

## Conversations with the Experts

### Work-Life Integration and Children's Mental Health

**Bios:**

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#### An Interview with Julie M. Rosenzweig and Eileen M. Brennan

by Judi Casey and Karen Corday

**Casey:** Why did you explore the intersection between children's mental health and work-life integration?

**Rosenzweig:** We are located at a national research and training center that emphasizes children's mental health and family support. When we began to look at the employment issues of the parents of children with mental health disorders, it became apparent to us that these parents were significantly challenged by finding and keeping employment. There were few work or community resources to support their efforts to meet both their caregiving and employment needs. We began to look at the notion of work-life integration for these families, which led to us examining where the research on children's mental health and work-family studies intersect. One of our efforts is to start a dialogue between mental health professionals and work and family professionals. Mental health professionals are just beginning to talk to families about their employment issues, and workplaces are just beginning to recognize that there is a set of parents in the workforce with children with disabilities.

**Casey:** Why do you use the term "work-life integration" instead of "work-life balance" or some other term?

**Rosenzweig:** "Work-life integration" is more a more inclusive term which moves away from the strictly "family and work" association. For us, using the concept "work-life integration" is a way to address the need for more fluidity across the work-life boundary. "Balance" implies that there is equal time and attention across any 24-hour period. Another reason, is the connection with the disabilities community, which focuses on the concept of community integration. Work-life integration allows us to address this related concept, as the community is so necessary to sustain work and a better quality of life for all family members.

**Casey:** What are the unique work-life challenges for working parents of children with serious emotional or behavioral disturbances?

**Brennan:** Lisa Stewart and [Linda Roundtree](#) have called the challenges they face exceptional caregiving." It means that in addition to the challenges of raising a child with typical development, families that are giving exceptional care often face crises which they have to work through every day. They're not really sure how long their child's treatment or condition will last; there's a level of unpredictability.

Most parenting demands subside with time. When you have a child with an emotional or behavioral disorder, parenting demands can increase with time, particularly during the transition from adolescence to adulthood. That can be the most difficult time of all; the demands are great and the systems tend to break down. The transition from the children's mental system to the adult mental health system or adult life is very uneven. There was a recent conference in Washington, DC at which American and Canadian mental health

professionals, policymakers, and youth gathered to examine this issue.

Another issue is that the community supports set up for working parents are, by and large, for parents raising children who are developing typically. Ordinary supports that most parents can count on are not available to parents of children with emotional or behavioral disabilities.

Stigmatization is another concern. These parents are often seen as bad or ineffectual parents because people judge the quality of their parenting on the basis of their children's behaviors or outcomes, rather than understanding the challenges the parent is helping their child overcome.

**Casey:** How do these challenges impact families emotionally, financially, and in their careers?

**Rosenzweig:** The level of unpredictability, which is not written about or conceptualized very often, is very important. There is generally a 3- to 4-year gap between when the parent suspects that their child is not progressing along traditional developmental norms and an initial diagnosis. That's a long time for families to be in limbo—it causes an enormous amount of stress and strain on all family members, and that diagnosis is just an initial phase in the overall journey.

Generally, parenting a child with this type of disability negatively affects marriages. There can be positive bonding that results, but generally, it strains marriages, primarily because there is unevenness in terms of who is caring for the child. In most cases, in two-parent families, the mother will quit her job, leave the workforce, and be the primary caregiver, while the father will work, often very long hours, which keeps him out of the family loop. The marital relationship takes a big hit. The sibling relationships are just starting to be recognized as very stressful for nondisabled siblings. Beginning qualitative studies discuss the first-person experience of the siblings without a disability, who report having to grow up sooner and not being able to put demands or expectations on their parents, as the parents are so committed to the care of the child with a disability. The child with the disability really directs the family into or out of the community. When there are no accessible services or recreational opportunities available, it impacts the whole family, who are then all less involved or uninvolved with their community.

Depending on the culture and nature of the disability, extended family members may or may not be involved in the care of the child. For some mental health disorders, the nature of the disorder is so overwhelming that the child does not respond well to changes in transportation or caregivers, so the burden of the care is primarily on the parents.

In terms of labor force participation, in addition to mothers leaving the workforce, often both parents will sidestep their career paths and decline promotions and opportunities, which translates into less money and benefits for the family. There are a greater percentage of families of children with disabilities living in poverty than families of children with typical development.

**Brennan:** Frances Lynch of Kaiser Permanente's Center for Health Research has done a [recent study](#) on the economic impacts of this issue. It's very costly to have a child with an emotional or behavioral disorder in terms of the extra services they have to fund for the child, and until recently, mental health services haven't been on parity with health services. There has been some progress with the recent passage of parity in health insurance as part of the federal economic recovery bill.

**Casey:** What about child care needs? What strategies are used to secure quality care?

**Brennan:** Finding inclusive child care can be very difficult. I like to use the term "inclusive" in speaking about child care, because what is really needed for children to develop is to be in a child-care setting with children who are developing typically. This is good for typically and nontypically developing children, as they learn from each other. Children with emotional or behavioral disabilities are often expelled from child care; [Walter Gilliam](#) of the Yale Child Development Center has done a study in which he showed that a child with this type of disability is much more frequently expelled from preschool than from high school. It's a major issue. In the United States, the Americans with Disabilities Act applies to child care, but providers are sometimes reluctant to make so-called reasonable accommodations. Most providers have not been trained about children's behavioral health or the special supports needed for children with disabilities, so they are unwilling or unable to provide that care.

We studied some preschools and child-care centers that are very effective in providing care to children with disabilities. It takes leadership on the part of the child-care administrators, dedication on the part of the staff, and good training. Many centers are wonderful; in the book, I point out the Fraser School in Bloomington, Minnesota, at which 350 children are successfully cared for in preschool with all sorts of disabilities alongside

typically developing children. This is a model of an effective center. A lot of parents can't find that kind of care, so they end up working split shifts, "tag team parenting," and generally getting little assistance from extended family members, who often feel unable to provide the needed care.

**Rosenzweig:** Parents of children with typical development can often rely on before or after school care to help them get through the workday. These care resources rarely have the capacity to include children with mental health disorders, which puts additional strain on the family.

**Casey:** How do families cope? What personal adaptation strategies and community supports help with work-life integration?

**Brennan:** When we've talked to families where the child's principal caregiver is employed, they talk about the flexibility they've been able to find. They've looked for employment with flexibility built in, which may allow them to work offsite, to telecommute, and to use flexible hours. They also work out child-care solutions within the family; adult siblings or grandparents shift with each other to make sure the child receives care and supervision during parents' work times. [Suzan Lewis](#) and [Carolyn Kagan](#) have done wonderful work in the United Kingdom, looking at families of children with disabilities. They point out that people choose communities on the basis of their available resources, including the necessary child-care options, parental support organizations, and mental health treatment. The parents want flexibility in the community as well as at work.

Families have varying experiences with their children's schools. Some school systems can handle mental health crises and difficulties within the school day; parents can drop their children off in the morning and feel comfortable that their children will be cared for during the day, and that they will only be involved in issues they wish to be involved in while they are working. Parents want to find the conjunction of formal organizations and family support through peer networks.

The notion of disclosure is fascinating to us and worthy of much more research. Parents have a strategy of who they are going to tell about their family's special needs in the workplace and in the community; the disclosure ranges from at the time of a job interview to the time of a crisis. The disclosure may include specifics, or they may just say that their child has a chronic illness. This is one way parents navigate the fit between their family responsibilities and their work responsibilities.

**Casey:** Is this related to the "double jeopardy" stigmatization in the workplace?

**Rosenzweig:** Yes; when we talk about "double jeopardy" stigmatization, we refer to discrimination and judgment extended to the parents of children with a disability. We find that on one hand, disclosure may help parents gain access to flexible work options, but at the same time, there's a risk that they will receive additional stigmatization as an inadequate parent AND an incompetent employee. Disclosure can cut both ways; some parents are willing to roll the dice, others keep it very much to themselves.

We do see parents watching and seeing how other parents are treated when they disclose their work-life integration needs. Some will decide to disclose to a co-worker so they can trade shifts and rely on them for support. We see some informal reciprocity going on at the co-worker level that may not ever extend to supervisors or HR.

**Casey:** What is the role of HR practitioners? How can they provide support?

**Brennan:** They can be a significant support to families; HR is often in touch with management as well as employees, so they cross ranks within organizations. They can assist in crafting and designing policy and advocating for adoption to executives as well as helping supervisors understand the different dynamics of the work-life experience for these parents.

**Casey:** What is the current HR knowledge base? How many are knowledgeable about this topic?

**Brennan:** We did a survey with WorldatWork, and we asked about the amount of training HR professionals had in certain areas. Children's mental health is an area in which most HR staff had had no training at all. What they bring to the workplace is what they have learned through life experience, such as having family members with children who have emotional disorders. This is a fairly common experience; many families have a child who at one point or another has these difficulties. Formal training is infrequent.

**Rosenzweig:** One question we are asked a lot is, "What, really, is the difference for parents who care for a child

with a mental health disorder?” People are mystified that there are significant differences between parenting a child with an emotional or behavioral disorder and parenting a child with typical development. Once we lay out all the pieces of the puzzle, people get it in a big way. As Eileen said, almost everyone knows someone who has a child with special needs, and they finally understand the caregiver strain that comes with exceptional caregiving.

**Casey:** What legal supports and public policies exist, and what else can be done to assist these families?

**Brennan:** It’s important to look at Joan C. Williams and [WorkLifeLaw](#)'s work on family responsibilities discrimination. FRD is a huge problem; people tend not to know the laws prohibiting this type of discrimination. Other issues include the FMLA, which is used frequently to care for children experiencing health crises; we have seen in the literature that families who should take this time off can’t do it because it’s unpaid leave. Even in states that offer paid leave, the take-up rate is not as high as you’d expect because the leave doesn’t replace all wages, but merely a percentage of them. Finally, real support could be provided in the area of child care. Higher levels of government subsidy and more training for child care providers would make inclusive child care more readily available across the United States.

Finally, only one in four children with mental health needs receives treatment in the United States. This often has to do with the way they are covered by insurance, as well as a lack of children’s mental health services. Rural areas have few available providers, for example.

A recent finding from the National Survey of Systems Care Implementation states that families who have received treatment for children’s mental health issues are better able to maintain employment and work the hours they need to work. Treating children for mental health issues makes their parents more productive workers.

Early intervention and childhood education is not usually thought of as a way to keep parents employed, but I think we need to consider a new model of return on investment and cost-benefit analysis of services that—on the surface—only benefit children. These services actually benefit the entire workforce.

**Casey:** What further research is needed to expand the knowledge base about employed parents caring for children with emotional and behavioral disorders?

**Brennan:** What is needed is a set of longitudinal studies in which the development of children is tracked from the time the disability surfaces to the start of treatment and so on, tracing the trajectory of what happens when children receive appropriate treatment and what happens when they do not. This is important in terms of their own life chances as well as the life chances of their parents and siblings.

In some cases, this could be done easily by including a few questions about employment to the studies of children with disabilities. Another option is including questions about disabilities of children in studies of workers over time. Research on this topic can be built into studies that are already in place. Studies on the effect of specialized supports—such as child care, early intervention, special education, transportation services, and flexible work arrangements—on parents’ employment are important as well. I would also like to see some comparative policy studies that look at the effects in other countries of different types of policies.

Transportation is a huge problem for families with children with emotional or behavioral disabilities, as they are often unable to use public transportation. Often, they are also unwelcome on school buses, so parents are frequently responsible for driving their children everywhere. There are some programs in place, but for the most part, this is the parents’ responsibility.

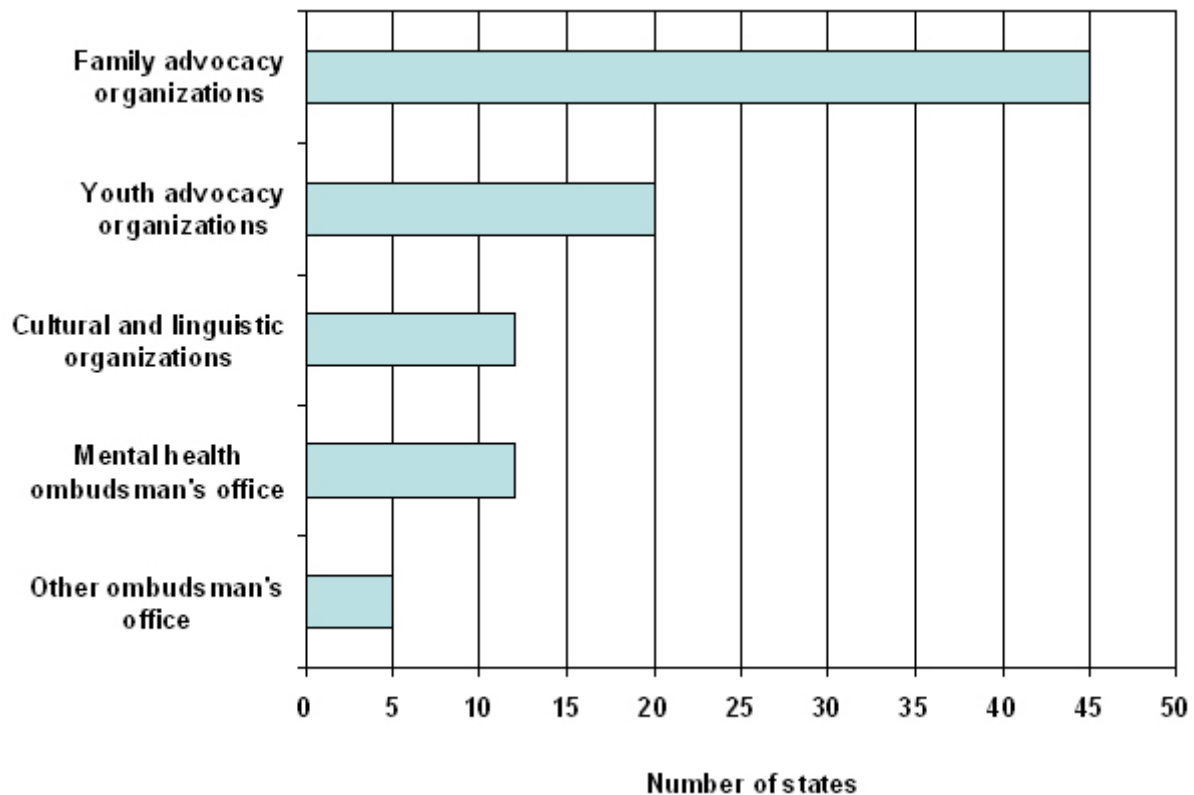
**Rosenzweig:** I’d like to add the need for more understanding of the experiences of single parents versus dual-parent families, hourly employees versus salaried employees, and other diversity issues.

**Brennan:** We need to do a lot of social marketing so people understand that a large number of families are affected by this issue, and the bottom line of the workplace is affected as well. Heads of corporations need to have this on their radar screen.

Visit the [Work-Life Integration Project](#).

[Work, Life, and the Mental Health System of Care: A Guide for Professionals Supporting Families of Children with Emotional or Behavioral Disorders](#) is available from Brookes.

## Type of Advocacy Organizations That States Fund



**Source:** Cooper, J.L., et al. (2008). *Unclaimed children revisited: The status of children's mental health policy in the United States*. Retrieved from [http://www.nccp.org/publications/pdf/text\\_853.pdf](http://www.nccp.org/publications/pdf/text_853.pdf)

### Additional Resources Related to Work-Life Integration and Children's Mental Health

**Family Voices:** Family Voices is a national grassroots organization that provides information and education about ways to ensure and improve family-centered health care for children and youth with disabilities and chronic conditions.

- <http://www.familyvoices.org>

**National Federation of Families for Children's Mental Health:** "We are a national family-run organization dedicated exclusively to helping children with mental health needs and their families achieve a better quality of life. We:

Provide leadership to develop and sustain a nationwide network of family-run organizations

Focus the passion and cultural diversity of our membership to be a potent force for changing how systems respond to children with mental health needs and their families

Help policy-makers, agencies, and providers become more effective in delivering services and supports that foster healthy emotional development for all children."

- <http://www.ffcmh.org>

**Special Needs and the Moving On Projects:** “The Special Needs and Moving On Projects provide resources and support for workers at the post office whose children have disabilities. The projects are available to members of the Canadian Union of Postal Workers and the Union of Postal Communications Employees (Public Service Alliance of Canada). The Special Needs Project is geared to families with young children; the Moving On Project is for adult sons and daughters with special needs. Life is more demanding when you work and have a child with special needs.”

- <http://www.specialneedsproject.ca>

**Topic Page: Parents Caring for Children With Disabilities:** “Employed parents caring for children with special health care needs often find the integration of work and family responsibilities very challenging. The strain of caring for a child with a disability is a common yet hidden problem that negatively impacts both employment and poverty rates. Employers offering greater flexibility in the workplace can help ease the strain for all families, particularly those caring for children with special health care needs.”

- <http://wfnetwork.bc.edu/topic.php?id=40>

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