members/needs

# Framework: Mediating Variables





# Framework: Outcome Variables

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## Outcome Variables

**Parental Health**
Depression, Anxiety, Substance Abuse, Stress, Physical health

**Child Outcomes**
Developmental, Mental Health, School Performance

**Role Quality**
Parental, Work, Couple

**Workplace Outcomes**
Participation, Absenteeism, Work Interruptions & Distractions, Tardiness

**Community Integration**
Employment, Education, Recreation

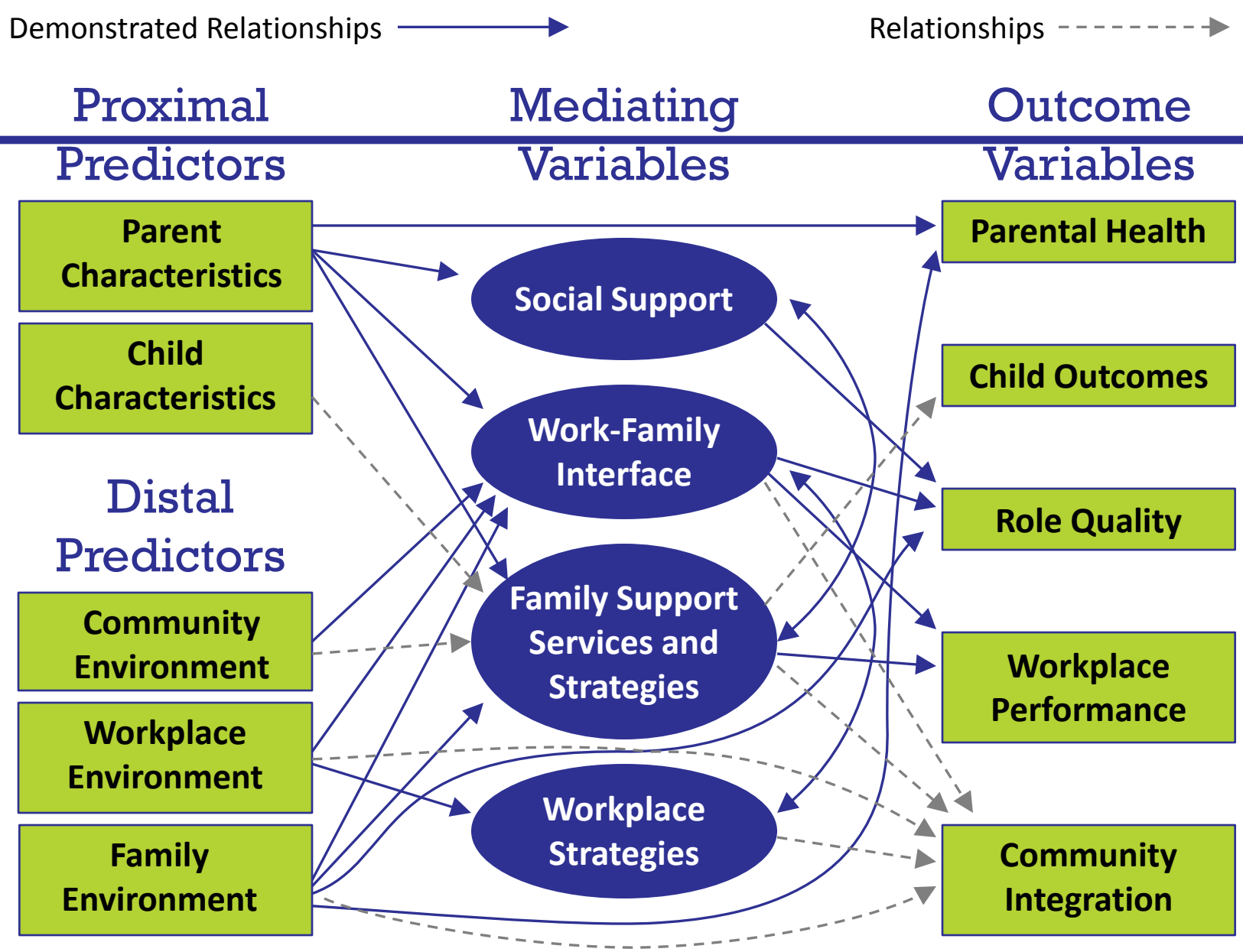


Figure 1. Conceptual Model of Factors Influencing Work Life Integration for Employed Parents of Children with Serious Emotional Disorders

# Next Wave



- National studies comparing employed family members giving exceptional vs. typical care.
- National studies of exceptional caregivers regarding their employment.
- Dissemination studies to compare effectiveness of inclusion messaging modes for different target groups.

# Acknowledgments/Funders

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